THIS WEEK IN CAREGIVING



May 10, 2023



CAREGIVING IN THE NEWS

'Something for Me': The National Strategy to Support Family Caregivers

"Sometimes I have trouble worrying," admits Nayma, a young caregiver from Los Angeles who looks after her two younger siblings with autism. "I worry more about them [than myself]." The constant pressure, she says, caused her first anxiety attack.

"That was new for me," she explains. "I've never experienced that before."

From: Next Avenue | Published: May 2, 2023

READ MORE

New AARP Poll: Voters Want More Support from Congress for Family Caregivers

Heads up, Congress: A new AARP poll finds that when voters 50 and older gear up for future elections, how candidates address their concerns about key family caregiving issues will greatly influence their vote.

The survey found that a majority of voters — 70 percent — say they are more likely to support a candidate who backs proposals to support family caregivers, such as tax credits, paid family leave and respite services.

From: AARP | Published: May, 2023

5 Ways Technology Can Make Life Easier for Caregivers of Dementia Patients

Everyday technology that people use around the house — including doorbell cameras, smart speakers and wrist-worn trackers — can help those suffering from cognitive decline.

The tech may ease the burden on caregivers, too.

"Every family caregiver's number one priority is their loved one's safety," says Jennifer Reeder, director of educational and social services for the Alzheimer's Foundation of America.

From: AARP | Published: May 1, 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

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

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

VIEW THE REPORT



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

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

Included in this report:

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

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

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

VIEW THE REPORT



EVENTS & OPPORTUNITIES

MAY





Essentials of Family Caregiving

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

Please join Dr. Max Zubatsky, PhD, LMFT- Associate Director, Gateway Geriatric Education Center, Saint Louis University for training on Essentials of Family Caregiving reviewing common caregiver questions, areas of needed support, and how to avoid burnout. This is 2 of 3 aging-related training topics hosted virtually and sponsored by the Systems Change for Aging & Behavioral Healthcare (Systems ABC) Grant awarded by the Missouri Foundation for Health.

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

A Caregiver's Guide to Finances

May 10, 2023 | 6:00 PM - 7:00 PM ET | Online

Are you expecting to care for someone – or are you already caring for someone – facing Alzheimer's disease, dementia or another chronic illness? It's never too early (or too late) to put smart plans in place to help protect your own and your loved one's financial security.

Join us to learn strategies for managing someone else's finances, how to prepare for future care costs and the benefits of early planning. We'll cover such topics as designating a power of attorney, protecting against financial abuse and fraud, and finding helpful legal and financial resources.

How to Join

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

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

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6th Annual Older Adult Mental Health Awareness Day Symposium

May 11, 2023 | 10:00 AM - 5:00 PM ET | Online

The National Council on Aging is proud to host the 6th annual Older Adult Mental Health Awareness Day Symposium. It will feature leaders in the field who are successfully partnering across sectors to provide equity-focused solutions to improve older adult mental health.

This event is co-sponsored with the U.S. Administration for Community Living, the Health Resources and Services Administration, and the Substance Abuse and Mental Health

Services Administration. Registration is free and includes a full day of sessions on how to best meet the mental health needs of older adults. In partnership with Rush University's E4 Center of Excellence for Behavioral Health Disparities in Aging, NCOA anticipates offering free continuing education credit for several professions.

To learn more or to register for the symposium, click the red button below.





Care to the End of Life

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

Tune in on May 11th for a pre-recorded session featuring Dr. Tam Cummings. Dr. Cummings will give important information: Preparing the Caregiver for End-of-Life Care. Understanding how people die is a difficult but necessary topic. Recognizing the signs and behaviors as persons enter into the process of Actively Dying helps us know what is normal as the body slowly ceases its function. Grief, guilt, and the reality of loss will be discussed.

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



Why You Need Medication Literacy

May 11, 2023 | 6:00 PM - 7:00 PM ET | Online

About the Event

Insufficient medication literacy -- the ability to obtain, process and use information about medicines -- may be one reason that some older adults struggle with taking their drugs.

Taking the right medicine in the right way and at the right time can definitely be challenging, as is managing multiple drugs for yourself or a loved one. This discussion will explore what medication literacy is, how different levels of literacy can impact the ability to

make sound medication decisions, and ways to improve your medication literacy. This event is part of a series for caregivers offered by AARP Massachusetts.

How to Join

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

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

REGISTER >



Understanding Dementia for Family and Friends

May 12, 2023 | 10:00 AM - 12:00 PM ET | Online

Join CaringKind on May 12th for a seminar that will provide family members and friends information about Alzheimer's disease and other dementias, discuss the different stages of the disease and what to expect. The presentation will include an overview of CaringKind's programs and services and other available resources and services.

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

REGISTER >

Women's Health and Aging Q&A

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

To kick-off National Women's Health Week, NIA and the <u>Office on Women's Health</u> (<u>OWH</u>) will host a live Q&A on women's health and aging. Join experts to discuss popular women's health topics, including menopause, sarcopenia, and cognitive health.

To learn more about this event, click the red button below.



Permanente Live: Meeting the Health Needs of an Aging Population

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

Older adults are the fastest growing population in the United States. By 2040, people older than 65 will comprise more than 22% of the population, up from 17% in 2020. To ensure that the needs of this population are met, a health care delivery system that promotes aging with dignity, independence, and choice is necessary.

On May 15th, join Kaiser Permanente for a conversation with some of the nation's most renowned health and aging leaders, as they discuss strategies for caring for Baby Boomers, the generation revolutionizing healthy aging while at the same time living longer with more complex health and social needs. This panel of experts will cover topics such as the importance of prevention, the role of family caregivers, health care system innovations, the role of primary care, recruiting and workforce retention, and policy recommendations needed to help bring about change.

To learn more about this event, click the red button below.

REGISTER



Addressing the Rising Mental Health Needs of an Aging Population: A Workshop

May 15-16, 2023
Online and in-person at the National Academies Keck Center (Washington, DC)

On May 15-16, a National Academies of Sciences, Engineering, and Medicine planning committee will organize and host a public workshop to explore the current state of mental health care for older adults in the United States and potential strategies to address the mental health needs and challenges of our aging population.

Invited presentations and discussions will be designed to:

- Discuss the incidence and prevalence of mental health and substance use conditions among older adults as well as the range and availability of services to address those needs.
- Explore strategies to improve the quality, capacity, equity, and access of community-based and institutional mental health services for older adults.
- Consider ways to build and sustain comprehensive programs to support the well-being of older adults with mental health conditions (e.g., dementia).
- Explore current and new approaches to help older people with mental health disorders to live where they prefer in the community and to support their family caregivers.
- Review knowledge gaps that impede progress in identifying and providing appropriate care for individuals with mental health and substance use conditions, which could be addressed through new research

This event can be attended online or in-person. To register, click the red button below.

REGISTER >

A Caregiver Roadshow

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

Join AARP on May 17th for a conversation designed for unpaid family caregivers who are the backbone of our health care system. Gain an understanding of what you need to know as you navigate the care journey: how to start a conversation with loved ones about their wishes, making an effective caregiving plan, types of caregiving supports and services that might be available in your community, AARP resources for family caregivers, options for paying for care, and how to take care of yourself while you're on your caregiving journey. This session is live and not recorded.

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

REGISTER



Role Changes in Caregiving Families

May 17, 2023 | 2:00 PM - 3:00 PM ET | Online

Millions of adult children act as family caregivers for their aging parents. How does this role reversal impact relationships? Tune in on May 17th for a presentation by MemoryLane Care Services that will discuss how family roles change from the points of view of the family caregiver and the person receiving care. The session will also share practical tips to purposefully strengthen connections.

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





Enhancing Care Program for Care Partners Information Session

May 17, 2023 | 6:30 PM - 7:30 PM ET | Online

Join the Alzheimer's Society of Durham Region in Ontario for a Zoom session for care partners of a person living with dementia and health care providers to learn more about the Enhancing Care Programs, TEACH and CARERS, two programs developed by Reitman Centre at Sinai Health System to support the needs of caregivers and aid in the enhancement of coping and practical skills.

TEACH: TEACH stands for Training, Education and Assistance for Caregiving at Home. TEACH is a therapeutic group intervention with the goal of providing education while enhancing coping skills of care partners. A vital aspect of TEACH is the group support where care partners have the opportunity to share and learn from other care partners, often discussing common problems and strategies that have worked for others. TEACH is widely open to any kind of care partner, whether they are just starting out in this role or have been caregiving for a long period of time.

CARERS: CARERS stands for Coaching, Advocacy, Respite, Education, Relationship, Simulation. CARERS is an eight-week program for primary caregivers of people living with dementia and this program is more in-depth than TEACH and consists of 2-hour sessions each week. CARERS focuses on practical skill-based tools and emotional supports needed to provide care for someone with dementia. It is structured around therapeutic relationships, adult learning which includes experiential learning through the use of simulation and problem-solving techniques.

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



A Caregiver's Guide to Wellness

May 18, 2023 | 12:00 PM - 1:00 PM ET | Online

Join AARP of North Carolina on May 18th for an online event featuring Shevel Mavins and Kaii Marie Robertson, cofounders of the Behavioral Health Mind Body Academy, that will explore the importance of developing a caregiver self-care plan and how to go about doing so. For example, it's a good idea to consider the benefits of arranging for respite care when you're taking care of a loved one at home and of making time for walking and exercise.

Effective caregivers understand their limitations and request help as needed, so identifying a backup support system is a key step. While it can be tough to call on assistance, the presentation will cover how to discuss sharing the responsibility of caring for a loved one with your family. You'll also get suggestions of apps that can help you manage your loved one's medical affairs.

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



Making 'Cents' of Caregiving Costs

May 18, 2023 | 6:00 PM - 7:00 PM ET | Online

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

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

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



The Transplant Community Unmet Needs Summit

May 19, 2023 | 10:00 AM - 3:00 PM ET | Online

The Transplant Community Coalition is launching the inaugural Transplant Community Unmet Needs Virtual Summit May 19th! The one-day virtual event will feature empowering and educational sessions such as Building Your Mental Health Toolbox, Being the CEO of Your Care, State of Transplant Policy and more.

To learn more or to register for this event, click the red button below.





Conversations and Events

Advance Care Planning: Advance Directives Deep Dive

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

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

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

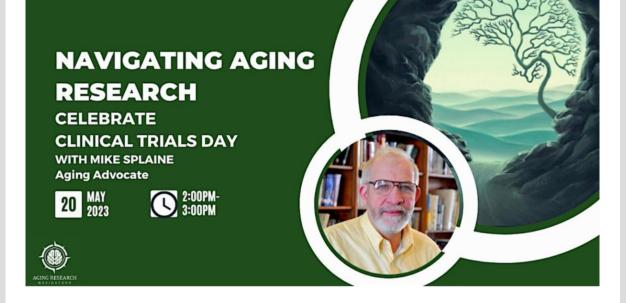
All online discussions begins with a basic overview of the day's topic before opening up to the group for Q&A and conversation. This session should feel as supportive as it does educational, so bring your questions and comments, or feel free to just listen. Together, we'll explore real life examples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

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

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

REGISTER

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Clinical Trials Day - Navigating Aging Research with Mike Splaine

May 20, 2023 | 2:00 PM - 3:00 PM ET | Online

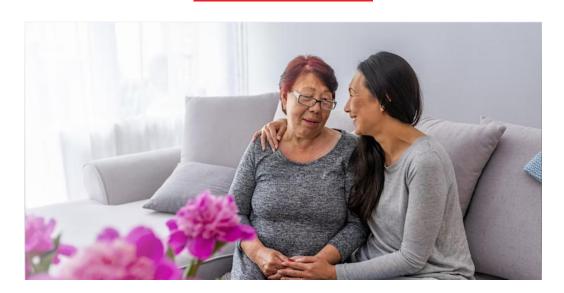
Progress on cognitive health, dementia, caregiving, and aging treatments lags because there are simply not enough people volunteering to participate in research.

Clinical trials range from things one can do from the couch or home office, to complex clinical trial in major medical centers, but sharing reputable information is an easy step we can all take.

Aging Research Navigators hosts aging advocate Mike Splaine for a virtual coffee chat on May 20th to discuss the hows and whys of participating in brain health research. This presentation is helpful for anyone interested in research, especially those living with Alzheimer's disease or a related dementia.

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

REGISTER



Comfort for Caregivers: Strategies for Dealing with Caregiver Stress

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

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

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



Sundowning

May 24, 2023 | 8:30 AM - 10:00 AM ET | Online

You may have heard the term "sundowning". It refers to the agitation or state of confusion occurring in the late afternoon and lasting into the night experienced by someone with dementia. It's a really common side affect of dementia and it is particularly apparent in the autumn and winter months as the days are shorter and the night rolls in earlier.

Sundowning can cause different behaviors, such as confusion, anxiety, aggression or ignoring directions. It can also lead to pacing or wandering. These behaviors can be particularly difficult for a carer to manage and can increase your own anxiety as the late evening / afternoon starts to approach.

Join the UK's Dementia Carers Count on May 24th for a presentation and exploration of sundowning. This session is for you if you ...

- want gain a better understanding of the factors that may contribute to early evening agitation or sundowning
- would like to consider your own needs at this time as well as the person with dementia
- want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- would like to 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.

REGISTER >



Eldercare Caregiving Grief and Guilt

May 24, 2023 | 1:00 PM - 2:00 PM ET | Online

When you become a caregiver, quite often some huge emotions come along for the ride.

Emotions such as Grief & Guilt.

Join Amy Friesen, Founder of Tea & Toast, Best-Selling Author, Speaker and Educator, and Margaret Dennis, Founder of Evolv Coaching as they explore these big emotions. Why do these emotions happen & how to recognize them (it isn't always what you think!).

Learn strategies on how you can support yourself and your loved ones when these emotions surface.

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





Stages and Progression of Dementia

May 24, 2023 | 2:00 PM - 3:00 PM ET | Online

Dementia is the umbrella term for the category of illnesses that cause memory loss and the deterioration of mental functioning. Dementia occurs due to physical changes to the brain. Join MemoryLane Care Services for a webinar that will discuss the stages and progression of dementia as well as resources to support you and your loved ones.

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

REGISTER >



Understanding Dementia Better

May 25, 2023 | 1:00 PM - 3:00 PM ET | Online

Tune in on May 25th for an online session hosted by the UK's Dementia Adventure, "Understanding Dementia Better." Its expert training team will support you to understand dementia better, offering you small and easy steps that can make a big difference.

This 2-hour session will be informal, and a great opportunity to meet and learn from other people in situations similar to yours.

We actively encourage questions, which you can ask during the session or send to us before-hand.

You can expect to understand:

- The common symptoms of dementia.
- How dementia can affect the senses, communication and behaviour.
- The importance of seeing the person before the condition.
- Practical ways to connect with a person with dementia.
- Strategies to overcome communication barriers.
- Solutions for adapting the environment.
- The benefits of a connection with nature and the outdoors.

Following the session, we will send you an email with a link to resources we mention throughout the session.

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

REGISTER >



A PROGRAM OF THE FENWAY INSTITUTE

What You Need to Know about Informal Caregiving and the LGBTQIA+ Community

May 25, 2023 | 2:00 PM - 3:00 PM ET | Online

Tune in on May 25th for a webinar presented by the <u>National LGBTQIA+ Health</u> <u>Education Center</u> and the <u>National Center for Equitable Care for Elders</u> (NCECE). It will focus on the unique experiences and considerations for supporting both LGBTQIA+ caregivers who provide care or assistance to a family member, chosen family, or friend and those providing care to LGBTQIA+ older adults.

After participating in this webinar, participants will be able to:

- 1. Understand various roles, responsibilities, and models of informal caregiving.
- 2. Explain best practices for addressing needs or concerns related to education, access to services, and overall wellness for LGBTQIA+ caregivers and care recipients.
- 3. Implement strategies to provide affirming care and connect LGBTQIA+ caregivers to inclusive and affirming support services.

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

REGISTER >



CONFIDENCE Financial Education Program: May 25 - June 22, 2023

Thursdays, May 25 - June 22, 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 in 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.



Setting Boundaries for Healthy Relationships and Caregiver Self-Care

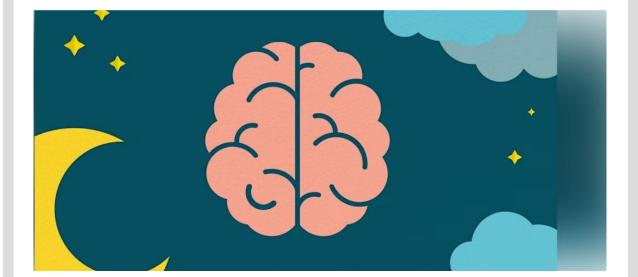
May 25, 2023 | 7:00 PM - 8:30 PM ET | Online

Healthy boundaries are essential for any caregiver supporting a loved one living with depression. Boundaries provide structure in relationships and ensure that everyone involved is respected and gets their needs met. By setting clear limits, you can prioritize your wellness while continuing to be a support for your loved one.

Taking the time to nurture yourself emotionally, mentally, and physically can help you remain strong despite the demands of caregiving and avoid caregiver burnout. Learn how to develop and affirm your boundaries to promote your own wellness and strengthen your relationship with your loved one.

Join Families for Depression Awareness on Thursday, May 25, 2023, from 7:00 PM to 8:30 PM ET to hear from Jenny Woodworth, LISW, to learn how to define boundaries as they relate to familial relationships. You'll learn why boundaries are necessary when supporting a loved one with a mood disorder and how to apply boundaries as a form of self-care.

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



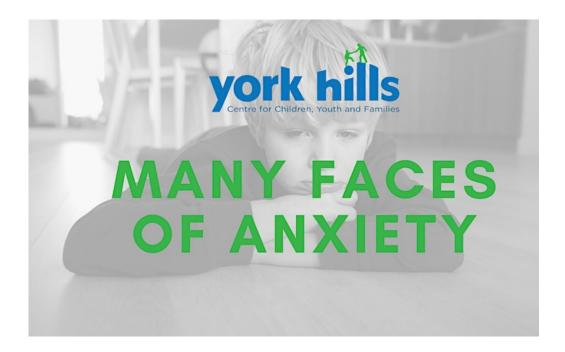
Sleep & Dementia

May 29, 2023 | 2:30 PM - 4:00 PM ET | Online

Disturbances in the sleep cycle are common with people suffering from dementia. Join the Alzheimer's Society of Durham Region in Ontario for an online event that will explore how sleep affects our brain, and how changes influence behaviours, and ways to ensure good sleep hygiene.

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

REGISTER >



Many Faces of Anxiety

May 29, 2023 | 6:30 PM - 8:30 PM ET | Online

Joint the York Hills Centre for Children, Youth and Families on May 29th for a workshop that will provide valuable information to caregivers of children and adolescents who experience anxiety. Topics include: Understanding different types of anxiety, causes, how the mind and brain are connected, coping strategies for caregivers; and what caregivers can do to help.

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

REGISTER >



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

May 30, 2023 | 10:00 AM - 11:00 AM ET | Online

On May 30th, join HopeHealth Hospice & Palliative Care for an online presentation twill 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 workshop, click the red button below.

REGISTER



Reminiscence in Caregiving

May 31, 2023 | 2:00 PM - 3:00 PM ET | Online

People living with dementia struggle with short-term memory limitations. Recalling memories from the past is a great way to connect. Join MemoryLane Care Services on May 31st for an online session that will discuss ways to incorporate reminiscence and the life story into caregiving.

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



Trust It or Trash It? Techniques for Evaluating Health News Stories

May 31, 2023 | 2:00 PM - 3:00 PM ET | Online

Too often health and medical news reporting is unreliable, at best. Ten years ago one study found nearly 90% of all health news stories contained inaccurate information, and it's only gotten more difficult since then to sort out the useful information from hype, advertisements, or genuinely fake news. In the effort to make their stories catch readers' eyes, journalists frequently mistake, exaggerate, or spin reports. Often reporters also miss details that make all the difference when it comes to transforming research findings into useful medical treatment.

However, there's good news too. With critical thinking skills, tools, and techniques, careful readers (even without a science background) can spot inaccurate or unreliable health reporting.

Join the Family Caregiver Alliance on May 31 for a program that will describe DIY techniques that anyone can use to detect bias, spin, and scam warning signs; identify trustworthy go-to sources for quick and efficient searching. This presentation will also explain how to read and evaluate medical research reports. Being able to identify what is valid and relevant information amidst all the noise of our news media can be essential for people with serious or chronic illness, and for those who help care for them.

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



Sleep Hygiene

May 31, 2023 | 9:00 PM - 10:00 PM ET | Online

Join the Family Caregiver Alliance on May 31st for a workshop that will discuss sleep and the body, sleep and aging, sleep-wake cycle changes, chemicals and hormones, health conditions, lifestyle, sleep disorders, and sleep deprivation. This is an evening event to accommodate working caregivers.

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



JUNE



Family Reactions to Mental Illness

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

Understanding why people experience things differently can help to ease tension and increase acceptance. Join Jaymi Dormaier, a licensed therapist, on June 1st for a discussion of the caregiving experience, the stages of emotional response, and learn how to respond and cope.

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

REGISTER



Dealing With Dementia

June 1, 2023 | 5:00 PM - 9:00 PM ET | Online

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

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

REGISTER >

Aspects of Caregiving

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

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

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

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

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

REGISTER



Money Matters for Family Caregivers

June 5, 2023 | 6:00 PM - 7:00 PM ET | Online

Join financial counselor Kate Grayson on June 5th for an online discussion of money matters in the context of caregiving.

This workshop, will examine:

- Money and family caregiving: How to create separation between your personal finances and your care recipient's money
- Understand your money: Learn where your money stands today, and plan for your future
- Talking to family about money: How to have productive conversations with family

about one of life's most fraught topics - money

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

REGISTER

Under the Umbrella: The Clinical and Lived Experience of Vascular Dementia

June 7, 2023 | 4:00 PM - 5:30 PM ET | Online

Join the Banner Sun Health Research Institute on June 7th for a webinar about Vascular Dementia. This session is the second in a three-part series discussing some of the less common, though very real, forms of dementia that people are facing.

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

REGISTER

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Caring for Your Caregiver

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

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

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

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

Why Dementia is Different for Everybody

June 12, 2023 | 1:30 PM - 3:00 PM ET | Online

Dementia affects each person in a different way, depending on multiple factors. These factors can include neurology, physical health, personality, our biography and background and the social environment in which we live. The signs and symptoms of dementia can therefore be quite different depending on the individual.

Did you know that there are more than 100 types of dementia? Understanding the different types of dementia, how they are diagnosed and their effects on different people is important in providing the best care for the person with dementia.

Join the UK's Dementia Carers Count for an introductory course on June 12th that will examine the different factors that affect a person's experience of dementia and how these might influence the role of the carer. By better understanding dementia, you will be better equipped to deal with the challenges you both might have to face.

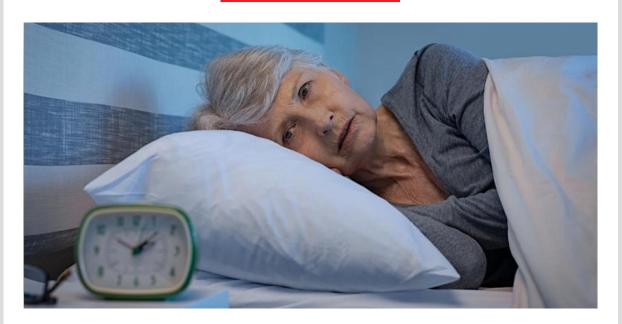
The course is for you if you would like to:

- Gain a better understanding of your friend or family member
- Learn about the different factors which can contribute to a persons experience of having dementia
- Understand why no two people with dementia have the same experience
- Spend time with experienced healthcare professionals who will answer your questions in a safe and 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.

REGISTER

>



Caregiving Coffee: Managing Restlessness and Sleep Issues

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

People with dementia often have trouble sleeping or may experience changes in their sleep schedule. There are many things you can do to help your family member sleep better. Join MemoryLane Care Services on June 14th for a webinar that will provide tips and resources.

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





Defining Dementia: Progression, Treatment & Strategies

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

This online class reviews the basics of dementia from the various types to progression and treatments available. Most importantly, caregivers will learn the 8 most essential strategies to avoid many of the unwanted behaviors that arise due to the demands of the illness.

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





Essentials of Caregiving: Learning to be a Caregiver

June 23, 2023 | 2:00 PM - 3:30 PM ET | Online

Whether you have recently taken on the new role of a family caregiver or have been established in the role for some time, join School of Nursing at UT Health San Antonio on June 23rd (2:00 PM ET) for an online session that will assist you in navigating the experience of caring for your loved one.

The School of Nursing's presenters bring their professional and personal experiences to this informational opportunity. Sheran Rivette, Family Caregiver Specialist at the School of Nursing, cared for her late husband who lived with dementia. She brings her expertise in care management and will provide tips and tricks that supported her in her role. Dr. Sara Masoud brings her experience as a former family caregiver and her expertise as the Program Manager at the university's Caring for the Caregiver program.

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



Preventing and Managing Falls

June 21, 2023 | 2:00 PM - 3:00 PM ET | Online

Falls are a threat to the health of older adults and their ability to remain independent. Join MemoryLane Care Services on June 21st for a webinar that will discuss ways to eliminate trip hazards from your home to keep your family safe.

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





Young Onset Dementia

June 26, 2023 | 2:30 PM - 4:00 PM ET | Online

Join the <u>Alzheimer Society of Durham Region</u> (Canada) on June 26th for an online workshop that will distinguish Young Onset dementia from other types of dementia by identifying its core symptoms and by understanding the possible causes/risk factors that bring changes to brain structure and function. It will also discuss general ways of supporting people living with young onset dementia.

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

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

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

REGISTER >

PATIENT AND CAREGIVER STUDIES



Illness Perceptions and Illness Perception Incongruence as Predictors of Psychological Distress Among Caregivers in the Context of Chronic Multi-Symptom Illness

Are you a caregiver for someone with chronic pain, fatigue, or other symptoms? Researchers at the University at Albany, SUNY are seeking volunteers for a research study to understand the experiences of caregivers for individuals with chronic symptoms. We are conducting a short (20 minute) survey to understand how you think about the illness you are caring for. The goal of this study is to understand what factors should be considered when supporting caregivers.

You are eligible to participate if you are:

- Over the age of 18
- Currently caring for an individual with chronic symptoms

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

LEARN MORE

In-Home Technology to Measure Activities of Daily Living

Start: Nov. 1, 2021 End: Dec. 31, 2023 Enrollment: 100

Who is sponsoring this study? BioSensics LLD

Where is this study located? Texas

What is this study about?

Difficulties carrying out daily activities, such as managing medications, can be an early sign of dementia. To help improve early dementia diagnosis, this study will test the effectiveness of a sensor-based, in-home technology system, named IADLSys, that monitors daily functioning to distinguish between people with or without early dementia. All participants will receive a computer tablet and five sensors to wear and place on items in their home. For one week, the sensors will collect data on the participants' movements throughout the house and interactions with the tagged items. At the start and end of the study, participants will fill out questionnaires and complete cognition tests. Researchers will assess daily functioning, physical activity, and depression.

Do I qualify to participate in this study?

Minimum Age: 50 Years Maximum Age: 95 Years

Must have:

- Normal cognition, mild cognitive impairment, or early dementia
- Able to walk without assistance
- Living at home with a caregiver or other person

Must NOT have:

- Unable to engage in daily activities essential for independent living (e.g., using the telephone, preparing meals, and managing medication)
- Any significant medical or psychiatric condition that could interfere with the study
- Stroke within the past six months
- Major hearing or vision impairment
- Injury that may impact the activities of daily living (e.g., fracture, foot ulcer, recent surgery)
- Living in a nursing home or receiving hospice care
- Unable to communicate in English

For more information call Bijan Najafi at (713)798-7536 or email him by clicking on the red button below.

LEARN MORE >

Electrical Stimulation and Verbal Memory in Alzheimer's Disease

Start: August 1, 2020 End: July 31, 2025 Enrollment: 60

Who is sponsoring this study? Johns Hopkins University

Where is this study located? Maryland

What is this study about?

Transcranial direct current stimulation (tDCS) is a safe, noninvasive, non-painful electrical stimulation of the brain that is used to support nerve cell function. Progressive damage to nerve cells in the brain leads to cognitive decline in Alzheimer's disease and related dementias. This study will test tDCS treatment to prevent or slow nerve cell damage in the brain and improve verbal memory in people with Alzheimer's disease. Participants will receive a word-list learning intervention plus either tDCS or a sham treatment for two learning cycles of two weeks each, with five sessions each week. Between the first and second cycle, there will be three months with no treatment. After each learning period, the researchers will schedule follow-up sessions with participants to conduct testing that will include functional magnetic resonance imaging (fMRI) tests, magnetic resonance spectroscopy, memory tests, and collection of physical and behavioral information.

Do I qualify to participate in this study?

Minimum Age: 50 Years Maximum Age: 75 Years

Must have:

Aphasic/atypical AD participants:

- Must be right-handed
- Must read and speak English well
- Must have a high-school education, at minimum
- Must be diagnosed as having logopenic variant primary progressive aphasia with Alzheimer's disease (AD) biomarkers. Other possible diagnoses for the aphasic AD variant dementia with speech issues would be mild cognitive impairment or possible AD according to 2011 NIA-AA guidelines

Amnesic/typical AD participants:

- Must be right-handed
- Must read and speak English well
- Must have a minimum of high-school education
- Must be diagnosed with probable AD in specialized diagnostic centers with neuropsychological and AD biomarkers according to 2011 NIA-AA guidelines

Must NOT have:

- Left-handed individuals
- Previous neurological disease including vascular dementia (e.g., stroke, developmental dyslexia, dysgraphia, or attentional deficit)
- Significant hearing loss (>25 decibel, using audiometric hearing screen)
- Uncorrected vision loss
- Advanced dementia or severe language impairments with Mini-Mental State Exam
 <15, or Montreal cognitive assessment <10, or language Frontotemporal Dementia-specific Clinical Dementia Rating = 3
- People with preexisting psychiatric disorders such as behavioral disturbances, severe depression, or schizophrenia that make it difficult to follow the study schedule and requirements
- Inability to undergo MRI (severe claustrophobia, cardiac pacemakers or ferromagnetic implants, pregnancy)

For more information call Kyrana Tsapkini at (410)736-2940 or email her by clicking on the red button below.

Stress and Cognitive Decline in People at Risk for Alzheimer's Disease

Start: March 1, 2023 End: March 1, 2029 Enrollment: 240

Who is sponsoring this study? Johns Hopkins University

Where is this study located? Maryland

What is this study about?

This study will evaluate the effects of stress and genetics on cognitive decline and blood biomarkers for Alzheimer's disease in people with mild cognitive impairment. All participants will attend three study clinic visits. At the first visit, participants will answer questions about their daily activities, and take cognitive tests. They will also provide a blood sample to test for genes and proteins associated with the risk of Alzheimer's. One month later, participants will return to the clinic to undergo a brief, stressful activity, and provide saliva samples to measure stress hormones. Two years later, they will return to the clinic to answer questions about daily functioning, complete cognitive tests, and provide a blood sample. For the first and third study visits, participants must bring a study partner (someone who knows them well) to answer questions about the participants daily functioning.

Do I qualify to participate in this tudy?

Minimum Age: 60 Years Maximum Age: N/A

Must have:

- Mild cognitive impairment (MCI), based on tests at study screening
- If MCI is due to early Alzheimer's, participant must be functionally independent at the start of the study
- Body Mass Index > 17 and < 30
- · Native English speaker
- Availability of a study partner to:
 - Attend the first and third study visits
 - Answer questions about the person with MCI

Must NOT have:

- Dementia
- Current smoker
- Current or history of major psychiatric illness, including schizophrenia, bipolar disorder, obsessive-compulsive disorder, post-traumatic stress disorder
- Diagnosis of a neurological disorder, including Parkinson's disease and Huntington's disease
- · Current or history of immune disorder, including multiple sclerosis
- Current or history of drug dependence
- Treatment within the last six months with antidepressants, neuroleptics, sedative hypnotics, or glucocorticoids
- History of stroke, seizure, or head injury with loss of consciousness for more than half an hour
- Surgery within the last three months
- Major, untreated vision or hearing problem

For more information call Cynthia Munro at (410)550-6271 or email her by clicking on the red button below.

Family/Friend Caregivers for the Elders

Researchers from Washington University in St. Louis invite you to participate in a study that seeks to learn more about people who are working while taking care of their elderly family and friends.

If you agree to participate, we would like you to respond to this survey. The entire process should take 15 - 30 minutes and you will be provided with \$10 gift card if you agree to participate and respond to the follow up survey. The response will be recorded only for research purposes.

<u>Survey</u>

The survey questions are about your eldercare responsibilities, feelings about eldercare, and demographics. Only people in the research team will have access to survey responses. There are no known risks from being in this study. You will receive \$10 gift card being in this study. However, we hope that others may benefit in the future from what we will learn in this study. You will not have any costs for participating in this research study.

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



The Impact of Intervention Programs for Helping Informal Caregivers Deal with Caregiver Burden and Depression

Northcentral University seeks participants for a study about about the effectiveness of intervention programs for informal caregivers (ICs) for relieving caregiver burden and depression.

You are eligible to participate in this research if you are:

- 18 years or older
- live with and provide unpaid care for an individual with dementia
- live in the US
- have access to a computer

The study is recruiting two groups (180 participants). You qualify for the respite group if you have used respite services (such as adult daycare or in-home respite) once a week over the past six months. If you have not used respite, you would qualify for the non-respite group.

If you decide to participate you will be asked to:

- Complete a pretest online survey about yourself, respite care, caregiver burden and depression (20 minutes).
- You may be randomly selected to complete an education course (1 hour weekly for 6 weeks) about how to care for someone with dementia; if you are not randomly assigned, no activities are required.
- You may be invited to participate in an online recorded one-on-one interview (45-60 minutes).
- Complete a post-test online survey about caregiver burden and depression.

To learn more about this study, click the red button below.

Enhancing Health and Quality of Life for Individuals with Dementia Through Individualized Caregiver Training

The University or Oregon invites to participate in a research study that seeks to determine if participating in a personalized education program improves mealtime outcomes in persons with dementia and their caregivers. This study is being done by David Bayne, a PhD candidate, and Dr. Samantha Shune from the University of Oregon; both researchers are licensed Speech-Language Pathologists.

If you are interested in participating in this study, you will be asked to complete the questionnaire that begins on the next page. This questionnaire will take approximately 3-minutes to complete and will determine if you are eligible to participate in the full study. If you meet eligibility requirements, you will be asked to provide contact information so the research team can set up a time to complete your enrollment in the study.

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



Nuestros Dias: Study on the Daily Experiences of Latino/a Caregivers

The University of Alabama at Birmingham is conducting a study for Hispanic and Latino Caregivers of individuals living with dementia. Participants will help us identify factors that increase resilience to stress and help us establish the evidence base for culturally responsive, integrative interventions to support caregivers and dementia patients from the Hispanic and Latino community.

You may qualify for this study if you:

- · Are Hispanic or Latino/a
- Are 18+ years
- Take care of a relative living with dementia
- Live with the person living with dementia you care for
- Have a computer, phone or tablet with reliable internet access

This study involves:

- Surveys performed online.
- Three extended surveys (30 minutes to complete), the baseline, and two follow-ups (six- and twelve-months after).
- After the extended surveys participants will complete a series of daily surveys for 21 days. These surveys take between 5-7 minutes to complete
- Participants will be compensated for participating in the study
- All the surveys are available in English or Spanish

To learn more about this study or to participate, call (205)996-0364 or send an email to the study's administrators by clicking on the red button below.

LEARN MORE

and Cognitive Decline

Start: June 20, 2022 End: Dec. 31, 2026 Enrollment: 260

Who is sponsoring this study? Massachusetts General Hospital

Where is this study located? Massachusetts

What is this study about?

This study will evaluate the effectiveness of two programs designed to teach coping skills and lifestyle strategies to improve physical, cognitive, and emotional functioning in older adults with chronic pain and cognitive decline. Participants will be randomly assigned to either a mindfulness-based program or a lifestyle education program. Both programs will be delivered online in eight, weekly, 90-minute group sessions using Zoom. All participants will receive a treatment manual and a wrist device to track sleep and physical activity. At the start and end of the study and after six months, researchers will measure levels of cognition, pain, depression, stress, loneliness, and other factors related to well-being. Pain will be measured each week during the study.

Do I ualify to participate in this study?

Minimum Age: 60 Years Maximum Age: N/A

Must have:

- Chronic pain, not related to cancer, for more than three months
- Early cognition problems with:
 - Telephone Interview for Cognitive Status score > 17
 - Functional Activities Questionnaire score < 9
- Able to perform a six-minute walk test at an accelerated pace
- Able to read and speak English fluently
- Willing and able to wear a digital activity tracker on wrist and use a smartphone app to view and track step count and sleep data
- If currently using digital activity tracker, must be willing to stop wearing the tracker for the duration of the study
- If taking psychotropic or pain medication, must either stop at least two weeks prior to starting the study or dosage must be stable for at least six weeks and remain stable throughout the study
- Able to obtain clearance from a medical doctor for study participation and have no personal concerns about physical functioning

Must NOT have:

- Dementia or neurodegenerative disease diagnosis
- Current medical illness expected to worsen in the next six months
- Diagnosis of a serious, untreated mental illness (e.g., schizophrenia) or untreated substance use disorder
- · Suicide risk or ideation
- Engaged in a mindfulness practice > 45 min/week or have had cognitive behavioral therapy in the past three months
- Engaged in regular intensive physical exercise for >30 minutes daily

For more information call Ana-Maria Vranceanu at (617)643-7996 or email her by clicking on the red button below.

IN CASE YOU MISSED IT...

Beware of Caregiving Fraud



Arranging for care in the home can be complicated and costly. Finding a caregiver you can trust is one of the most important concerns of families venturing out on this journey. Listen to a discussion on how to find a reputable, reliable care provider and protect yourself and your loved one from caregiving fraudsters and scammers. We cover the benefits of using an agency, tips on monitoring a new caregiver, and ways to protect against financial abuse.



RESEARCH & RESOURCES



How to Sustain Brain Healthy Behaviors

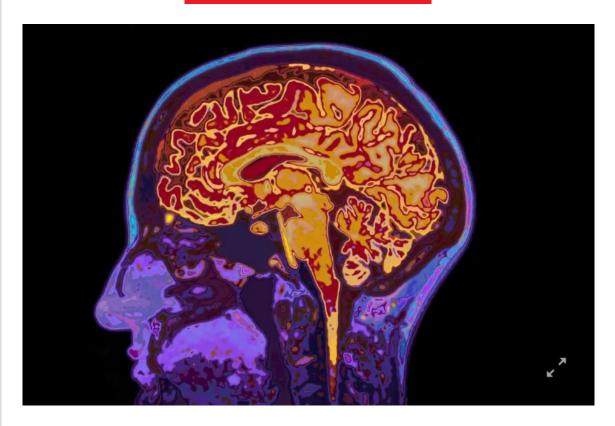
The Global Council on Brain Health (GCBH) is an independent collaborative of scientists, health professionals, scholars, and policy experts from around the world who are working in areas of brain health related to human cognition. The GCBH focuses on brain health underlying people's ability to think and reason as they age, including aspects of memory, perception, and judgment. AARP convened the GCBH to offer the best possible advice about what adults age 50 and older can do to maintain and improve their brain health

In this report, the GCBH shares what it has learned about how to persuade and motivate people to maintain brain-healthy lifestyles, and how community policies can be shaped to

promote this vital goal. It concluded that an effective strategy to enhance brain health should focus not only on individuals but on the social and environmental factors that influence their behavior.

To view the report, click the red button below.

VIEW THE REPORT >



Bilingualism May Stave Off Dementia, Study Suggests

Speaking two languages provides the enviable ability to make friends in unusual places. A new study suggests that bilingualism may also come with another benefit: improved memory in later life.

Studying hundreds of older patients, researchers in Germany found that those who reported using two languages daily from a young age scored higher on tests of learning, memory, language and self-control than patients who spoke only one language.

To learn more, click the red button below.



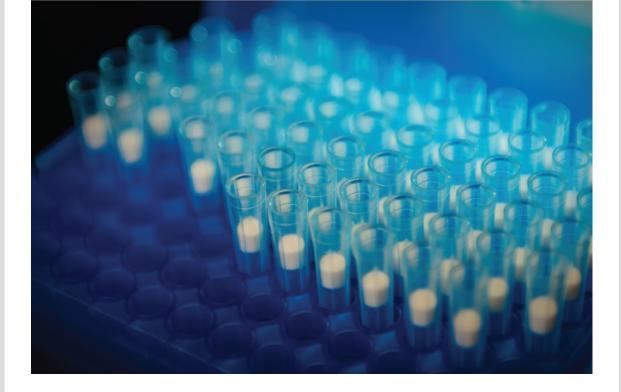
11 Myths about Alzheimer's Disease

Alzheimer's disease is a leading cause of death in the United States, and millions of Americans are affected by the disease. It's important to distinguish the facts from the myths about Alzheimer's, especially when it comes to finding information online.

To learn more, click the red button below.

LEARN MORE

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Parkinson's Disease Biomarker Found

In an enormous leap forward in the understanding of Parkinson's disease (PD), researchers have discovered a new tool that can reveal a key pathology of the disease: abnormal alpha-synuclein — known as the "Parkinson's protein" — in brain and body cells. The breakthrough, announced last night as it was published in the scientific journal The Lancet Neurology, opens a new chapter for research, with the promise of a future where every person living with Parkinson's can expect improved care and treatments — and newly diagnosed individuals may never advance to full-blown symptoms.

To learn more, click the red button below.

LEARN MORE

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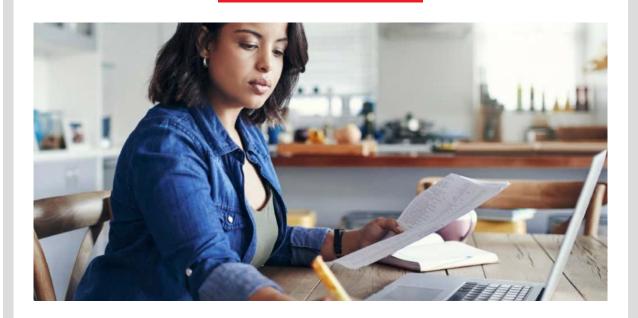


Advances in ALS: Unraveling Its Causes and Finding Treatments

People with ALS usually die from respiratory failure. The muscles that control their breathing eventually shut down. The average lifespan of a person after they're diagnosed is three to five years.

Over the past decade, researchers have uncovered more molecular clues about how ALS develops. They're hoping this will eventually help identify people with ALS sooner. Scientists are also looking for ways to better track and treat the disease.

To learn more, click the red button below.



How to Manage Finances as an Unpaid Adult Caregiver

Caregiving can be a very demanding role. It not only impacts your physical, mental, and emotional health, but it also takes a toll on your finances.

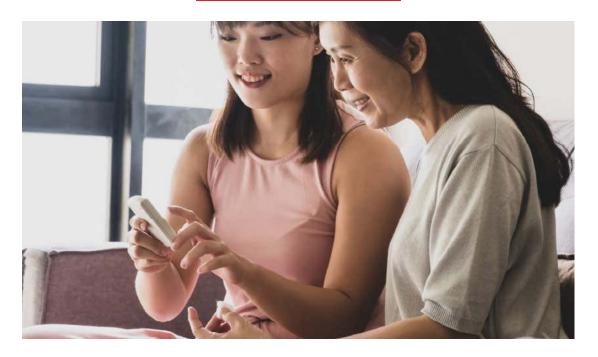
Your finances are likely to be affected if you're paying for the household expenses, medical bills, and other fees for the relative out of your pocket. Another way being an unpaid adult caregiver hurts your finances is by making it next to impossible to get a paid job.

Thus, it gets tricky for family caregivers to make ends meet as caregiving can be incredibly expensive.

To learn more, click the red button below.

LEARN MORE

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How to Be a Caregiver for Someone with Diabetes

Whether you're a family member to someone with diabetes or are a direct care worker, being a caregiver can get overwhelming fast. You may be juggling multiple visits to specialists, constantly taking inventory and restocking a long list of diabetes care supplies, checking lab work results online, or trying to follow their doctor's insulin therapy protocol.

You may have many questions. Can they eat that piece of pie? What do you do when they feel dizzy?

The National Council on Aging provides information to help answer these and other questions about caregiving for someone with diabetes.

To learn more, click the red button below.

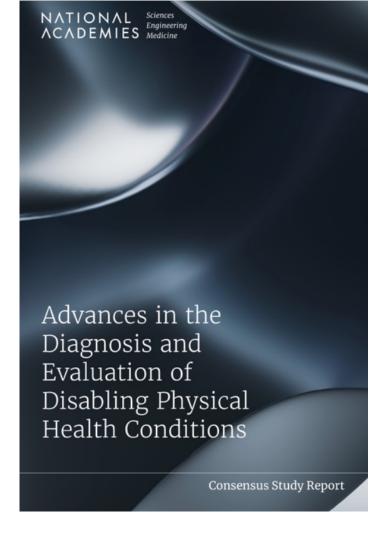


Schizoaffective Disorder Information Resource Sheet

Schizoaffective disorder is like an intersection between schizophrenia and bipolar disorder. It is a genetic disorder which has aspects of psychosis, mood swings, communication challenges, and cognitive disruptions. Your loved one is likely going through a lot.

Courage to Caregivers has compiled a list of resources available for caregivers supporting a loved one with schizoaffective disorder.

To learn more, click the red button below.



Report: Advances in the Diagnosis and Evaluation of Disabling Physical Health Conditions

The U.S. Social Security Administration (SSA) provides benefits to adults and children who meet the eligibility requirements for a disability as described in Title II and Title XVI of the Social Security Act. To determine whether more accurate or precise techniques exist for determining if a previously evaluated physical impairment is either more or less severe, SSA requested the National Academies assemble a committee to review new or improved diagnostic or evaluative techniques that have become generally available within the past 30 years for cardiovascular, neurological, respiratory, hematological, and digestive conditions. The resulting report presents a summary of the evidence and information around a selected subset of diagnostic and evaluative techniques.

To learn more, click the red button below.

VIEW THE REPORT >

PREVIOUSLY APPEARED



Guide for Caregivers of a Child with Serious Illness

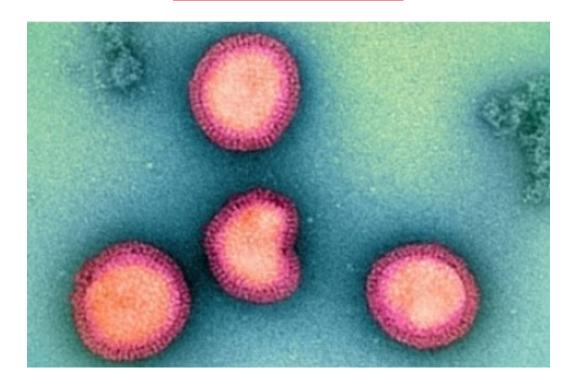
Talking about the kind of health care we want through the end of life can be hard. It can be even harder when a child we care for is living with a serious illness.* But it's very important to talk with your child to learn about what matters most to them. If you talk about it, and understand what their wishes are, you will be better able to make health care decisions for them.

The Conversation Project has created a guide to help you talk with your child, understand what matters to them, and feel some comfort knowing that you can help guide their care and honor their wishes. Keep in mind that a conversation can vary depending on the age of the child, the type of illness, and their current treatment options.

To view the guide, click the red button below.

VIEW THE GUIDE

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Could a Viral Illness Increase Chances of Developing Alzheimer's Disease?

Some viral illnesses may increase a person's chances of later developing Alzheimer's disease or another neurodegenerative disorder. Though a causal link cannot be confirmed, an NIH study in which researchers mined the medical records of hundreds of thousands of people in Finland and the United Kingdom found significant associations.

To learn more, click the red button below.

LEARN MORE

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Shared Decision-Making Resources and Treatment Cost Information

As we get older, knowing how to navigate the healthcare system and choosing the best care for ourselves is crucial. With funding from The John A. Hartford Foundation, FAIR Health created this section for older adults. It includes tools you can use to plan for the costs of your care and make better healthcare decisions—whether you make them alone or with a caregiver who helps you.

To learn more, click the red button below.

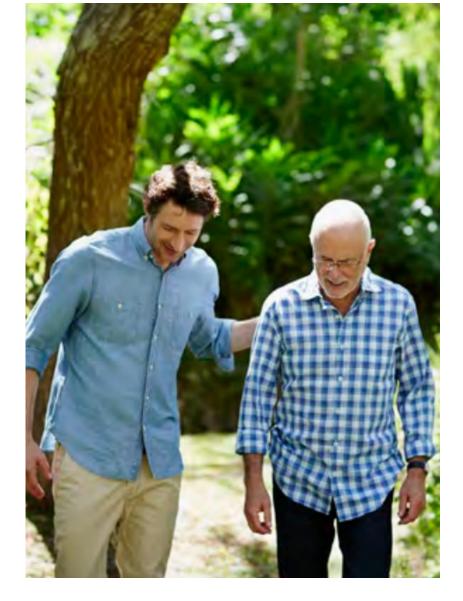
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Holding a Family Meeting

When taking care of an elderly parent or another relative, family members need to work cooperatively. The more people participating in care, the less alone a caregiver feels in his/her role. Books and articles about caregiving often mention the family meeting as a way to facilitate this process. But how does one go about having such a meeting?

To learn more, click the red button below.



Conversation Starter Guide for Caregivers of People with Alzheimer's or Other Forms of Dementia

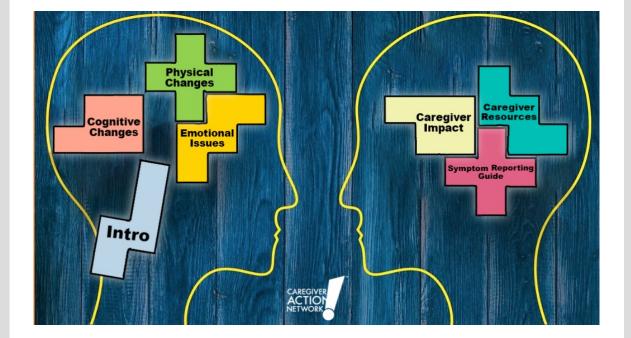
It can be hard to start conversations about health care through the end of life with someone you care for. It can be even harder when the person has Alzheimer's disease or another form of dementia. Over time, they begin to lose their memory, capability to independently perform daily routines and tasks, or reasoning ability.

As dementia progresses, it will become harder for the person you care for to express their wishes for care. Having conversations early and often can help you know their values and wishes. Then, you will be better informed to make health care decisions on their behalf.

That's why it's best to start a conversation before any treatment decisions need to be made. Sometimes, we might avoid the conversation by telling ourselves, "it's too soon." But it always seems too soon, until it's too late.

The Conversation Project has produced a guide intended to help caregivers prepare for making care decisions for those they care for as the need arises. The goal of this guide is to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected.

To view the guide, click the red button below.



Traumatic Brain Injury Caregiving Puzzle

As a caregiver for a loved one who has suffered a traumatic brain injury (TBI), there are many decisions to make. What is the best treatment plan to unlock your loved one's path to recovery? You want to meet the expectations your loved one has for recovery, but the decisions you make also need to factor in the feasibility of execution by both the patient and their support team.

If your loved one has a TBI, there is no single clear path to deal with the changes they'll go through. The time it takes to heal varies from person to person and depends on many factors, including how long it takes to receive the most appropriate medical treatment.

To learn more, click the red button below.



There's No Place Like Home: Creating Safe Environments

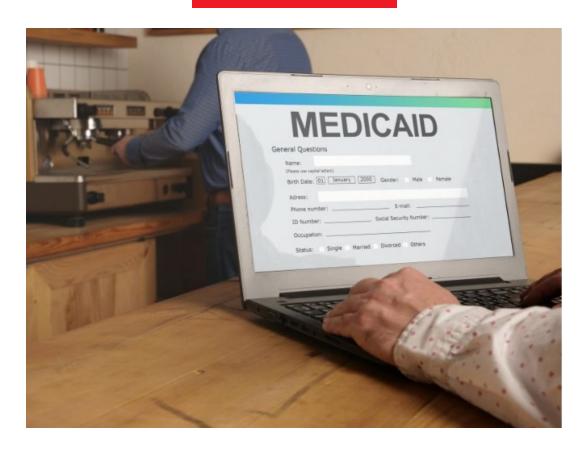
for People with Late Stage Dementia

As any poll on the living preferences of older adults will tell you, the majority want to age in place in their current home—and that includes people with dementia and/or intellectual and developmental disabilities (IDD). This preference remains strong whether or not the person will be living alone; in fact, around one third of people with dementia live on their own. Though there are challenges posed by not living in a specialized setting, it's also true that change can be very stressful for those with dementia and IDD, and that familiar environments provide a great amount of comfort and stability. The famous The Wizard of Oz quote says it best: "There's no place like home."

That said, the home may not always be the safest or most convenient place for people with dementia and IDD to live. Effective and sustainable aging in place requires more than just wanting to do it: it involves planning, anticipating problems, devising solutions and modifying the home to a loved one's needs. As a caregiver, you can play a part in helping your loved one continue to live safely in familiar surroundings by assessing their home.

To learn more, click the red button below.

LEARN MORE



A Beginner's Guide to Medicaid

Medicaid is a federally controlled, state-administered health insurance program that covers vulnerable Americans at all stages of life. As of November 2022, it insures more than 88 million Americans from birth through age 65 and beyond. Given the scope of its coverage base, it's not surprising that the system is incredibly complex, and the rules may seem even more confusing if you're thinking about nursing home placement and trying to navigate important long-term care decisions at the same time.

Although Medicaid has been insuring low-income families since 1965, the program is more important than ever due to the high cost of care. The continual increase in cost of medical care services takes the biggest toll on people who often need it the most like children, pregnant mothers, disabled adults, and seniors. These communities depend on programs such as Medicaid to be able to afford the services and support that they need to thrive.

Medicaid is an excellent resource for seniors as it provides comprehensive coverage and works hand-in-hand with Medicare. But, it can be a challenge to understand how the program works, what it covers and who qualifies, especially since requirements vary by state and differ based on an applicant's medical needs and financial situation.

To view the guide, click the red button below.

LEARN MORE



Financing the Future

People with intellectual and developmental disabilities (IDD) must plan for how they will pay for the things they want and need in their life.

You don't need a lot of money to plan — but you do need to make a plan!

A financial plan lays out the money and financial resources a person has, ways a person will save money over time, and items a person may want to pay for over their life.

To learn more, click the red button below.

LEARN MORE

THE DEMENTIAS

Hope Through Research

The Dementias: Hope Through Research

This guide from the National Institute of Health is an overview of research on Alzheimer's, vascular dementia, mixed dementia, CTE, frontotemporal disorders, Lewy body dementia, and more.

To view the guide, click the red button below.

VIEW THE GUIDE



Managing Older Adults' Chronic Pain: Higher-Risk Interventions

The American Journal of Nursing (AJN), in conjunction with the AARP Public Policy Institute, has published a paper, "Managing Older Adults' Chronic Pain: Higher-Risk Interventions." For health care providers, family caregivers, and care recipients, treating chronic pain while balancing concerns about adequate pain relief, functional improvement, and harm avoidance can be challenging. When lower-risk treatment approaches (such as acetaminophen, topical medications, heat or cold, and massage) don't sufficiently alleviate older adults' pain, riskier treatments (such as nonsteroidal anti-inflammatory drugs [NSAIDs], adjuvant analgesics, opioids, and interventional procedures) may be needed.

This article discusses evidence-based, higher-risk strategies to control chronic pain and considerations for caregiver involvement in treatment planning and monitoring.

To view the research paper, click the red button below.

VIEW THE PAPER



The Saving Power of a Caregiving Journal

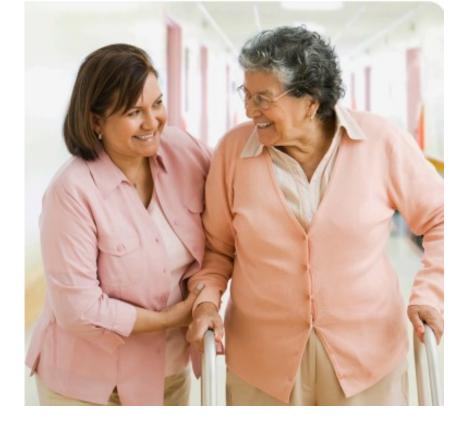
Throughout my tenure as a family caregiver, I used my journal as a historical record and place to vent without troubling anyone else. Other caregivers' journals are filled with worry lists or angry diatribes at a loved one's doctors, or used as a means of monitoring their own thoughts and moods. Still others keep gratitude journals in which they write down three moments of joy or humor they experienced during that day for which they felt grateful, as proof that caregiving isn't always gloom, doom and drudgery.

Regardless of the journaling format, research suggests that writing down our experiences decreases the likelihood we'll become depressed. As the website for the branch of popular psychology known as positive psychology notes, journaling "helps [people] build a buffer between their negative thoughts and their sense of well-being."

To learn more, click the red button below.

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Let's Talk about Being a Stroke Family Caregiver

Caregivers for stroke victims can be spouses, family members or friends. Often one person—spouse, adult child or parent—will provide most of the care.

It's important that caregivers and stroke survivors be "care partners." The challenges to adjust to your new role may be easier if both share in decision-making. It's also important to share how you're feeling.

There is no "job description" for caregivers. Each caregiver's responsibilities vary with the unique needs of the stroke survivor. Role changes and new skills may need to be learned.

To learn more about caring for a stroke victim, click the red button below.



Support for Caregivers of Cancer Patients

If you're helping your family member or friend through cancer treatment, you are a caregiver. There are different types of caregivers. Some are family members, while others are friends. People of different races and cultures give care to others in their own way. Every situation is different and there isn't one way that works best.

Caregiving may be:

- helping with day-to-day activities such as doctor visits or preparing food
- giving medicines or helping with physical therapy or other clinical tasks
- helping with tasks of daily living such as using the bathroom or bathing
- · coordinating care and services from a distance by phone or email
- · giving emotional and spiritual support

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Among those who take prescription medication: Among those who take prescription medication: are willing to stop taking one or more medications if their health care provider said it was possible had stopped taking at least one prescription medication taken for more than a year

Views on Medication Deprescribing

Among Adults Age 50-60

Many older adults take multiple prescription medications, over-the-counter medications, and dietary supplements. Medications are important for preventing and managing a wide range of health conditions, but not all medications provide benefit for the person taking them, and some may become unnecessary or even unsafe over time.

In January 2023, the University of Michigan National Poll on Healthy Aging asked a national sample of adults age 50–80 about their medication use and experiences with stopping prescription medications. A full 80% of adults aged 50 to 80 would be open to stopping one or more of the prescription medicines they've been taking for more than a year, if a health care provider said it was possible. Already, 26% said they have done so in the past two years.

To learn more, click the red button below.

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Caring for Someone Who is Vocally Ungrateful

If you're caring for someone who doesn't appreciate your effort, who verbally abuses you, or who generally harms your emotional health, the ideal choice is to leave. At least, from the outsider's perspective, it seems like that's the case. However, it's not always that easy.

So, if you can't leave, aren't ready to, or don't want to, what can you do when someone's vocally ungrateful for you and your care?

To learn more, click the red button below.

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PREPARE for THEIR Care

PREPARE, a leading provider of evidence-based advance care planning tools, has launched a new, easy to use program to support people as they help family and friends with their medical planning and decision-making. The new program, PREPARE for THEIR Care, provides videos and step-by-step guides to learn how to help other people with their

medical planning and how make medical decisions on someone else's behalf.

After over ten years of empowering people to have a voice in their medical care through PREPARE for YOUR Care, PREPARE is using their platform to now help caregivers and surrogate decision makers with communication and decision-making skills so they feel more comfortable initiating advance care planning conversations with their family and friends.

PREPARE for THEIR Care shares valuable information about how to bring up the topic of medical planning, how to talk with family members and friends about their medical wishes, and how to help them write those wishes down. It also provides guidance on how to make medical decisions for those who can no longer speak for themselves, including understanding patients' quality of life priorities, how to talk with medical providers about treatment benefits, risks, and options, and how to deal with potential family conflict.

To learn more, click the red button below.

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Sense of Smell Linked to Speed of Brain Loss and Cognitive Decline

Having a good sense of smell is associated with slower loss of brain volume and cognitive decline in older adults, and the link between sense of smell and brain and cognitive changes may be especially pronounced among those who develop cognitive impairment or dementia. These are the key findings from NIA-led research published recently in *Neurology*.

To learn more, click the red button below.



Alzheimer's May Increase DNA Variants in Brain Neurons

Neurons in the brains of people with Alzheimer's disease accumulate more DNA changes, called somatic variants, and these changes differ from those found in individuals without the disease. The findings from this NIA-funded study, published in Nature, suggest a link between genomic damage to neurons and the development of pathological hallmarks of Alzheimer's.

To learn more, click the red button below.

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Falls and Fractures in Older Adults: Causes and Prevention

A simple accident like tripping on a rug or slipping on a wet floor can change your life. If

you fall, you could break a bone, which thousands of older adults experience each year. For older people, a broken bone can also be the start of more serious health problems and can lead to long-term disability.

If you or an older adult in your life has fallen, you're not alone. More than one in four people age 65 years or older fall each year. The risk of falling — and fall-related problems — rises with age. However, many falls can be prevented.

To learn more, click the red button below.

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Relieving Treatment-Resistant Depression in Older Adults

Depression is common among older adults, and treatment with standard antidepressants doesn't always work. When a person's depression persists after trying at least two different antidepressant drugs, it is called treatment-resistant depression. In these cases, physicians may add a second medication. Alternatively, they might suggest switching to a different class of antidepressant. But there's only limited evidence from clinical trials about which approaches might be best.

To learn more, click the red button below.

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Be Good to Yourself by Practicing Self-Care

Dealing with depression or bipolar disorder also takes a toll on you, the caregiver, and your relationships with other family members and friends. It can be a balancing act between helping the person living with a mood disorder while still supporting yourself and others in your life. Taking time for self-care and setting and enforcing boundaries can help you maintain this balance.

To learn more, click the red button below.

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Getting Started with Long-Distance Caregiving

Anyone, anywhere, can be a long-distance caregiver, no matter your gender, income, age, social status, or employment. If you are living an hour or more away from a person who needs your help, you're probably a long-distance caregiver. Anyone who is caring for an aging friend, relative, or parent from afar can be considered a long-distance caregiver.

Long-distance caregivers take on different roles. Over time, as your family member's needs change, so will your role as long-distance caregiver.

To learn more, click the red button below.



Eight Tips for Long-Distance Caregiving

Long-distance caregiving presents unique challenges. If you find yourself in the long-distance caregiving role, here is a summary of things to keep in mind.

Experienced caregivers recommend that you learn as much as you can about your family member or friend's illness, medicines, and resources that might be available. Information can help you understand what is going on, anticipate the course of an illness, prevent crises, and assist in healthcare management. It can also make talking with the doctor easier. Make sure at least one family member has written permission to receive medical and financial information. To the extent possible, one family member should handle conversations with all health care providers.

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Brain Donation: A Gift for Future Generations

Brain Donation FAQs: A Gift for Future Generations

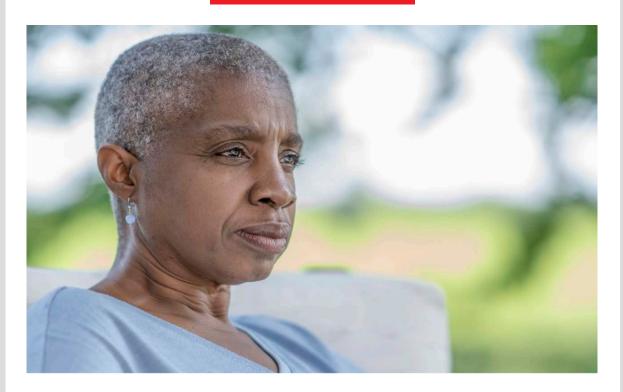
Brain donation helps researchers study brain disorders, such as Alzheimer's disease and related dementias. One donated brain can make a huge impact, potentially providing information for hundreds of research studies. This helps researchers learn how the brain is affected by diseases and how we might better treat and prevent them.

The National Institute on Aging has provided an infographic to help spread the word about brain donation.

To view the infographic, click the red button below.

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Alzheimer's Disease Facts and Figures

The 2023 edition of *Alzheimer's Disease Facts and Figures*, an annual report released by the Alzheimer's Association, reveals the burden of Alzheimer's and dementia on individuals, caregivers, government and the nation's health care system.

The accompanying special report, *The Patient Journey in an Era of New Treatments*, examines the importance of conversations about memory at the earliest point of concern, as well as a knowledgeable, accessible care team to diagnose, monitor disease progression and treat when appropriate. This is especially true now, in an era when treatments that change the underlying biology of Alzheimer's are available.

To view the report, click the red button below.

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What Causes Alzheimer's Disease?

Scientists don't yet fully understand what causes Alzheimer's disease in most people. The causes probably include a combination of age-related changes in the brain, along with

genetic, environmental, and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of Alzheimer's disease may differ from person to person.

Alzheimer's disease is a progressive brain disease. It is characterized by changes in the brain—including amyloid plaques and neurofibrillary, or tau, tangles—that result in loss of neurons and their connections. These and other changes affect a person's ability to remember and think and, eventually, to live independently.

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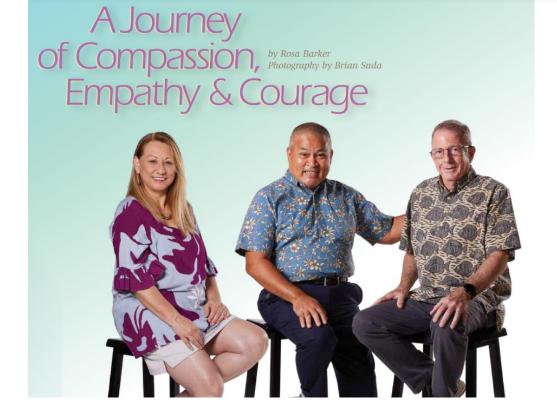


Aging & Disabilities Issues 2023: A Guide for Hawai'i's Legislators, Organizations and Citizens

This 2023 issue of the Aging & Disabilities Issues report is the 18th annual publication that offers an overview of legislative issues dealing with aging, disability, caregiving, and long-term care services and supports in Hawai'i. This report calls attention to the priority issues that deserve the serious attention of our lawmakers, advocates, and the public. It is a joint project of the Hawai'i Family Caregiver Coalition (HFCC), the Policy Advisory Board for Elder Affairs (PABEA), the Executive Office on Aging (EOA), the Hawai'i Pacific Gerontological Society (HPGS), and the Maui County Office on Aging (MCOA).

To view the guide, click the red button below.

VIEW THE GUIDE



A Journey of Compassion, Empathy & Courage

A common thread runs through a tapestry of three stories. Having experienced the caregiving role themselves, Savina Makalena, Gary Simon and Gary Powell all saw the need to support individual caregivers and the various entities involved in providing that support. And seeing that need, they all decided to help fulfill it, each in their own way.

To view the guide, click the red button below.

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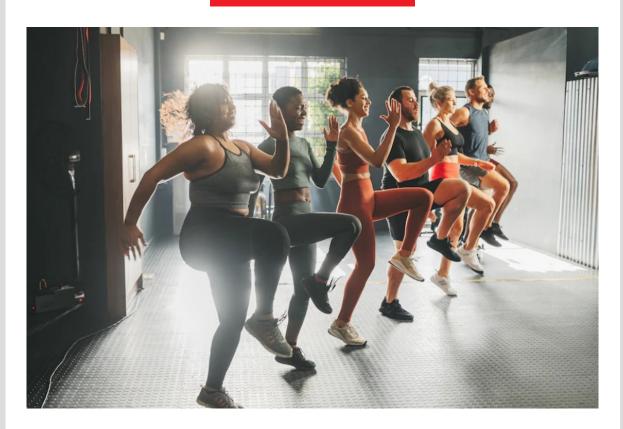
Racial Disparities in Pulmonary Fibrosis Outcomes

Pulmonary fibrosis (PF) involves progressive scarring of lung tissue. The disease usually occurs in people older than 50. Smoking increases the risk for PF, but in many cases the cause of the disease isn't known. There is no cure, and up to half of patients die within five years of diagnosis. Racial and ethnic minority groups generally face increased risks of illness and death due to health disparities. But in the case of PF, little has been known about whether the disease affects people from different racial and ethnic groups differently.

To learn more, click the red button below.

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How Exercise Leads to Sharper Thinking and a Healthier Brain

To build a better brain, just exercise.

That's the message of two important new studies of how physical activity changes our minds. In one, scientists delved into the lives, DNA and cognition of thousands of people to show that regular exercise leads to much sharper thinking.

Another study helps explain why exercise is good for the brain. Researchers found that just six minutes of strenuous exertion quintupled production of a neurochemical known to be essential for lifelong brain health.

To learn more, click the red button below.

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How to Support Your Loved One with Pulmonary Fibrosis

It is not always clear how you can help someone with pulmonary fibrosis. It is a disease that is very stressful and a diagnosis can be difficult on family, friends and caregivers. Here are some ways you can support a loved one diagnosed with PF.

To learn more, click the red button below.

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Alzheimer's and HRT: Study Suggests Sweet Spot to Avoid Dementia

Alzheimer's disease strikes women harder than men — over two-thirds of those who descend into dementia's devastating twilight are female at birth. That's likely due to biological reasons that remain poorly understood, according to the Alzheimer's Association.

One key piece of the enigma: Women lose sexual hormones such as estrogen when they undergo menopause, either naturally through the body's decreased production or by removal of the ovaries via surgery. However, just how the loss of those hormones and the impact of hormone replacement therapy, or HRT, affects dementia risk is also unclear.

A new study may have uncovered a piece or two of the puzzle. Women who underwent early (age 40 to 45) or premature (before age 40) menopause or women who began hormone replacement therapy more than five years after menopause had higher levels of tau in their brains, according to the study.

To learn more, click the red button below.



How to Forgive Others after Family Caregiving Ends

During my caregiving years, I had a list of people in my mind with whom I was angry. There was the family member who made weak excuses to avoid caring for my mother with dementia. There was the distant relative who unfairly criticized my caregiving. And there was my mother herself, resentful of my intrusion into her life, who treated me as if I were her enemy. My anger seemed to me like a perfectly justifiable response. I did not need them working against me to make caregiving any harder than it already was.

This month marks six years since my mother died and my job as a caregiver suddenly ended. Nowadays, my better self tells me I should have long ago forgiven the people on my old list. But on too many occasions, I still find myself sourly recalling how others disappointed me and then feeling fresh indignation.

To learn more, click the red button below.

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10 Tips for Splitting Caregiving Costs Among Siblings

Jaclyn Strauss has four words of advice for siblings who want to share the costs of

parental caregiving: play to your strengths.

That's precisely what she and her brother have done in preparation for what they both know will be substantial caregiving costs for their 78-year-old father living in Tampa, Florida. Even though his caregiving needs have started out relatively small — with a paid aide just a couple of hours a day for home care — the siblings have been preparing for this moment for several years, with regular communication and digital transparency of all their parents' important documents and paperwork. Their mom, a 72-year-old retired schoolteacher, has not needed long-term care, but is too physically and financially stretched to care for her husband.

To learn more, click the red button below.





Preventing Alzheimer's Disease: What Do We Know?

As they get older, many people worry about developing Alzheimer's disease or a related dementia. If they have a family member with Alzheimer's, they may wonder about their family history and genetic risk. As many as 6.5 million Americans age 65 and older live with Alzheimer's. Many more are expected to develop the disease as the population ages —unless ways to prevent or delay it are found.

To learn more, click the red button below.



Caregiving for Someone After a Stroke

When a loved one suffers a stroke, it can be a relief that they survived and are getting good care. But recovery can take time for the patient. Making sure they get the care they need can be a challenge for the spouse, grown child or other loved one who is providing that care at home. Fortunately, resources exist to help you through this difficult time while taking the best care of your loved one and yourself.

To learn more, click the red button below.



Taking Care of YOU: Self-Care for Family Caregivers

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too.

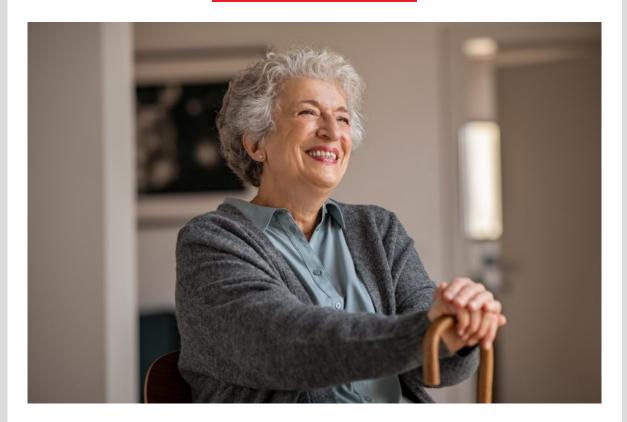
To learn more, click the red button below.



Can I Get Paid to Care for a Family Member?

Unfortunately, very few programs pay family members or friends on a regular basis to provide care. Medicare (government health insurance for people age 65 and older) does not pay for long-term care services, such as in-home care and adult day services, whether or not such services are provided by a direct care worker or a family member. Sometimes, however, caregiving families may obtain financial relief for specific purposes, such as for respite care or to purchase goods and services, and in some cases, pay for caregiving. In some states there are programs that pay family members to provide care to those receiving Medicaid (government health insurance for low-income people — this program may go by a <u>different name in your state</u>). And in a very few states there are programs available to those who do not qualify for Medicaid. NOTE: These programs vary widely, often with complicated criteria for eligibility.

To learn more, click the red button below.



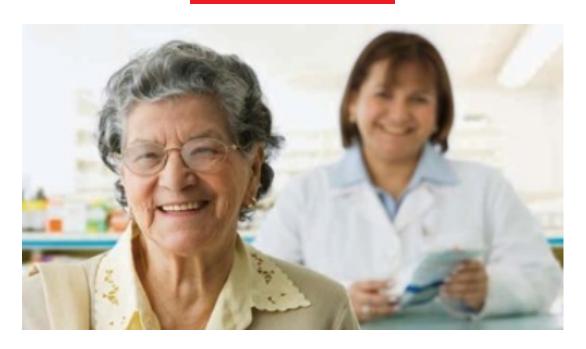
A Guide to Assistive Technology for Seniors

If you're like most seniors, you'd prefer to stay independent and age in place. A 2021 study found that 77% of seniors want to remain in their current home over the long term, and this has been consistent for more than a decade. Thankfully, an increasing number of tools and devices can improve your independence and enhance your safety. Known broadly as assistive technology, or AT, this equipment can help you overcome the challenges that come with aging.

To learn more, click the red button below.

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Taking Medicines Safely as You Age

Medicines are intended to help us live longer and healthier, but taking medicines the wrong way or mixing certain drugs and supplements can be dangerous. Older adults often have multiple medical conditions and may take many medicines, which puts them at additional risk for negative side effects.

To learn more about how to safely take and keep track of all your medicines, click the red button below.

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Caregivers and Depression

"Life feels so heavy. It's as if there is a gray cloud that hovers over everything I do."

"Decision making has become so frightening for me. I think I'm losing my mind."

"I wish I could sleep forever."

If you recognize these feelings in yourself, and if you've been feeling this way day after day, month after month, even year after year, you may be suffering from something more than a simple case of "the blues." You may have a mood disorder - and you may be suffering from depression.

Many caregivers, whose lives have been radically and unexpectedly changed by caring for an ill or disabled loved one, slip into depression disorders. In fact, virtually half of the

respondents to the NFCA caregiver survey said they have experienced prolonged depression because of their caregiving responsibilities. So you're definitely not alone. That in and of itself may not make you feel any better, but here's something that will. Depression is an illness, and it can be cured. You don't have to go through the rest of your life feeling sad and miserable.

To learn more, click the red button below.



Advance Health Care Directives and Physicians Orders for Life-Sustaining Treatment (POLST)

The Advance Health Care Directive (ADHC) allows you to appoint someone (health care agent, attorney-in-fact, proxy, or surrogate) to make a decision for you if you cannot speak for yourself. It is also called the Durable Power of Attorney for Health Care, Natural Death Act, Directive to Physicians, or a Living Will. (The living will is slightly different; check on what is recognized in your state.) Every state recognizes the ADHC, but states have their own forms, as laws vary from state to state.

To learn more, click the red button below.





College & Autism: Insight and Resources for Students with ASD

The lead-up to college can be a stressful time for any student. With so many changes on the horizon, your anxiety may kick up a notch or two. For some, this pre-college anxiety is manageable but for others, it may be harder to handle. If you have autism spectrum disorder (ASD), you may be especially impacted by the thought of incoming change and loss of your routine. However, taking the time to create a preparation game plan for your college transition can make a big difference when it comes to your overall success. So, where do you start?

Before enrolling and heading to campus, learning exactly what you're getting into can help eliminate surprises along the way. Whether it's getting familiar with some of the common challenges, finding the right college to meet your needs and wants, or getting acquainted with your on-campus resources, it's never too early to map out your move to college.

To learn about the obstacles on the road ahead and get expert advice on thriving as a student with ASD before you take the leap into higher education, click the red button below.

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