

THIS WEEK IN CAREGIVING



April 19, 2023



CAREGIVING IN THE NEWS

Drained: The Plight of Unpaid Caregivers

The growth in America's aging population and a shortage of professional caregivers means many people are sacrificing their health, hobbies and financial stability to provide unpaid care. Fortunately, caregivers can take advantage of a growing list of tools and resources that can help them access convenient, affordable and quality care, both for their loved ones and for themselves.

From: U.S. News | Published: April 12, 2023

READ MORE



What SuperAgers Show Us about Longevity, Cognitive Health as We Age

Aging often comes with cognitive decline, but "SuperAgers" are showing us what is possible in our golden years.

"These are like the Betty Whites of the world," Emily Rogalski said. She is a cognitive neuroscientist at Northwestern University's Feinberg School of Medicine and associate director of the Mesulam Center for Cognitive Neurology and Alzheimer's Disease.

From: Washington Post | Published: April 13, 2023

READ MORE



Nearly 1 in 3 Have Left Their Jobs to Help Ailing Family, and the Cost of Lost Wages Could Hit \$147 Billion by 2050

Jacquelyn Revere was just 29 years old when she quit her job in New York City to become a full-time, unpaid caregiver.

The former TV writer moved across the country to Los Angeles to live with her mother and grandmother, both of whom had Alzheimer's.

"I took what I thought would be a 21-day leave from my job. I ended up staying here," she says.

From: Yahoo! Finance | Published: April, 2023

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NAC NEWS AND UPDATES



JUST RELEASED!

Supporting Diverse Family Caregivers: A Guide for Patient Advocacy Groups

DOWNLOAD NOW

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

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

To learn more, click the red button below.

LEARN MORE



Caregiving is
an emotional
experience.



CALL: 1.888.665.2190

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



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

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

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

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

We want to know:

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

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

To learn more, click the red button below.

LEARN MORE





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](#)
>

The image shows the cover of a report. The title 'Chronic Disease Family Caregiving Through a Public Health Lens' is in white font. Below the title, the subtitle 'THE FRAMEWORK FOR FAMILY CAREGIVING AND PUBLIC HEALTH' is in red font. The date 'SEPTEMBER 2022 REPORT' is printed. The background of the cover features a group of people. Logos for NAC, the National Association of Public Health Directors, and the John A. Hartford Foundation are visible at the bottom.

JUST RELEASED!

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

[DOWNLOAD NOW](#)

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

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

Included in this report:

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

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

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

VIEW THE REPORT



EVENTS & OPPORTUNITIES

APRIL



Make Your Voice Heard: Tips for Effective Caregiver Communication

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

Caregivers navigate many relationships between the care recipient, healthcare

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

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

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

REGISTER



What's Next for Me After Caregiving Ends?

April 21, 2023 | 1:00 PM - 2:00 PM ET | Online

When a personal caregiving experience ends, you may wonder: What's next for me?

Because of your personal caregiving experience, you'll look at your life's work with a fresh perspective. During this interactive workshop, caregiving coach Denise Brown will help you see possibilities for your career or your volunteer work. She'll also share how other family caregivers transform their personal caregiving experience through Denise's training programs.

About Denise Brown

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

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



Caring for Our Own: Showing Up and Showing OUT Registration

April 21, 2023 | 10:00 AM - 6:00 PM ET | Online

Join the Alzheimer's Association for its 3rd Annual Caring for Our Own LGBTQ Caregiver Seminar: Showing Up and Showing OUT to hear from experts about dementia, caregiving, and LGBTQ aging needs. This is an online event.

Risk factors for Alzheimer's and other dementias can occur at any age, but in LGBTQ communities we are learning about particular impacts and challenges to our loved ones and ourselves as we get older and care for one another. Moderated by Dallas-area drag queen, Demanda Refund, the seminar will review LGBTQ insights into brain health, caregiving, and resources.

This year's featured speaker is Jason Flatt, Assistant Professor of Public Health at the University of Nevada-Las Vegas and a leading researcher of LGBTQ older adults. Dr. Flatt will highlight intersections between LGBTQ identities, care, aging, and dementia and discuss ongoing efforts to improve LGBTQ inclusion in medical research. Additional sessions will link lifestyle factors to brain health, compare caregiving experiences across generations and identities, and introduce ways LGBTQ communities and professionals can show up for one another and for themselves through aging advocacy and community-based services.

3.0 CEUs will be available to social workers, licensed professional counselors, and nurses at no cost.

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

REGISTER



Mental Capacity

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

Join the UK's Dementia Carers Count on April 24th for an online discussion of mental capacity and the way in which it is assessed. The lasting powers of attorney roles and main considerations of a best interest decision for people who do not have capacity for a decision are also discussed.

This session is for you if:

- you would like to gain a better understanding the mental capacity act
- you are looking for strategies to support a person to be involved in decision making
- you want to know what to do if the person does not have capacity for a decision
- you want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- you would like to meet other people who are taking care of a friend or family member with dementia in a similar situation

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

REGISTER



The Fourth Summit: Geroscience for the Next Generation

April 24 - 26, 2023 | 9:00 AM - 5:00 PM ET

Online and In-person at NIH's Natcher Conference Center (Bethesda, MD)

On April 24-26, 2023, the NIH Geroscience Interest Group (GSIG) will host the fourth Geroscience Summit with in-person and virtual options. This landmark event will bring together researchers and clinicians interested in geroscience and aging to explore the state of the science.

The Summit will be an opportunity to further develop and implement geroscience in an equitable manner, while considering the breadth and heterogeneity of physiology among individuals across all populations. Researchers and clinicians will have an opportunity to discuss new approaches to understanding and addressing multimorbidity and geriatric syndromes, two clinical conditions that place a significant burden on older populations.

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

REGISTER



Creating an End-of-Life Plan

April 25, 2023 | 11:30 AM - 12:30 PM ET | Online

Thinking and talking about your final wishes can be tough. But doing the work of deciding, discussing, documenting and sharing those wishes with your loved ones has proven to provide peace of mind for everyone.

Getting the practical side of your affairs in order will give reassurance that "everything is taken care of" to those you care most about and unburden them from having to make difficult yet necessary decisions as they grieve and mourn.

Attend this webinar and learn how to:

- Plan and document your wishes in case of medical or other emergencies
- Track important medical and insurance information
- Store key information on property, vehicles and non-financial assets
- Document what you have and what you owe
- Make the "unseen" visible by creating a digital estate plan
- Express your final wishes for how you'd like to be remembered
- Provide grief support to your loved ones before and after your death
- Store and digitally access all your final wishes documents

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 webinar via Zoom prior to the event.

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

REGISTER





Helping Teens Heal from Trauma

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

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

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

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

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

REGISTER



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

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

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

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

REGISTER



Take Charge! Advance Care Planning Tips

April 26, 2023 | 2:00 PM - 3:00 PM ET | Online

Advance care planning is a process, not an event, and is planning for future care based on your values, beliefs, preferences, and specific medical issues. An advance health care directive is the record of that process.

YOU decide your plan and you update it whenever you'd like, because it's your life and it's worth your time.

-Why did YOU decide?

-Was it for a specific family member? Yourself? Your beloved pet?

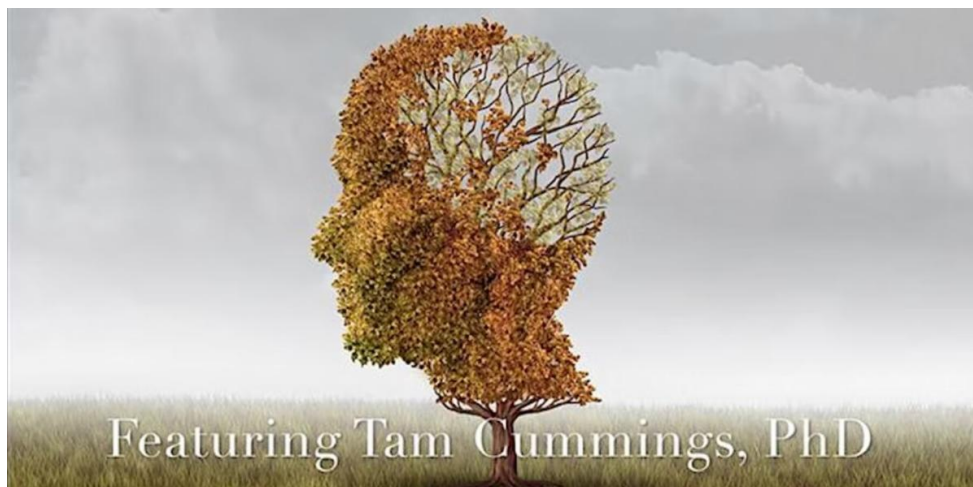
-Did you/will you share your plan with loved ones to ensure they don't have to guess?

Are you ready to learn more? Join the Family Caregiver Alliance on April 26th for an online session that will further explore advance care planning.

Materials to review in advance of the evening can be found online by clicking [here](#).

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

REGISTER



Pain and Other Assessments in a Person with Dementia

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

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

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

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

REGISTER
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MAY



Caregiver Mental Health: How to Reduce Anxiety for Better Living

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

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

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

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

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

REGISTER



As Dementia Progresses: Moderate to Advanced Stage

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

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

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

REGISTER



THE MATHISON CENTRE
for MENTAL HEALTH RESEARCH & EDUCATION

Understanding Dementia: Causes, Treatments and Living Your Best Life

May 4, 2023 | 8:00 PM - 9:00 PM ET | Online

Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. There is no proven cure for dementia. Research suggests that combining healthy habits promotes good brain health and reduces risk of cognitive decline. Join experts from the Mathison Centre in

Calgary to discuss research on the causes, treatments, impact and what resources there are to support patients and families.

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

REGISTER



What's My Caregiving Impact?

May 5, 2023 | 1:00 PM - 2:00 PM ET | Online

According to recent research:

*Eight in 10 (80%) family caregivers are interested in paying for products or services to help them manage

*Almost nine in 10 (87.9%) cannot identify any companies that stand out in helping them as caregivers.

Family caregivers need a local resource who can guide them, support them and encourage them. They need someone like you.

When a personal caregiving experience ends, you may wonder: How can I make a difference to make the experience easier for family caregivers?

Because of your personal caregiving experience, you'll look at your life's work with a fresh perspective. Join Denise Brown on May 5th for an interactive workshop that will help attendees see possibilities for their careers or volunteer work.

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

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

REGISTER





Parkinson's IQ + You, Mid-Atlantic

May 6, 2023 | 8:00 AM - 1:15 PM ET | Wilmington, Delaware
Chase Center on the Riverfront (815 Justinson Street)

Join the Michael J. Fox Foundation in Wilmington, Delaware on May 6, 2023, for Parkinson's IQ + You, a free educational event designed for people with Parkinson's and their loved ones. This in-person event features a program with sessions on navigating Parkinson's, managing care and learning about research participation. The accompanying Partner Expo includes information on treatment options and local resources for the Parkinson's community.

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

LEARN MORE
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Advance Directives: What Families Should Know

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

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

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

REGISTER



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

May 9, 2023 | 4:00 PM - 5:30 PM ET | Online

For centuries, we've known that the health of the brain and the body are connected. But now, science is able to provide insights into how to make lifestyle choices that may help you keep your brain and body healthy as you age. Join the Kedlac Neurological Resource Center on May 9th to learn about research in the areas of diet and nutrition, exercise, cognitive activity and social engagement, and use hands-on tools to help you incorporate these recommendations into a plan for healthy aging.

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

REGISTER



**SAINT LOUIS
UNIVERSITY™**

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.

REGISTER



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.

REGISTER



Register Now!

6th Annual Older Adult Mental Health Awareness Day Symposium

May 11, 2023

CEUs offered for multiple disciplines



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.

REGISTER



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



Alzheimer Society
D U R H A M R E G I O N

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.

REGISTER
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**METTLE
HEALTH**

Conversations and Events

Advance Care Planning: Advance Directives Deep Dive

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

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

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

All online discussions begins with a basic overview of the day's topic before opening up to

the group for Q&A and conversation. This session should feel as supportive as it does educational, so bring your questions and comments, or feel free to just listen. Together, we'll explore real life examples and address your questions on the topic.

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

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

REGISTER



Comfort for Caregivers: Strategies for Dealing with Caregiver Stress

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

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

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

REGISTER





Dealing With Dementia

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

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

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

REGISTER



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.

REGISTER



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



**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.

REGISTER





Setting Boundaries for Healthy Relationships and Caregiver Self-Care

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

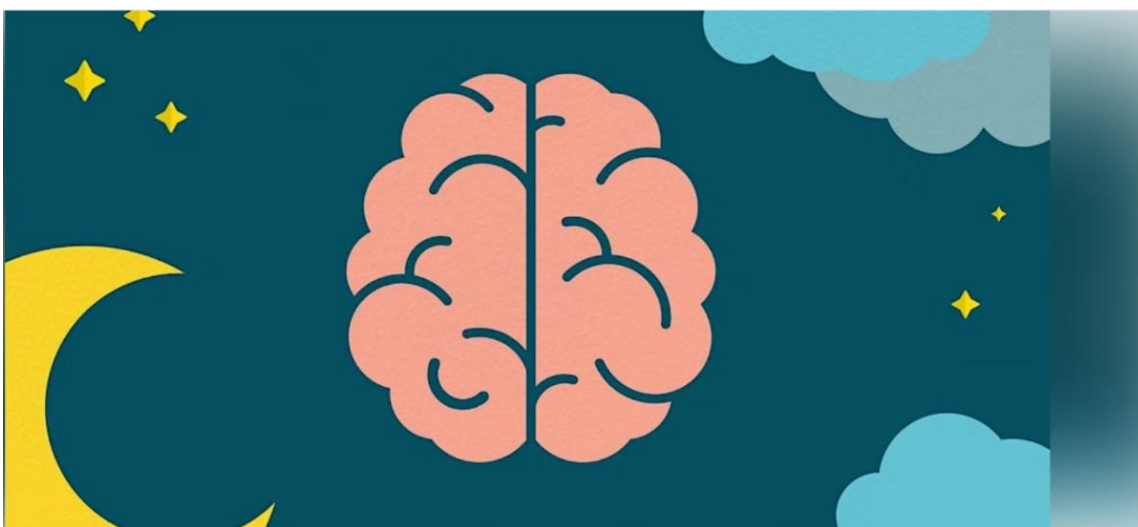
Healthy boundaries are essential for any caregiver supporting a loved one living with depression. Boundaries provide structure in relationships and ensure that everyone involved is respected and gets their needs met. By setting clear limits, you can prioritize your wellness while continuing to be a support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

REGISTER



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
>

JUNE

Aspects of Caregiving

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

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

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

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

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

REGISTER
>



Caring for Your Caregiver

June 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.

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.

REGISTER



Defining Dementia: Progression, Treatment & Strategies

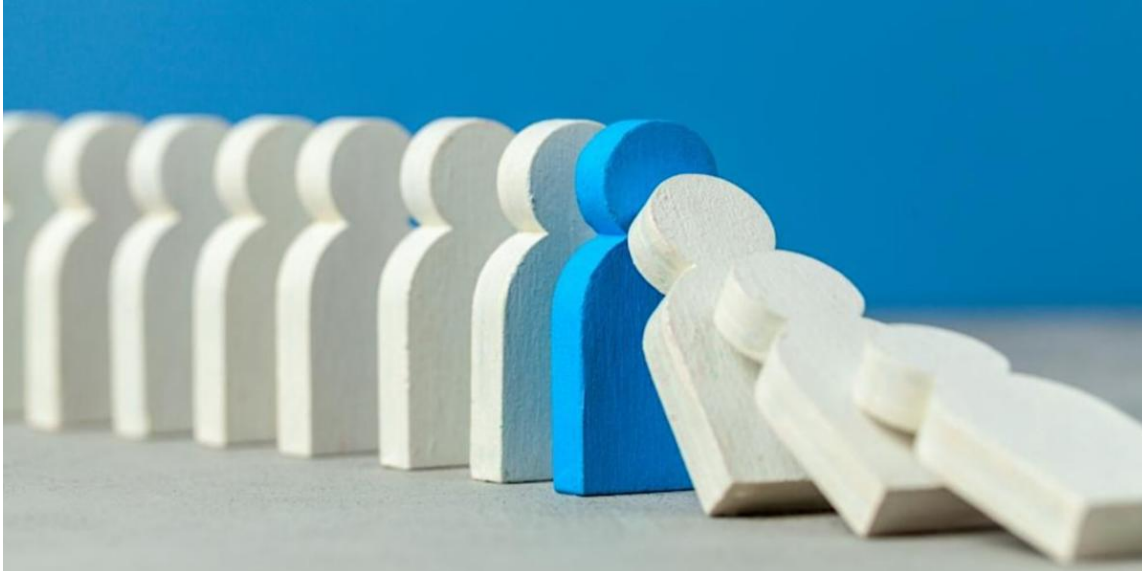
June 15, 2023 | 1:00 PM - 2:00 PM ET | Online

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.

REGISTER





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.

REGISTER



Young Onset Dementia

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

Join the [Alzheimer Society of Durham Region](#) (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

Online Therapy for Caregivers of People with Memory Loss

Start: February 16, 2023

End: June 2024

Enrollment: 100

Who is sponsoring this study? Utah State University

What is this study about?

This study will examine the effectiveness of a self-guided, online therapy program to increase overall well-being for caregivers of people with dementia or other significant memory loss. The therapy program is designed to build skills of acceptance, being present, and committed action to foster a sense of meaning in life. Participants will be randomly assigned to receive the program either right away or after one month. All participants will complete six online, self-guided, 30-minute sessions within one month. At the start of the study, after one month, and at a six-week follow-up, participants will answer questions about their mental health, caregiving experience, sleep, quality of life, and overall experience with the program.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: N/A

Must have:

- Family caregiver to a person with dementia or other significant memory loss (caregiver is not required to live with the person with dementia to join the study)
- Distress due to caregiving role
- Able to read and write in English
- Access to a computer, smartphone, or tablet with internet connection

Must NOT have:

- Lives outside of the United States

For more information call Audrey Juhasz at (435)797-1594 or email her by clicking on the red button below.

LEARN MORE
>

Support Program to Reduce Pain Management Stress in

Family Caregivers of Hospice Patients with Dementia

Start: July 15, 2022

End: Aug. 30, 2027

Enrollment: 300

Who is sponsoring this study? University of Pennsylvania

Where is this study located? Pennsylvania

What is this study about?

This study will evaluate the effectiveness of a videoconference support program, named ENCODE, to improve quality of life and reduce stress in informal caregivers managing pain for a person with dementia in hospice. Participants will be randomly divided into two groups. Both groups will have 40-minute videoconferencing sessions with a skilled professional once a week for three weeks. One group will also receive the ENCODE support program designed to address the caregivers' pain management challenges and concerns. Researchers will measure changes in quality of life, mental health, and pain levels experienced by the person with dementia at the start of the study, after three weeks, and after 40 days in follow-up.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: N/A

Must have:

- Family or informal caregiver of a person with Alzheimer's disease or a related dementia who is in hospice
- Have concerns about effectively managing the pain of the person with dementia
- Normal cognition or mild cognitive impairment
- Able to speak and read English
- At least a sixth-grade education

Must NOT have:

- Significant hearing loss that would interfere with the caregiver's ability to complete assessments by phone

For more information call George Demiriz at (215)898-8559 or email him by clicking on the red button below.

LEARN MORE



Online Memory Training to Promote Independence in Older Adults with Mild Cognitive Impairment

Start: February 1, 2022

End: December 2025

Enrollment: 65

Who is sponsoring this study? University of Delaware

What is this study about?

This study will evaluate the effectiveness of an online memory training program designed to improve independent living skills in older adults with mild cognitive impairment. Participants will be randomly assigned to either begin the training program right away or to wait eight weeks. During the seven-week training, participants will interact in group online classes for one hour each week to learn strategies for using three different types of memory aids (calendars, timers, and notes). At the start of the study, and after eight and 16 weeks, all participants will complete questionnaires about their memory, daily functioning, and the use of memory aids and strategies. A small group of participants will also be randomly selected for video interviews after completion of the training. Researchers will measure changes in memory, everyday functioning, cognition, quality of life, and self-efficacy. Each participant will be involved in the study for approximately 18 weeks total.

Do I Qualify To Participate in This Study?

Minimum Age: 60 Years

Maximum Age: 90 Years

Must have:

- Amnesic mild cognitive impairment (primarily affects memory) from probable Alzheimer's disease
- If taking nootropic medication, dosage must be stable for at least two months prior to starting study
- Speak English

Must NOT have:

- History of a major psychiatric disorder (e.g., schizophrenia)
- Untreated major depression
- History of a medical disease or disorder that could contribute to cognitive impairment
- Major vision, hearing, or motor impairment that would affect the ability to complete study procedures, including the phone screening evaluation
- Substance use disorder in the past five years
- Current participation in another study related to memory

For more information call Alyssa Lanzi at (302)831-0420 or email her by clicking on the red button below.

LEARN MORE



Smart Reminders to Promote the Use of Home-based Cognitive Training

Start: Nov. 7, 2022

End: March 1, 2024

Enrollment: 190

Who is sponsoring this study? Florida State University

Where is this study located? Florida

What is this study about?

This study will evaluate the effectiveness of an adaptive, personalized reminder system to improve adherence to a home-based cognitive training for older adults. All participants will engage in a cognitive training program from home, using a computer tablet. Participants

will be randomly assigned to receive training reminders through either the smart reminder system or phone text messages over six months. Researchers will measure adherence to the cognitive training program and changes in cognition. Information about personality, busyness, and technical skills will also be collected to inform the design of the personalized reminder system.

Do I Qualify To Participate in This Study?

Minimum Age: 65 Years

Maximum Age: N/A

Must have:

- Normal cognition
- Normal or corrected-to-normal vision

Must NOT have:

- Parkinson's or Alzheimer's disease, or any other neurodegenerative disease
- Terminal illness
- Blindness or deafness
- Severe motor impairment
- Not living in the Tallahassee area for the entire six-month study period
- Unable to read at or above a sixth-grade level

For more information call Walter Boot at (850)645-8734 or email him by clicking on the red button below.

LEARN MORE



UNIVERSITY OF MINNESOTA
Driven to DiscoverSM

Do You Know Someone with Memory Loss Living at Home?

The University of Minnesota is investigating a new technology that could make visiting with others easier.

The Smartwatch Reminder System is designed to help people with memory loss remember names and relationships by displaying photos and information about home visitors on a wristwatch.

What

*A 6 month research study with 3 surveys. A few participants will be selected for in depth interviews.

Who is eligible

*People with mild to moderate memory loss and their care partner.

Where

*Participate from the comfort of home.

Why

*To understand whether and how the Smartwatch Reminder System can help people with memory concerns.

Each pair will receive up to \$150 for participating.

To learn more about this study, call (612)626-9576 or send an email to memoryaid@umn.edu.

To participate in the study, click the red button below.

JOIN THE STUDY



Boston Cognitive Assessment: Online Cognition Testing

Start: October 1, 2019

End: October 1, 2029

Enrollment: 10000

Who is sponsoring this study? Alzheimer's Light LLC

What is this study about?

The Boston Cognitive Assessment (BoCA) is an online test to measure cognition over time. BoCA uses random tasks that are different each time to assess various cognitive functions including memory, visual-spatial perception, attention, mental math, and language. Each time a participant completes the test, they receive their score immediately, followed by an email with a link to a full report and progress chart. The study aims to increase access to cognitive testing to support the monitoring of cognition over time. If changes in cognition are detected, the BoCA test may help doctors figure out if cognitive decline is caused by an underlying condition and provide appropriate care.

Minimum Age: 50 Years

Maximum Age: N/A

To enroll and participate, clicking on the red button below.

ENROLL



Genetic Characterization of Movement Disorders and Dementias

Start: February 12, 2003
End: December 31, 2059
Enrollment: 12,000

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

Where is this study located? Maryland

What Is this study About?

In this observational study, researchers will examine the genes of families with a history of movement disorders (such as Parkinson's disease) and dementias (such as Alzheimer's disease) to try to find a genetic cause of these disorders. Participants include individuals with a clinical diagnosis of a movement disorder or dementia, their affected and unaffected family members, and unrelated, healthy individuals (to provide control samples). This study usually requires one visit to the NIH Clinical Center where participants will give a blood sample and/or a saliva sample.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: 100

Must have:

- Diagnosis of a movement disorder or dementia accompanied by sufficient clinical and/or laboratory evidence
- Clinical confirmation of a movement disorder or dementia by the investigator and his associates, either by physical examination and/or review of medical records
- Family member of a person diagnosed with a movement disorder or dementia
- Have no known movement disorder or dementia, or family member with a movement disorder or dementia
- Able to provide consent or, in the case of minors and cognitively impaired individuals, have a legally authorized representative to provide consent
- Able to understand and participate in study procedures or have a legally authorized representative that can consent on participant's behalf

Must NOT have:

- Any movement disorder or dementia caused by a specific environmental exposure, birth injury, metabolic disorder, or brain infection such as encephalitis
- Clinically significant anemia that would make drawing blood unsafe, and participant is unwilling to provide saliva sample
- Clinically significant bleeding that would make drawing blood unsafe, and participant is unwilling to provide saliva sample
- Any medical condition that would make drawing blood unsafe or undesirable (for example, a serious medical illness such as unstable heart disease or unstable chronic obstructive pulmonary disease), and participant is unwilling to provide saliva sample

For more information call Bryan Traynor at (301)451-7606 or email him by clicking on the red button below.

LEARN MORE



Problem Adaptation Therapy for Mild Cognitive Impairment and Depression

Start: July 1, 2017
End: March 31, 2024
Enrollment: 80

Who is sponsoring this study? Weill Medical College of Cornell University

Where is this study located? Maryland and New York

What is this study about?

Psychotherapy, also known as talk therapy, is the use of psychological methods to help a person change and overcome problems in desired ways. This study will explore a form of psychotherapy called Problem Adaptation Therapy in people with mild cognitive impairment. Problem Adaptation Therapy includes a combination of emotion regulation techniques, tools (notes, checklists, calendars, etc.), and caregiver participation. Participants will meet with certified mental health clinicians 15 times over six months to engage in either Problem Adaptation Therapy or supportive therapy. Researchers will look for changes in cognition, depression, memory, and stress reduction.

Do I Qualify To Participate in This Study?

Minimum Age: 60 Years
Maximum Age: 85 Years

Must have:

- Amnesic mild cognitive impairment (MCI)
- Not taking or on stable dose of antidepressants, cholinesterase inhibitors or memantine, without any medical recommendation to adjust dosage in next three months
- Clinical Dementia Rating = 0.5 at screening
- Capacity to consent
- Fluent in English

Must NOT have:

- Significant suicide risk
- Too unstable medically or neurologically to safely enroll in a research trial
- Too psychiatrically unstable to safely enroll in randomized trial of psychotherapy; requires psychiatric hospitalization
- Current involvement in psychotherapy

For more information call Dimitris Kiosses at (914)997-4381 or email him by clicking on the red button below.

LEARN MORE



Memory Aid App to Improve Cognition in People with Mild Cognitive Impairment

Start: Jan. 20, 2023
End: May 20, 2024
Enrollment: 50

Who is sponsoring this study? Washington State University

Where is this study located? Washington

What is this study about?

This study will examine the effectiveness of a personalized, online training program to teach older adults with cognitive impairment how to use EMMA, a memory aid app. The EMMA app works on a computer or smartphone and is designed to support memory and healthy behaviors. In one month, all participants will complete six online training lessons to learn how to use EMMA, with access to technical support. Half of the participants will be randomly assigned to also receive brief phone check-ins with a clinician each week. For the next three months, researchers will track how much the participants use the EMMA app. All participants will complete two phone interviews about their perceived cognitive skills, as well as thinking, memory, and daily functioning tests at the start of the study and after six months of using the app.

Do I Qualify To Participate in This Study?

Minimum Age: 50 Years

Maximum Age: N/A

Must have:

- Self-reported cognition problems, based on questions at study screening
- Able to read and speak English

Must NOT have:

- Any medical, neurological, or psychiatric diagnosis that explains current cognitive issues (e.g., stroke)
- Severe vision or hearing problems that would interfere with the completion of the study procedures

For more information call Margaret Dines at (509)335-4033 or email her by clicking on the red button below.

LEARN MORE
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STRIDE: Stress Reduction in Dementia Caregivers

Dr. Ana-Maria Vranceanu and Dr. Jennifer Huberty are conducting a research study to explore the impact of a 12-week mobile app-based wellness intervention among caregivers of those with Alzheimer's disease or related dementias. Participants in the study will be asked to:

*Be randomized to one of two different groups that will include downloading a mobile health app

*Participate in the app for 10 minutes daily for 12 weeks

*Complete online questionnaires at baseline, postintervention, and follow-up

Qualifying and enrolled participants can earn up to \$50.

Drs. Vranceanu and Huberty invite you to complete a few surveys to determine if this study is a good fit for you. This will involve answering questions such as your status as a caregiver and your current health status.

You have the right not to answer any question, and to stop answering the questions at any time. Your participation in the screening questionnaires is completely voluntary. If you choose to stop answering the screening questionnaires at any time, there will be no

penalty. There is no direct benefit of answering these questions nor are there any foreseeable risks or discomforts from participation in the screening.

By completing this screening questionnaire, you are consenting to the collection of your name and contact information. This information will only be used to contact you about this study and it will not be shared outside of our data collection platform, nor to anyone outside of our team.

If you have questions or concerns, send an email to MGHSTRIDE@studypartners.org.

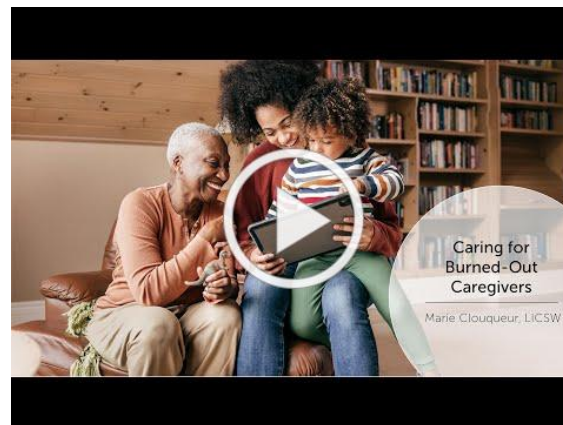
To take the survey, click the red button below.

LEARN MORE



IN CASE YOU MISSED IT...

Caring for Burned-Out Caregivers



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

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

Marie Clouqueur, LICSW, shares ways to identify burnout in caregiver populations, discusses how we can prevent burnout from happening, and answers questions about how caretakers can prioritize their own needs when it may feel difficult to do so.



RESEARCH & RESOURCES



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.

LEARN MORE





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.

LEARN MORE



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.

LEARN MORE
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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.

LEARN MORE
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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.

LEARN MORE



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.

[LEARN MORE](#)



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.

[LEARN MORE](#)





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.

To learn more, click the red button below.

LEARN MORE



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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PREVIOUSLY APPEARED



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.

VIEW THE REPORT
>

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.

To learn more, click the red button below.

LEARN MORE



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).

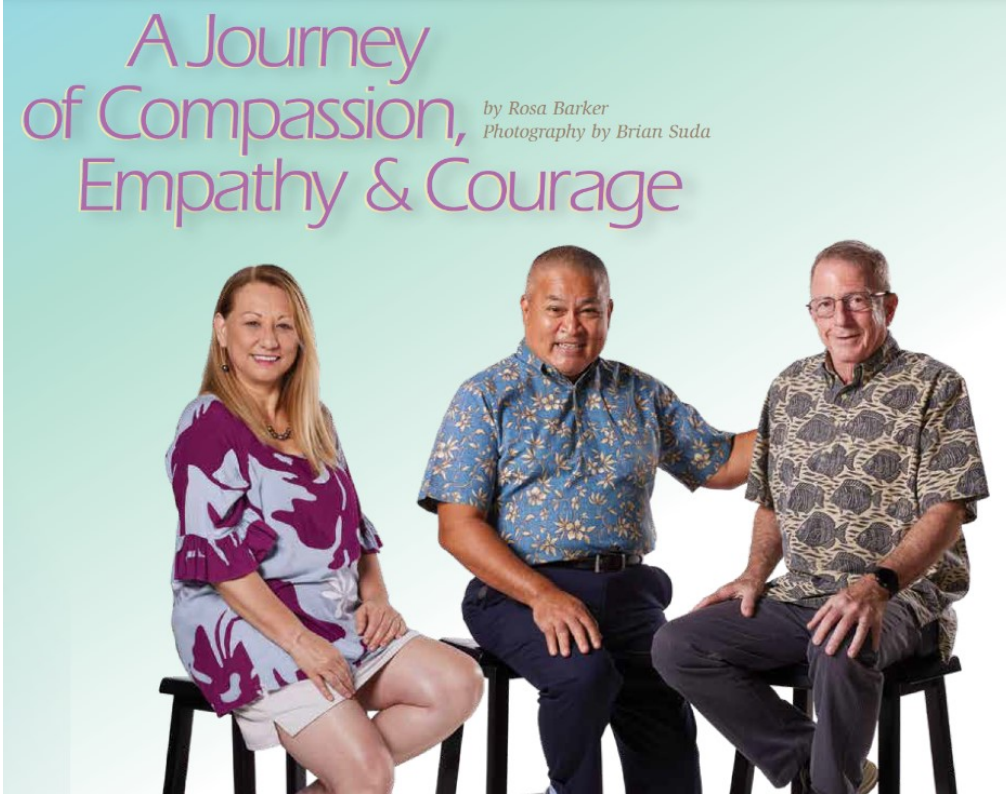
To view the guide, click the red button below.

VIEW THE GUIDE



A Journey of Compassion, Empathy & Courage

by Rosa Barker
Photography by Brian Suda



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.

LEARN MORE



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.

LEARN MORE



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.

LEARN MORE





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.

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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.

LEARN MORE





Your 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. [The Conversation Project](#) offers a free guide for how to begin this process.

To view the guide, click the red button below.

VIEW THE GUIDE





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.

LEARN MORE



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.

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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.

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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.

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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 [different name in your state](#)). 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.

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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.

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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.

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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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NICOA | National Indian
Council on
Aging

Understanding Disabilities in American Indian & Alaska Native Communities Toolkit Guide

The [National Indian Council on Aging \(NICOA\)](#) has released a toolkit dedicated to increasing awareness and knowledge of the needs of American Indian and Alaska Native persons living with disabilities. The toolkit — “Understanding Disabilities in American Indian & Alaska Native Communities” — contains information about disabilities, tribes and resources.

To view the toolkit, click the red button below.

VIEW THE TOOLKIT



Invite Your Caregiver to Your Next Video Visit

Many Veterans feel comfortable when their family member or caregiver is present at their VA appointment. They may offer support in a time of need or provide helpful insight for your VA provider. Now, you can have the same assistance at your video telehealth appointments by inviting up to five family members or caregivers to join you. Just ask about the Caregiver Connect option when scheduling your video visit.

After you provide your guest's name and email address, your VA care team can send them an email invitation with a unique link to take part in your video visit. Caregiver Connect makes it convenient for your family members and caregivers to add the appointment to their calendar and join through their personal link, regardless of their location.

To learn more, click the red button below.

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Resources, Gadgets and Tools to Care for an Older Adult at Home

According to AARP's "Home and Community Preferences" survey, 3 out of 4 adults age 50 or older say they want to stay in their homes and communities as they age. And many do: Nearly 9 in 10 care recipients live in their own home, in someone else's home or in their caregiver's home. Some homes are well-suited for aging and providing care, but many require modifications.

The goal is to help loved ones be as independent as possible at home, for as long as possible. To tailor your or your loved ones' residence for care at home, you can start with a home assessment by an occupational therapist, physical therapist, geriatric care manager (aging life care specialist), certified aging-in-place specialist (CAPS) or qualified professional via the area agency on aging or Department of Veterans Affairs.

To learn more, click the red button below.

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How to Assess When an Older Adult Requires Caregiving Assistance

Sometimes an older adult's need for additional help is obvious. It could be that he or she is having a hard time getting to appointments, seems confused by instructions or perhaps isn't paying bills on time. More often, though, the change happens gradually. That's where a professional assessment comes in. This comprehensive review of all aspects of person's mental, physical and environmental condition is one way to determine if your loved one needs assistance. This helps to evaluate his or her ability to remain safely independent and identify risks and ways to reduce them.

A family member or caregiver also has an opportunity to evaluate how a loved one is doing in terms of health, safety and quality of life. "The goal," says Ardeshir Hashmi, M.D., section chief of the Center for Geriatric Medicine at Cleveland Clinic, "is to pick up clues early, before they start to impact day-to-day life a significant way, so we can do something about them." Here are red flags to look for, which may signal a loved one needs further evaluation — and possibly more support.

To learn more, click the red button below.

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Safe Driving for Older Adults

While many older adults value the independence of driving, changes that happen with age may alter a person's ability to drive safely. You may notice driving becoming more difficult over time for yourself or for your loved ones. Changes in health, including medical conditions or injuries, also may impact a person's driving skills.

To learn more about the different factors that can affect driving as you age and signs of when it may be time to stop driving, click the red button below.

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Aging and Your Eyes

As you age, it is normal to notice changes in your vision. A few common changes for older adults include:

- Losing the ability to see up close
- Having trouble distinguishing colors, such as blue from black
- Needing more time to adjust to changing levels of light

These problems are often easily corrected. Glasses, contact lenses, and improved lighting may help and enable you to maintain your lifestyle and independence.

Your risk for some eye diseases and conditions increases as you grow older, and some eye changes are more serious. Keep your eyes as healthy as possible by getting regular eye exams so any problems can be spotted early.

To learn more, click the red button below.

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6 Indispensable Tech Tools for Family Caregivers

Last Updated: February 6, 2023

6 Indispensable Tech Tools for Family Caregivers

Caring for an elderly loved one is often a challenging job. Whether you care for a loved one at home or you're a long-distance caregiver, managing a loved one's needs can be exhausting and stressful. Most caregivers need all the help they can get, and more and more technologies are being developed that can offer some of this much-needed assistance.

Some of the stress that accompanies caregivers' daily lives can be relieved (even if just a little) with the right systems and gadgets in place, without compromising the health or comfort of your loved one. To help you manage your responsibilities, Caring.com created a list of some of the best tools for caregivers.

To learn more, click the red button below.

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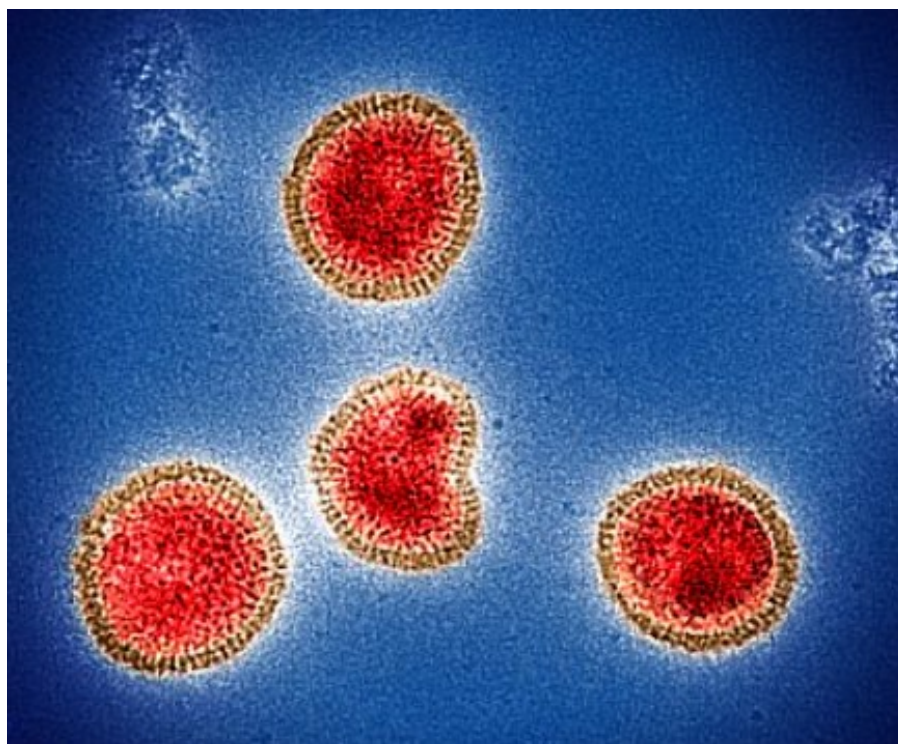
Finding the Right Caregiver Support Group

Being a caregiver for a loved one can be stressful and frustrating. You might even be angry at times. You are not alone. The right support group can be a great place of comfort where you can talk to people who have been through similar situations and faced the challenges you're facing. In a group, you can talk about how you're feeling with people who understand. A good support group can be a network of friends to whom you can turn to when you have questions or need help—and in turn, you can be there for them as well.

But what makes a good support group and where can you find one? Here are some things to think about when looking for a group.

To learn more, click the red button below.

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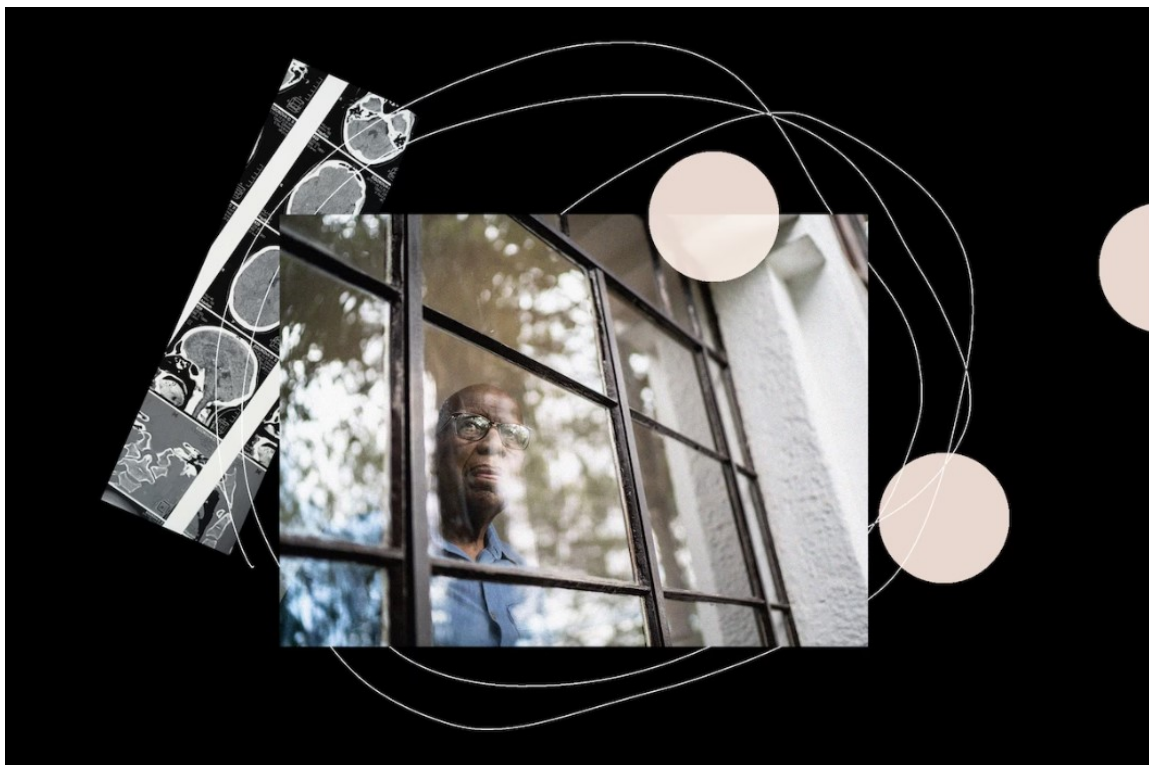
Links Found Between Viruses and Neurodegenerative Diseases

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

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

To learn more, click the red button below.

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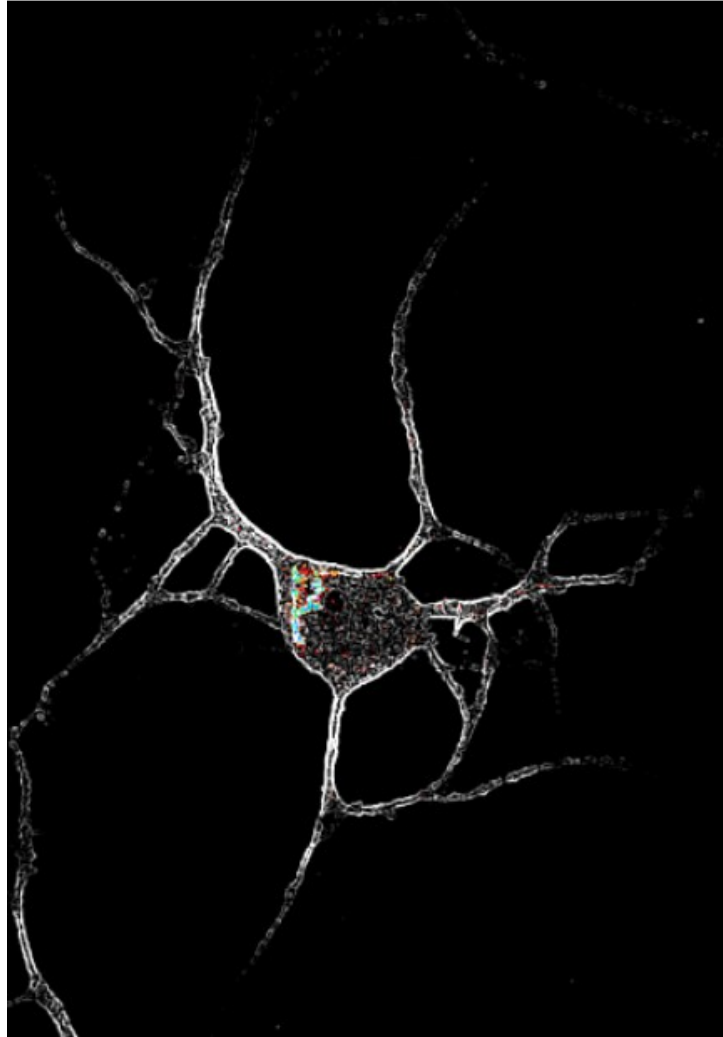
Ask a Doctor: Who Will the New Alzheimer's Drug Help?

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

To learn more, click the red button below.

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How Psychedelic Drugs May Help with Depression

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

To learn more, click the red button below.

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The Best Treatment for Depression? It Could be Exercise.

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

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

To learn more, click the red button below.

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Understanding Genetic Testing for Cancer Risk

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

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

To learn more, click the red button below.

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Building Your Caregiver Toolkit

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

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

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

To view the toolkit, click the red button below.

VIEW THE TOOLKIT





5 Tips When Shopping for Caregiving Tech

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

To learn more, click the red button below.

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Defining the Help You Need

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

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

To learn more, click the red button below.

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

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

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

Aimerd Alliance has summarized the concerns and practices raised during the roundtable meeting, and the report is now available [here](#).

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

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

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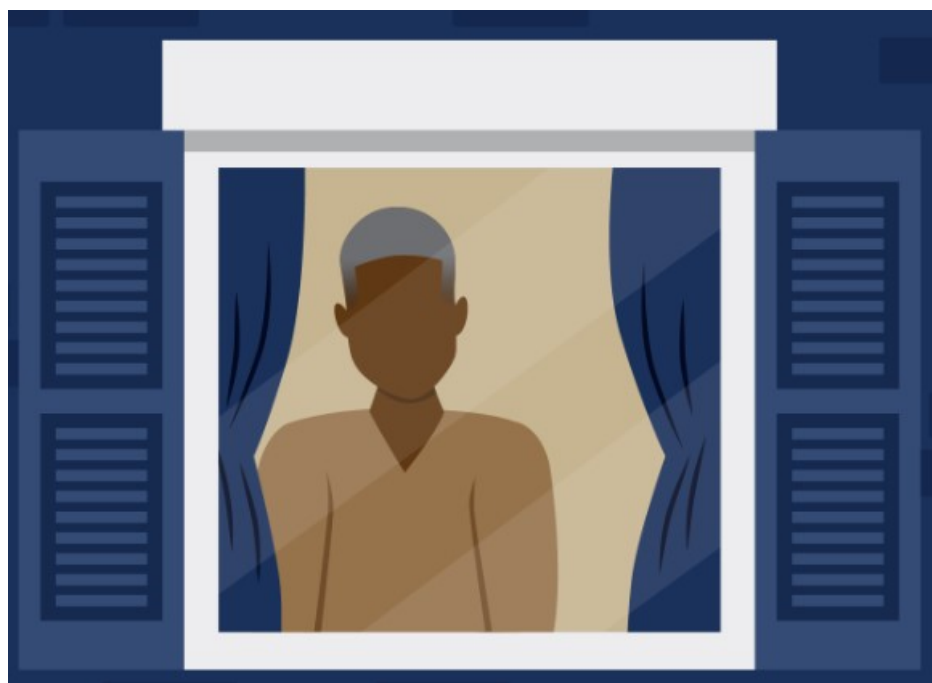


How to Identify, Prevent, and Fix Parent Burnout

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

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

To learn more, click the red button below.



Trends in Loneliness Among Older Adults from 2018-2023

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

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

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

VIEW THE REPORT
>



Top 17 Resources for Family Caregivers

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

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

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

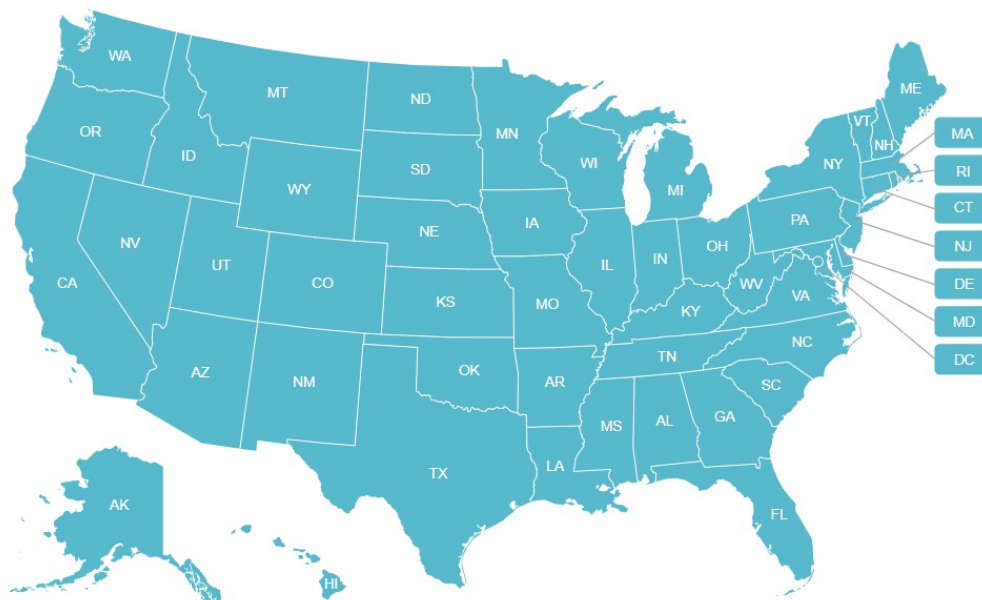
VIEW THE RESOURCE SHEET
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Caregiving with Your Siblings

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

To learn more, click the red button below.

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Family Caregiver Services by State

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

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

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Personal Care Agreements

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

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

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

To learn more, click the red button below.

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