# THIS WEEK IN CAREGIVING



March 29, 2023



## CAREGIVING IN THE NEWS

## The Sandwich Generation is Changing. The Stress Remains

Laura Bulson is torn. On one hand, she feels obligated to care for her 90-year-old mother who has dementia, even though the two were estranged for years. On the other, she doesn't like what moving her mother in with her family in 2017 has done to her relationship with her grown children, several of whom have lived at home at different times over the past few years. "The hardest part was our family dynamic changed," Bulson said.

From: Washington Post | Published: March 22, 2023

READ MORE

# The Challenges and Joys of Caregiving for a Grown Child with a Disability

"You might want to think about having other children to help when you and your husband are gone."

Eileen Flood O'Connor, 53, from Rye, New York, remembers her head nearly exploding when she heard those words from the doctor who diagnosed her then 22-month-old daughter, Erin, with a spectrum disorder caused by a rare chromosomal abnormality. At the time she had a 5-month-old son, Will, and she recalls a sense of dislocation and disbelief as she tried to digest the scale and scope of Erin's condition.

From: AARP | Published: March 23, 2023

## I Took Over My Father's Finances at 25. The Lessons Were Hard-Won.

Six years ago, I took over my father's finances. Two weeks before signing the power-of-attorney paperwork, I was in a neurological intensive care unit on Long Island, standing at the end of his hospital bed and clutching a ledger I had purchased from an office supply store. My father had suffered a grand mal seizure and was placed in a medically induced coma.

From: New York T | Published: March 25, 2023

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## NAC NEWS AND UPDATES



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

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

To learn more, click the red button below.

**LEARN MORE** 

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

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

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

If you would prefer to write out your response rather than leave an audio message, you may do so **here**.

#### We want to know:

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

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

To learn more, click the red button below.

**LEARN MORE** 



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

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

VIEW THE REPORT



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

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

Included in this report:

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

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

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

VIEW THE REPORT



## **EVENTS & OPPORTUNITIES**

#### **MARCH**



## **Anticipatory Grief: Grieving Before Death?**

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

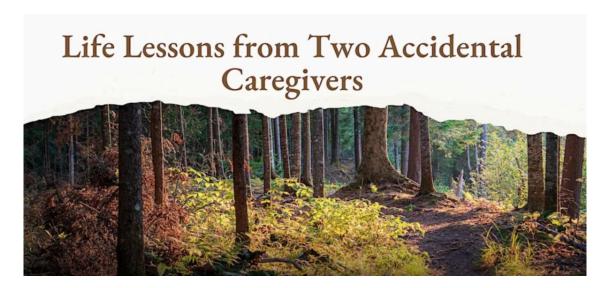
Please join the Breast Cancer Education Association (BCEA) on Wednesday, March 29th, for a discussion led by Allison Breininger, founder the non-profit **The Negative Space**.

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

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

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

REGISTER >



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

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

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

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

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

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

Innovation (CSI). In her spare time she joyfully pounds clay into useless objects.

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





## **Young Onset Dementia**

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

Join the <u>Alzheimer Society of Durham Region</u> (Canada) on March 29th for an online workshop that will distinguish Young Onset dementia from other types of dementia by identifying its core symptoms and by understanding the possible causes/risk factors that bring changes to brain structure and function. It will also discuss general ways of supporting people living with young onset dementia.

This session will be hosted on Zoom (with a phone in options) Zoom session: Once you have registered for the session, you will receive a link with instructions on how to connect.

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



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

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

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

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

#### **How to Join**

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

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



#### The Dr. Is In: Difficult Dementia Behaviors

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

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

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



#### **APRIL**

## The University of Manchester Institute for Collaborative Research on Ageing

## Hospice Staff and Family Carers & End-of-Life Dementia Care

April 4, 2023 | 9:00 AM - 10:00 AM ET | Online

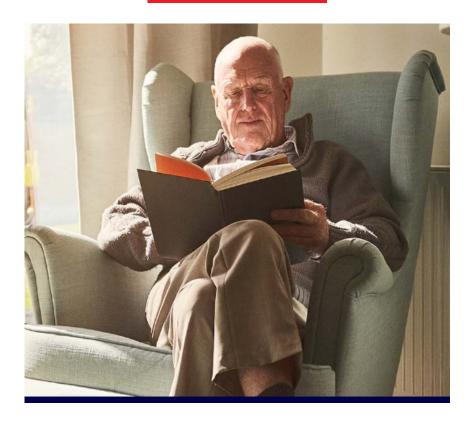
More than 50 million people live with dementia worldwide, with figures reaching to more than 75 million by 2030. Being a progressive condition, in its advanced stages, dementia reduces the opportunities of the person to receive proper care, and more specialist end-of-life care is needed to ensure that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

Hospices offer an interdisciplinary care model for the person and their family supporters. This type of care can occur in different settings (e.g., in-ward hospital, nursing home, long-term facilities), it can be offered on a home-based service and or directly offered in the hospice through inpatient care.

Whilst hospices are regarded as providers of gold-standard care for people requiring endof-life support, health care professionals working in these settings rarely receive dementia training and examples of evidence-based practices are currently lacking. More research is needed to investigate the experience of care delivery in hospice staff and family carers of people with dementia. Join the Manchester Institute for Collaborative Research on Ageing on April 4th for a seminar about a recent study on the experience of hospice clinical staff and family carers of end-of-life dementia care.

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

REGISTER



### **Caring for Burned-Out Caregivers**

April 6, 2023 | 11:00 AM - 12:00 PM ET | Online

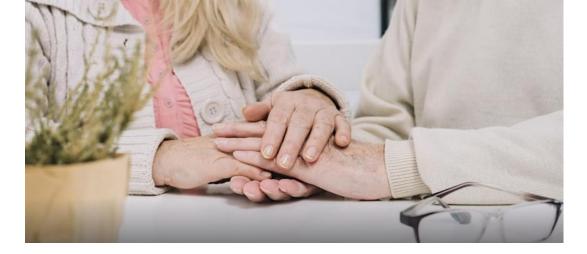
Caring for others can be a joyful and beautiful experience—or it can be detrimental to our well-being. Burnout in caretaker populations can go easily overlooked, as most attention may be given to the person being looked after. A caregiver with burnout often feels overwhelmed and may be physically, emotionally,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

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

Join Marie Clouqueur, LICSW, on April 6th (11:00 AM ET) as she shares ways to identify burnout in caregiver populations, discusses how burnout can be prevented from happening, and answers questions about how caretakers can prioritize their own needs when it may feel difficult to do so.

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

REGISTER



## Creating Safe Home Environment for People Living with Dementia and Alzheimer's

#### April 7, 2023 | 11:00 AM - 12:00 PM ET | Online

Direct care providers (personal care providers, home makers, and caregivers) are frequently undervalued in their impact and role in the caregiving profession. They often have limited opportunities and resources for specialized training, professional development, and as the result, subsequent career advancement. With the funds from the Training Grant, Amity Healthcare Group developed an accessible specialized trainings Alzheimer's and Dementia Caregiving at Home and Creating Safe Home Environment for People Living with Dementia and Alzheimer's Disease that will:

- Allow HCBS providers/caregivers to gain specialized, disease sensitive skills working with consumers with dementia and Alzheimer's disease that will result in improved quality of care, consumer outcomes, and quality of life.
- Allow HCBS providers/caregivers to use correct care management, behavioral and communication techniques necessary to effectively deliver care to individuals impacted by dementia and Alzheimer's.
- Help HCBS providers/caregivers to focus on individualized care and create a safe environment for staff and consumers in the home setting.

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

REGISTER

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

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

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

This workshop is part of a series designed to provide education, support, and resources for those caring for loved ones with an illness. There will be time for Q&A following each presentation.

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

**REGISTER** 

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## Childhood Trauma: Secondary Traumatic Stress in Caregivers

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

Supporting children who have experienced trauma can affect our own mental health and can lead to secondary traumatic stress. Learn how to safeguard yourself from emotional exhaustion & explore ways to manage stress reactions when helping children cope with their trauma. Sponsored by Polk County Iowa's Behavioral Health & Disability Services agency.

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

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

Susan has held positions as an in-home therapist, day treatment therapist, school-based therapist, outpatient therapist, hospital/clinic therapist, program supervisor, and director.

She has served as a trainer/writer for the Minnesota Child Welfare Training System, and as an Adjunct Professor at Adler Graduate School.

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



## **Beware of Caregiving Fraud**

April 11, 2023 | 12:00 PM - 1:00 PM ET | Online

Arranging for care in the home can be complicated and costly. Finding a caregiver you can trust is one of the most important concerns of families venturing out on this journey. Join us for a discussion on how to find a reputable, reliable care provider and protect yourself and your loved one from caregiving fraudsters and scammers. We'll cover the benefits of using an agency, tips on monitoring a new caregiver, and ways to protect against financial abuse. You can also download or order a free copy of the **AARP Family Caregiving Guide** and explore additional **AARP caregiving resources**.

#### How to Join

This event is part of a monthly series titled "Fraud Talk Tuesdays" in which we cover a different scam each time in 30 minutes or less. You will need to register separately for each class you are interested in attending. Please note that you must be signed in to your AARP.org account or create an account to register for events. Please do not opt out of event-related email, as you will be emailed a link to join the discussion via Zoom prior to the event.

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

REGISTER



## **Aging in Place: Know Your Housing Options**

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

Beginning on April 11th, the Benjamin Rose Institute on Aging will host "Aging in Place:

Know Your Housing Options," a three-day online course designed teach participants how to assess their homes for safety, accessibility, and affordability; explore ways to use home equity to stay in their homes; and discover housing options.

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





### **NCFS Caregiver Advocacy Program**

April 11, 2023 | 1:30 PM - 3:00 PM ET or 7:00 PM - 8:30 PM ET | Online

The University of Pittsburgh's National Center on Family Support (NCFS) is looking for caregivers who are interested in becoming involved in advocacy.

NCFS's newly-launched Caregiver Advocacy Program will consist of a series of virtual workshops that will empower unpaid family caregivers to learn about caregiving-related policies, and how to use their experiences to tell their story and advocate for change.

Caregivers don't need to be policy experts to take part – just interested in learning more about advocacy. By the end of our program, they'll have something tangible to share with legislators or advocacy groups.

The lives of caregivers are busy and free time is limited. The program's sessions will be virtual and offered both in daytime and evening sessions for scheduling flexibility. The first sessions will be held on April 11th.

If you have questions, you can reach out to Heather Tomko at <a href="mailto:caregiving@pitt.edu">caregiving@pitt.edu</a>.

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

REGISTER >



### **Heart Health for Family Caregivers**

April 11, 2023 | 2:00 PM - 3:30 PM ET | Online

Often, family caregivers ignore their own health while caring for loved ones. Keeping your heart healthy by de-stressing and making small lifestyle changes can significantly reduce the impact of caregiving on your health.

Join the American Heart Association on April 11th for this edition of Vantage Agings' monthly event, Caregiver Solutions, intended to help caregivers find support and resources.

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

REGISTER



## Understanding and Responding to Dementia-Related Behaviors

April 11, 2023 | 4:00 PM - 5:00 PM ET | Online

Behavior is a powerful form of communication and is one of the primary ways for people with dementia to communicate their needs and feelings as the ability to use language is lost. However, some behaviors can present real challenges for caregivers to manage. Join the Kadlec Neurological Resource Center on April 11th to how learn to decode behavioral messages, identify common behavior triggers, and learn strategies to help intervene with some of the most common behavioral challenges of Alzheimer's disease.

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

**REGISTER >** 



## **Nourishing the Stressed Caregiver**

April 11, 2023 | 7:00 PM - 8:00 PM ET | Online

Join Olivia Evans on April 11th for an interactive course about caregiver stressors, approaching stress, and avenues for self-care. Walk away with tangible tools to evaluate your own stress level and the confidence to make your own goals. This is appropriate for all caregivers, not just those caring for someone with dementia.

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

REGISTER

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### A New Model of Care: Dementia Connection Model

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

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

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

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

REGISTER >



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

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

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

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

#### Before joining us:

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

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

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

REGISTER >



Health and Aging Policy Fellowship 2023-2024
Call for Applications

#### Deadline to apply: April 17, 2023

With an aging population, one of the greatest challenges for the U.S. is ensuring that policies provide the best possible quality of life for all across all dimensions of society – from the communities where we live, the transportation we depend on, the food we eat, and the health care we receive. Success will require the translation of cutting-edge science and practical clinical experience into sound health policy. The goal of the Health and Aging Policy Fellows Program is to provide professionals in health and aging with the experience and skills necessary to help lead this effort, and in so doing, shape a healthy and productive future for older Americans.

The Health and Aging Policy Fellows Program offers two different tracks for individual placement: (1) a residential track that includes a 9-to-12-month placement in Washington, D.C. or at a state agency (as a legislative assistant in Congress, a professional staff member in an executive branch agency or in a policy organization); (2) a non-residential track that includes a health policy project and brief placement(s) throughout the year at relevant sites. The project may be focused at a global, federal, state or community level.

In addition, through our partnership with the veterans health administration, VA employees can participate in the VA track as a non-residential fellow.

Core program components focused on career development and professional enrichment are provided for fellows in all tracks.

To learn more about the fellowship, click **here**. To apply, click the red button below.

### APPLY FOR THE FELLOWSHIP

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

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

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

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

What You Will Learn:

Healthy Eating and Recipes

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

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

REGISTER



## Make Your Voice Heard: Tips for Effective Caregiver Communication

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

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

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

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

REGISTER

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## **Helping Teens Heal from Trauma**

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

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

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

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

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

REGISTER >

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

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

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

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



### Pain and Other Assessments in a Person with Dementia

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

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

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

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

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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

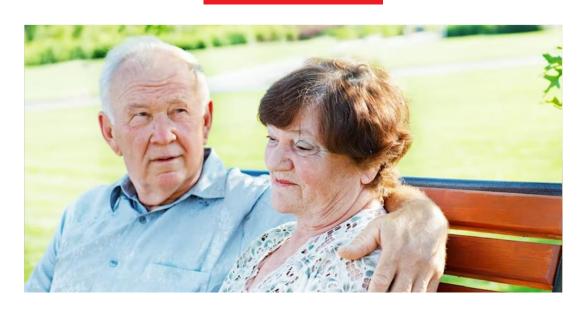
The caregiving role can bring forth many different feelings and emotions, and anxiety is one which can be problematic for those managing care. In observance of Mental Health Week this May, we welcome back Dr. Patrick McGrath to talk about:

- 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



### **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 >

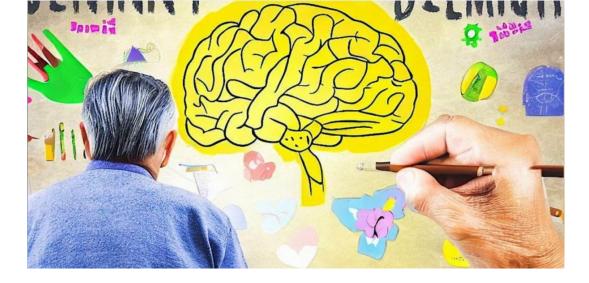
## Alzheimer's Program: Healthy Living for Your Brain & Body

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 >



## **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.





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



### **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 >



## 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 >

#### JUNE

## **Aspects of Caregiving**

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

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

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

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

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

REGISTER >



**Caring for Your Caregiver** 

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

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

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

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

REGISTER >

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

### The RISE (Research Inclusion Supports Equity) Registry

Are you LGBTQIA+, 18 and older, and caring for someone with memory loss or a memory loss diagnosis?

RISE is a research study being conducted by Emory University, the University of Nevada, Las Vegas, and the University of Tennessee, Knoxville.

The RISE study includes a research registry created to help ensure the LGBTQIA+ community is represented in Alzheimer's and related research.

The registry is for LGBTQIA+ people 18 and older who:

- Have memory concerns or a memory loss diagnosis such as Alzheimer's disease or a related dementia
- Are helping care for someone with memory loss or a memory loss diagnosis

#### Registrants can receive:

- Notice of research opportunities related to aging or caregiving in their area, and nationally
- Opportunities to participate in educational and advocacy events either online or inperson
- Invites to participate in additional questionnaires, interviews, or focus groups related to aging and the LGBTQIA+ population
- LGBTQIA+ friendly resources for adults with memory concerns and LGBTQIA+ caregivers

To learn more, visit **TheRiseRegistry.org**. To register, click the red button below.



## Understanding the Experiences of Family Caregivers of People with Dementia in Virginia and Surrounding States

Start: September 11, 2021 End: December 2024 Enrollment: 360

Who is sponsoring this study? Karen Roberto, Virginia Tech

Where is this study located? Virginia

#### What Is This Study About?

This telephone-based study, called CareEx, will gather information from family members who provide help for a relative living with dementia about their caregiving experiences. An initial phone interview will be conducted with each participant to collect background information about family relationships, and the participants caregiving role. Next, the researchers will call each participant once a day, for eight days in a row, to ask questions about the caregiving experience for that day, including any dementia care services or other support that was used to meet the needs of the person with dementia. This information will provide insights to improve the design and delivery of dementia care and support services.

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

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

- Be one of the main people providing hands-on care and/or overall management of care for a person with dementia
- Grandchild, sibling, niece/nephew, step-kin, adult child, or spouse of the person with dementia

- Live with the person with dementia or have face-to-face contact with the person with dementia at least three days each week
- Speak and read English
- Resident of Virginia or surrounding states

#### Must NOT have:

- Difficulty hearing and/or talking on the telephone
- Person living with dementia does not live in housing with enriched services (e.g., continuing care community), or a residential facility (e.g., assisted living, nursing home)

For more information and to enroll, click the red button below.



## Psychological and Immune System Health in Dementia Caregivers

Start: January 2022 End: December 2024 Enrollment: 250

Who is sponsoring this study? Stony Brook University

Where is this study located? New York

#### What Is This Study About?

This study will evaluate the effects of caring for a spouse, family member, or friend with dementia on the health of the caregiver. Participants will wear an activity tracker and complete a questionnaire. They will also provide a blood sample at the start of the study and after six and 12 months. Researchers will assess the social and overall health of the caregiver based on the results of the questionnaires and blood tests to measure hormones and other indicators related to stress, social interaction, and immune system activity.

Do I Qualify To Participate in This Study?

Minimum Age: 50 Maximum Age: N/A

#### Must have:

- Caregiver of a spouse, family member, or a friend with Alzheimer's disease or a related dementia disorder
- Assist the person with dementia with at least one activity of daily living (e.g., bathing, dressing, toileting, feeding, moving from sitting to standing) several times a month

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

- Any major endocrine diseases (e.g., diabetes, Cushing's disease, Addison's disease)
- If female, must not be on hormone replacement therapy

For more information call Erin Casella at (631)638-1544 or email her by clicking on the red button below.

### **Stress Management for Dementia Caregivers**

Start: January 8, 2021 End: January 31, 2024

Enrollment: 300

Who is sponsoring this study? Case Western Reserve University

Where is this study located? Ohio

What Is This Study About?

This study will compare different types of stress-reduction interventions and determine whether a caregiver's preferences for an intervention makes a difference. Participants will be randomly assigned to one of three behavioral intervention groups: audiovisual information on 12 activities (e.g., crossword puzzles, gardening, exercise); biofeedback (using a heart-rate tracking device to learn to change breathing); or resourcefulness training (learning stress management, problem-solving, and help-seeking skills). Using questionnaires, the researchers will measure changes in the caregivers general physical and mental health, risk behaviors, resourcefulness, perceived stress, and mood at the start of the study, at six months, and at one year. Some participants will also be asked to keep a journal to record their experiences.

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

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

- Have a living family member, or a recently deceased family member, diagnosed with Alzheimer's or another dementia. In addition, one of the following must apply:
  - Provides a minimum of four hours per day of supervision or direct care at home; began providing in-home dementia care within the past six months
  - Has a family member with dementia who moved into a nursing or assisted living facility within the past six months; visits their family member with dementia at least once per week
  - Has direct oversight of the personal belongings, estate, and finances of a family member with dementia who died within the past six months

#### Must NOT have:

- Currently pregnant
- Has a pacemaker
- Lives outside of the study area
- Knowledge of another family member, in the same household, enrolled in the study

For more information call Jaclene Zauszniewski at (216)368-3612 or email her by clicking on the red button below.



### **PAF Survey**

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

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

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

To complete the survey, click the red button below.

LEARN MORE
>

### **Dementia Caregiving Skills for Family Caregivers**

Start: May 2021

End: February 28, 2025

Enrollment: 332

Who is sponsoring this study? University of California, Irvine

Where is this study located? California

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

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

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

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

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

#### Must NOT have:

- Cognitive impairment that would interfere with providing consent or completing study surveys
- Chronic drug abuse
- Currently receiving treatment for cancer
- Need for hospice care
- Significant health problems that would interfere with wearing a smartwatch and smart ring (e.g., pacemaker, epilepsy, or neurologic disorder)

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



### **Escitalopram for Agitation in Alzheimer's Disease**

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

Who is sponsoring this study? JHSPH Center for Clinical Trials

Where is this study located? Multiple states

#### What Is This Study About?

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

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

Minimum Age: 18 Years Maximum Age: 109 Years

#### Must have:

- Alzheimer's dementia diagnosis
- Mini-Mental State Examination Telephone score of 3-20
- Meets criteria for agitation in cognitive disorders per the International Psychogeriatric Association
- Clinically significant agitation/aggression as assessed by the Neuropsychiatric Inventory
- Availability of a caregiver who spends at least several hours per week with the

- participant, supervises his or her care, and is willing to accompany the participant to study visits and participate in the study
- Use of antipsychotics for agitation or psychosis must be stable for at least seven days

#### Must NOT have:

- Major depression in the past 90 days
- Brain disease other than Alzheimer's that explains the dementia, such as extensive brain vascular disease, Parkinson's disease, dementia with Lewy bodies, traumatic brain injury, or multiple sclerosis
- Residence in a skilled nursing or long-term acute care facility
- Contraindication to escitalopram, such as use of monoamine oxidase inhibitors in past 30 days or sensitivity to escitalopram or citalopram (Celexa) or any inactive ingredients
- Prior failed treatment with citalopram or escitalopram for agitation
- Indication for psychiatric hospitalization or acute suicidality
- Changes in antipsychotics, anticonvulsants, or psychosis (delusions or hallucinations) within seven days requiring a change in antipsychotic treatment
- Abnormal corrected QT interval as determined on electrocardiogram (more than 450 ms for men and 470 ms for women)
- Severely reduced renal function in past 30 days as identified by a Glomerular filtration rate clearance of less than 30 ml per minute or reduced liver function
- Prohibited medications within seven days: antidepressants (other than 100 mg or less of trazodone per day at bedtime), benzodiazepines (other than lorazepam), or psychostimulants
- Changes in dextromethorphan/quinidine, prazosin, and pimavanserin within two weeks
- · Use of medical marijuana within two weeks
- Current participation in a clinical trial or study that may add a significant burden or affect study outcomes
- Significant communicative impairments that would affect participation
- Any condition that makes it medically inappropriate or risky to enroll in the trial

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



### **Lucidity in Severe End-Stage Dementia**

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

Who is sponsoring this study? NYU Langone Health

Where is this study located? New York

#### What Is This Study About?

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

recording device. Phase 2 of the study aims to expand the study population, improve study methods, and create a definition and measurement scale for lucidity to inform future research.

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

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

- · Study participants will include:
  - Adults with severe dementia based on neurological testing
  - Hospice workers, geriatric and palliative care physicians, and other health care providers
  - Family, friends, and caregivers of a person with severe dementia
- Participants with severe dementia will need to meet the following criteria:
  - · Currently admitted or accepted for hospice care
  - No longer being provided with nutrition or fluids
  - Dry or almost dry disposable underwear in any 24-hour period

#### Must NOT have:

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

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



## Retinal Imaging for Mild Cognitive Impairment and Alzheimer's Disease

Start: July 2017

End: December 31, 2025

Enrollment: 1000

Who is sponsoring this study? Duke University

Where is this study located? North Carolina

#### What Is This Study About?

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

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

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

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

#### Must NOT have:

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

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

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



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

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

Enrollment: 40

Who is sponsoring this study? Vaccinex Inc.

Where is this study located? Multiple states

#### What Is This Study About?

This Phase 1/2 study will assess the safety and effects of the experimental drug pepinemab, a monoclonal antibody treatment designed to improve memory, in older adults with early-stage Alzheimer's. Participants will be randomly assigned to receive either the study drug or a placebo by IV infusion once a month for one year. Throughout the trial, participants will undergo PET and MRI brain imaging, complete memory tests, and provide blood and spinal fluid samples. Researchers will monitor all participants for safety and any side effects throughout the trial and one month after the last treatment.

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

Minimum Age: 55 Years Maximum Age: 85 Years

#### Must have:

- Diagnosis of probable Alzheimer's with:
  - Global Clinical Dementia Rating of 0.5 or 1.0
  - Mini-Mental State Examination score of 17 to 26
- Must have either:
  - Positive amyloid PET scan before starting study
  - Positive amyloid cerebrospinal fluid test result before or at the study screening
- Availability of a study partner who has a close relationship with the participant and frequent in-person contact (> 3 times per week, for a minimum of 10 waking hours total per week)
- Female participants must be postmenopausal or surgically sterile

- Male participants must commit to a reliable method of birth control during the study and for six months after the last dose of the study drug
- · Adequate vision, hearing, and physical function to complete study tests
- If taking medications for Alzheimer's, dosage must be stable for at least two months
  prior to the study screening visit
- If taking medication to manage heart rate or blood pressure, dosage must be stable for at least two months prior to the study screening visit
- Overall good physical health over the last six months, based on medical history and study screening evaluation

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

- Participation in another clinical trial for an experimental drug or medical device within one month prior to study screening; if experimental drug was an antibody therapeutic, must wait 180 days from the last treatment or long enough for the therapeutic to clear the body
- Known allergy to any ingredient in the study drug formulation
- Body weight greater than 275 pounds
- · Serious risk of suicide or suicide attempt in the past year
- History of substance abuse within one year prior to study screening
- Treatment with any FDA accelerated approval therapy for treatment of Alzheimer's
- Any unstable or uncontrolled medical illness or condition that could interfere with the study, including:
  - Serious infection, including a history of human immunodeficiency virus or acquired immunodeficiency syndrome, hepatitis B virus or hepatitis C virus infection at study screening
  - Serious blood, liver, heart, or kidney disease
  - Malignant cancer within two years of study screening (non-melanoma skin cancers, superficial bladder and prostate cancers are allowed)
- Diagnosis of a neurological condition causing cognitive impairment other than Alzheimer's, such as:
  - Non-Alzheimer's dementia (e.g., Lewy body dementia, frontotemporal dementia)
  - Psychiatric conditions that could cause cognitive impairment (e.g., schizophrenia)
  - · History of frequent concussions
- Any serious medical, laboratory, or behavioral abnormality at study screening, including:
  - Electrocardiogram abnormalities
  - MRI brain scan findings that indicate stroke, tumor, tangled blood vessels, swelling
- Any condition that could make undergoing an MRI or PET brain scan unsafe, including:
  - Claustrophobia or inability to lie on scanner bed for 45 minutes
  - Poor vein access
  - Metal shrapnel, pacemaker, presence of metal objects in eyes, skin, or heart
  - Body size and shape that prevents a comfortable fit in scanners
  - Prior radiation exposure that, when combined with study PET scan, would exceed radiation limits
- If undergoing a spinal tap, must not have:
  - Untreated bleeding or clotting disorders
  - Skin infections near spinal tap location
  - Increased brain pressure
  - Serious spinal injury
  - · Allergies to numbing medications
  - Taking any of the following anticoagulant medications: coumarins and indandiones, Factor Xa inhibitors, heparins, or thrombin inhibitors

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

#### IN CASE YOU MISSED IT...

### Learn a Latte: Managing Medications as a Caregiver



Do you find yourself acting as 'pharmacist' while managing a loved one's prescriptions? Learn ways to organize and record medications for someone in your care. These handy tips will keep you on top of things and prevent you from deadly making mistakes.



### **RESEARCH & RESOURCES**



## Understanding Disabilities in American Indian & Alaska Native Communities Toolkit Guide

The <u>National Indian Council on Aging (NICOA)</u> 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.

LEARN MORE



# 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.

**LEARN MORE** 

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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.

**LEARN MORE** 

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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.

**LEARN MORE** 

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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.

LEARN MORE >



### **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.

LEARN MORE >



### **Finding the Right Caregiver Support Group**

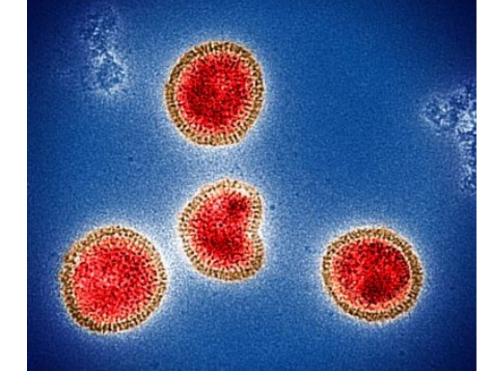
Being a caregiver for a loved one can be stressful and frustrating. You might even be angry at times. You are not alone. The right support group can be a great place of comfort where you can talk to people who have been through similar situations and faced the challenges you're facing. In a group, you 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.

LEARN MORE >

**PREVIOUSLY APPEARED** 



# Links Found Between Viruses and Neurodegenerative Diseases

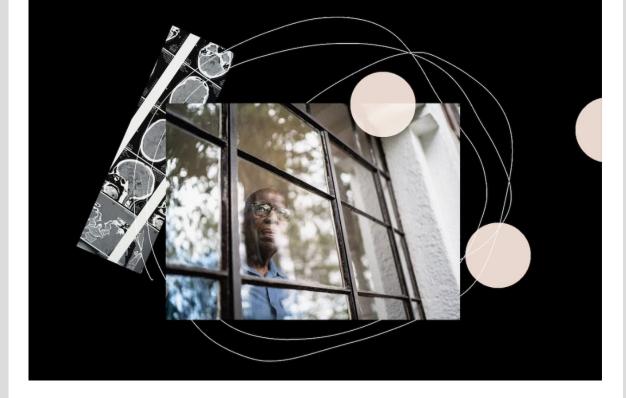
Neurodegenerative diseases can damage different parts of the nervous system, including the brain. This may lead to problems with thinking, memory, and/or movement. Examples include Alzheimer's disease (AD), multiple sclerosis (MS), and Parkinson's disease (PD). These diseases tend to happen late in life.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

**LEARN MORE** 

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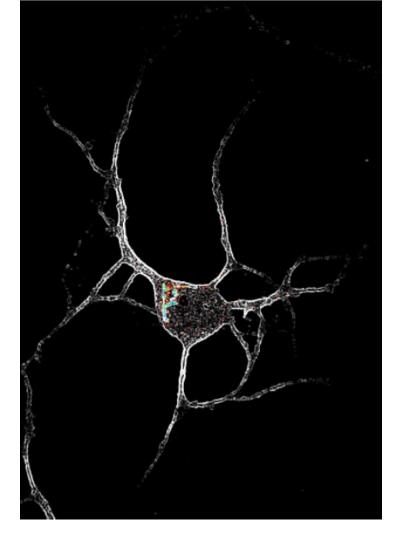
### Ask a Doctor: Who Will the New Alzheimer's Drug Help?

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.

**LEARN MORE** 

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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.

LEARN MORE



#### The Best Treatment for Depression? It Could be Exercise.

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

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

To learn more, click the red button below.

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### **Understanding Genetic Testing for Cancer Risk**

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

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

To learn more, click the red button below.



### **Building Your Caregiver Toolkit**

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

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

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

To view the toolkit, click the red button below.

**VIEW THE TOOLKIT** 

>



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

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

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

To learn more, click the red button below.

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

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

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

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

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

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



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

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

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

To learn more, click the red button below.

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

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

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

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





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

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

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

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

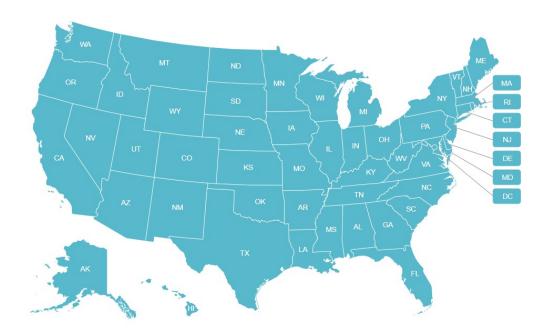
VIEW THE RESOURCE SHEET >

### **Caregiving with Your Siblings**

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

To learn more, click the red button below.





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

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

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



### **Personal Care Agreements**

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

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

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

To learn more, click the red button below.

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

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

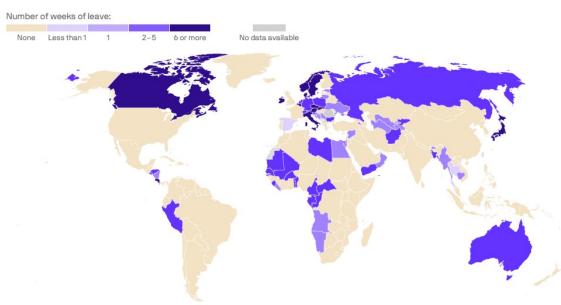
Tardive dyskinesia (TD) is an involuntary movement disorder that is characterized by uncontrollable, abnormal, and repetitive movements of the face, torso, and/or other body parts. TD is associated with prolonged use of certain mental health medicines (antipsychotics) that can be used to treat bipolar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

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

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

To view the toolkit, click the red button below.





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

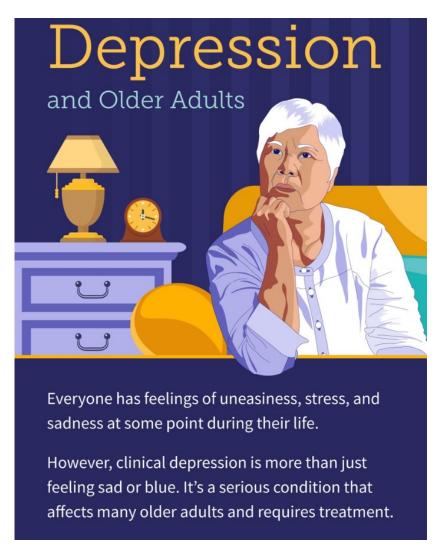
The lack of paid leave for new parents in the U.S. often grabs headlines, but there's a

different kind of leave becoming an increasingly urgent issue: time off for workers to care for a sick parent.

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

To learn more, click the red button below.





### **Depression and Older Adults**

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

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

To learn more, click the red button below.

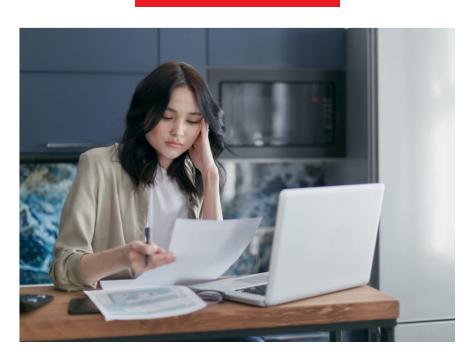


### 5 Free Mental Health Apps that Could Help Your Teen

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

To learn more, click the red button below.

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### The Challenge of Paying for Mental Health Care

Nothing is more important than physical and mental well-being. However, it can be

challenging and frustrating when you are the caregiver helping someone else get and pay for the mental health care they need.

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

To learn more, click the red button below.

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## Developmental Disabilities Awareness Month Resource Guide 2023

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

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

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

To view the guide, click the red button below.



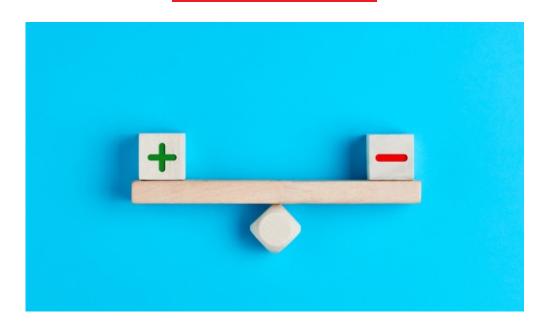
### 7 Myths About Caregiving You Shouldn't Believe

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

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

To learn more, click the red button below.

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

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

To learn more, click the red button below.

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

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

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

To learn more, click the red button below.

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

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

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

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

To learn more, click the red button below.

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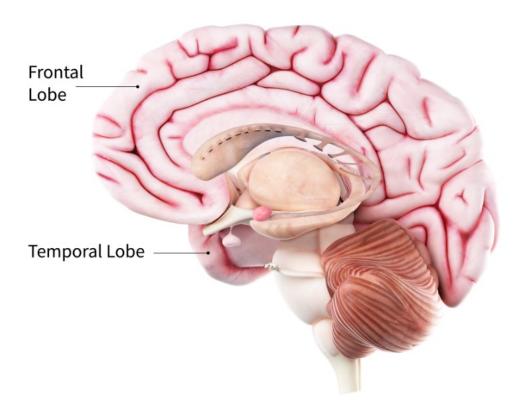
Learn more at autoimmune.org

#### **Autoimmune Awareness Month Toolkit**

March is Autoimmune Awareness Month. The Autoimmune Association has prepared a social media toolkit that contains resources organizations and individuals can use to help spread awareness about autoimmune disease, provide education, and communicate the urgent need for more research. Included are facts, sample social posts, graphics, and a sample video script.

To view the toolkit, click the red button below.





# What Are Frontotemporal Disorders? Causes, Symptoms, and Treatment

Frontotemporal disorders (FTD), sometimes called frontotemporal dementia, are the result of damage to neurons in the frontal and temporal lobes of the brain. Many possible symptoms can result, including unusual behaviors, emotional problems, trouble communicating, difficulty with work, or difficulty with walking. FTD is rare and tends to occur at a younger age than other forms of dementia. Roughly 60% of people with FTD are 45 to 64 years old.

To learn more, click the red button below.

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# Providing Care for a Person with a Frontotemporal Disorder

People living with frontotemporal disorders, sometimes called frontotemporal dementia, can have a range of symptoms, including unusual behaviors, emotional problems, trouble communicating, and difficulty walking. Caring for someone with a frontotemporal disorder (FTD) can be hard, both physically and emotionally. Caregivers may face challenges with managing the medical and day-to-day care, as well as changing family and social relationships, loss of work, poor health, stress, decisions about long-term care, and end-of-life concerns.

To learn more, click the red button below.

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# 15 Things Every Caregiver Should Know about Navigating Eating Disorders

Knowing the right thing to do or say is not always easy, and there is no one-size-fits-all solution to navigating eating disorders. In fact, the "right thing" to say one day may be the "wrong thing" to say the next. It is a challenge both for the individual battling an eating disorder and their support system.

In honor of World Eating Disorders Action Day on June 2, 2023, the National Eating Disorders Association is focusing on the caregivers of those with eating disorders. There will be a number of ups and downs, advancements and backtracks during your loved one's journey to recovery. To get you started, below is a list of 15 things those in the recovery community want all caregivers to know.

To learn more, click the red button below.



### **Living with IDB**

We've all heard the phrase "trust your gut." For people with inflammatory bowel disease (IBD), trusting one's gut is not so simple. When the body sounds an alarm that something doesn't feel right, taking that internal voice seriously and actively speaking up is critical. For someone starting to feel the pain or flares associated with IBD, learning to trust your gut first means *listening* to your symptoms.

Takeda Pharmaceuticals America recently launched *Living With IBD*, a website to help support people living with Crohn's disease or ulcerative colitis (UC) navigate life with IBD. *Living With IBD* recognizes that the pain of IBD is real and these chronic diseases can be mentally and physically exhausting, and sometimes hard to talk about.

The information and resources included on LivingWithIBD.com aim to help people better understand IBD, equip patients with the information and tools needed to have productive and honest conversations with healthcare providers, and connect patients with community resources like the National Alliance for Caregiving.

To learn more, click the red button below.

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### **Self-Care Tips for Caregivers: Your Health Matters, Too**

What did you want to be when you grew up? An author, an astronaut, an architect, an actor? Whatever life you dreamed of for yourself, you probably never imagined the possibility of juggling your personal and professional life while also being a caregiver for someone who is living with medical challenges.

Whether you're moving an aging parent into your home, taking care of a partner who has cancer or managing any other scenario in which you're caring for a loved one with health needs, one thing remains true: Caregiving can be incredibly stressful.

To learn more, click the red button below.



#### Stroke: Signs, Causes, and Treatment

Having a stroke is just as serious as having a heart attack. So, it's important to know the signs of stroke and act quickly if you suspect you or someone you know is having one. Stroke is the fifth leading cause of death in the United States and is the number one cause of serious adult disability. Stroke risk increases with age, but strokes can — and do — occur at any age. The good news is that most strokes can be prevented, and there are steps you can take that may lower your chance of having a stroke.

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

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### **Disability & Health Information for Family Caregivers**

If you are a family member who cares for someone with a disability, whether a child or an adult, combining personal, caregiving, and everyday needs can be challenging. The CDC offers general caregiving tips intended to provide families with information on how to stay healthy and positive. These tips can be used to address many family issues. Information, support, advocacy, empowerment, care, and balance can be the foundation for a healthy family and are appropriate no matter what the challenge.

To learn more, click the red button below.

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### Coping with Agitation and Aggression in Alzheimer's Disease

People with Alzheimer's disease may become agitated or aggressive as the disease gets worse. Agitation means that a person is restless or worried. He or she doesn't seem to be able to settle down. Agitation may cause pacing, sleeplessness, or aggression, which is when a person lashes out verbally or tries to hit or hurt someone.

Most of the time, agitation and aggression happen for a reason. When they happen, try to find the cause. If you deal with the causes, the behavior may stop.

To learn more, click the red button below.

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### Wandering and Alzheimer's Disease

Many people with Alzheimer's disease wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

To learn more, click the red button below.

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### Alzheimer's and Hallucinations, Delusions, and Paranoia

Due to complex changes occurring in the brain, people with Alzheimer's disease may see or hear things that have no basis in reality.

If a person with Alzheimer's has ongoing disturbing hallucinations or delusions, seek medical help. An illness or medication may cause these behaviors. <u>Medicines are</u> <u>available to treat these behaviors</u> but must be used with caution. The following tips may

also help you cope with these behaviors.

To learn more, click the red button below.

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# When a Person with Alzheimer's Rummages and Hides Things

Someone with Alzheimer's disease may start rummaging or searching through cabinets, drawers, closets, the refrigerator, and other places where things are stored. He or she also may hide items around the house. This behavior can be annoying or even dangerous for the caregiver or family members. If you get angry, try to remember that this behavior is part of the disease.

To learn more, click the red button below.

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**Managing Personality and** 

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

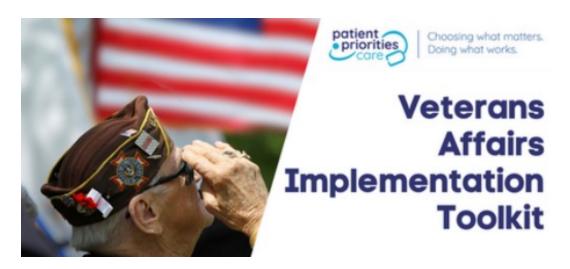
Alzheimer's disease causes brain cells to die, so the brain works less well over time. This changes how a person acts. Common personality and behavior changes you may see include:

- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren't there
- · Wandering away from home
- Pacing a lot
- Showing unusual sexual behavior
- Hitting you or other people
- · Misunderstanding what he or she sees or hears

You also may notice that the person stops caring about how he or she looks, stops bathing, and wants to wear the same clothes every day.

To learn more, click the red button below.

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### Patient Priorities Care Veterans Affairs Implementation Toolkit

<u>Patient Priorities Care</u> (PPC) helps patients and clinicians focus all decision-making and healthcare on what matters most: patients' own health priorities. It was developed by clinicians, patients, caregivers, health system leaders, and payers.

PPC is particularly suited for older adults who must manage multiple conditions and navigate multiple clinicians. People with multiple conditions receive a lot of care that is often burdensome and may not address what matters most to them. Patient Priorities Care recognizes that, when faced with tradeoffs, older adults differ in their own health outcome goals (what they want to achieve from their healthcare) and in their care preferences (what they can do to achieve their goals).

PPC has released a new toolkit on guiding PPC implementation within Veterans Affairs (VA) clinical settings to help identify and make treatment decisions based on what matters to older veterans.

To access the toolkit, click on the red button below.



### A Caregiver's Guide to the Dying Process

Grief is not experienced only after death. As a caregiver, you may be susceptible to two types of grief: anticipatory grief during your loved one's illness, and then grief that occurs after the person dies.

Many caregivers experience "anticipatory grief" as they observe the physical, psychological, and cognitive declines occurring as the illness progresses. For many caregivers of people with dementia this may be especially painful, as their loved one becomes almost unrecognizable compared to the person "they used to be."

After the death of a loved one, it can be difficult to see how to ever go on. The grief journey may seem like a mountain that is too difficult to climb. The Hospice Foundation of America offers a booklet, *A Caregiver's Guide to the Dying Process*, that provides guidance to care providers facing these circumstances.

To view the booklet, click the red button below.

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### Aging in Place: Growing Older at Home

Individuals intending to "age in place" in their own homes face a number of challenges. The good news is that with the right help you might be able to do just that.

Planning ahead is hard because you never know how your needs might change. The first step is to think about the kinds of help you might want in the near future. Maybe you live alone, so there is no one living in your home who is available to help you. Maybe you don't need help right now, but you live with a spouse or family member who does. Everyone has a different situation.

To learn more, click the red button below.

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### **Different Care Settings at the End of Life**

The three most common places people at the end-of-life die are at home, in a hospital, or in a care facility. While not everyone has the chance to decide where they will die, people who know the end of life is approaching may be able to plan ahead. Several factors may help with this planning, including knowing the type of care you need and want, where you can receive this level of care, <u>advance care directives</u>, <u>costs</u>, and availability of family and friends to help.

To learn more, click the red button below.

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### **Providing Care and Comfort at the End of Life**

Not all end-of-life experiences are alike. Death can come suddenly, or a person may linger in a near-death state for days. For some older adults at the end of life, the body weakens while the mind stays clear. Others remain physically strong while cognitive function declines. It's common to wonder what happens when someone is dying. You may want to know how to provide comfort, what to say, or what to do.

To learn more, click the red button below.



### **Legal Issues for LGBTQ+ Caregivers**

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

To learn more, click the red button below.

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### **Rush Caring for Caregivers (C4C)**

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

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

To learn more, click the red button below.

**LEARN MORE** 



#### Home Modification Toolkit: Lessons from the Field!

The University of Southern California Fall Prevention Center of Excellence and the Administration for Community Living have put together a toolkit designed to provide professionals with tools to enhance home modification availability and awareness for older adults and persons with disabilities. The Toolkit has a specific emphasis on enhancing the Aging Network's ability to deliver and promote access to best practice home modification programs through targeted resource development, training, technical assistance, and information dissemination.

The Aging Network is an interconnected system of agencies funded under the Older Americans Act of 1965. The National Aging Network includes 56 State Units on Aging (SUAs), 622 Area Agencies on Aging (AAAs), and more than 260 Title VI Native American aging programs.

To learn more, click the red button below.



### Caregiver's Guide to Medications and Aging

Modern medicines have contributed to longer life spans, improved health, and vastly improved our overall quality of life. Medications are the most common treatment for many diseases and conditions seen in older people and persons with disabilities. Medicines now not only treat and cure diseases that were untreatable just a few years ago, they aid in the early diagnosis of disease; prevent life-threatening illnesses; relieve pain and suffering; and allow people with terminal illnesses to live more comfortably during their last days.

However, for older adults and people with disabilities, medications—prescription, over-the-counter, social drugs such as alcohol, and herbal remedies/alternative medicines—can be a double-edged sword. When not used appropriately, effectively, and safely, medications can have devastating consequences.

To learn more, click the red button below.



#### When It's Time to Leave Home

The decision about whether your parents should move is often tricky and emotional. Each family will have its own reasons for wanting (or not wanting) to take such a step.

One family may decide a move is right because the parents can no longer manage the home. For another family, the need for hands-on care in a long-term care facility motivates a change.

To learn more, click the red button below.

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### **HIV-Associated Neurocognitive Disorder (HAND)**

Since the start of the AIDS epidemic more than three decades ago, doctors, family and friend caregivers, and patients have observed that some people with the disease experience decline in brain function and movement skills, as well as shifts in behavior and mood. This disorder is called HIV-associated Neurocognitive Disorder, or "HAND." Although advances in antiretroviral therapy from the past two decades have decreased the severity of HAND, symptoms still persist in 30–50% of people living with HIV. For many people, these symptoms continue to affect activities of daily living.

To learn more, click the red button below.

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### **Frequently Asked Questions about Caregiving**

Caregiving can be overwhelming, especially when you're starting out. Take a deep breath! Then tackle one task at a time.

First, assess your loved one's needs. What types of help are needed? Ask family members and friends to share tasks. Look for resources in your community, such as home health care or adult day care centers. The **Eldercare Locator** can help you find in-home help; transportation; resources to install ramps, grab bars, or other home modifications; and other resources in your area. It can also help you learn about options for paying for care.

To learn more, click the red button below.

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# How to Share Caregiving Responsibilities with Family Members

Caring for an older family member often requires teamwork. While one sibling might be local and take on most of the everyday caregiving responsibilities, a long-distance caregiver can also have an important role.

As a long-distance caregiver, you can provide important <u>respite to the primary</u> <u>caregiver</u> and support to the aging family member. First, try to define the caregiving responsibilities. You could start by setting up a family meeting and, if it makes sense, include the care recipient in the discussion.

To learn more, click the red button below.

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### **Dementia-Related Pain: What Caregivers Need to Know**

As dementia progresses, so does the likelihood that patients are experiencing pain. Between 50% and 80% of patients with moderate to severe dementia experience pain daily. Many patients receive inadequate treatment due lack of recognition. Alzheimer's disease causes the person to develop a mask-like facial expression. This minimizes typical facial expressions of pain, like a drawn mouth or furrowed brows. Also, patients may have lost the cognitive ability to tell caregivers about their pain with phrases such as "this hurts" or "I am in pain."

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### **Paying for Long-Term Care**

Many older adults and caregivers worry about the cost of medical care and other help they may need. These expenses can use up a significant part of monthly income, even for

families who thought they had saved enough. How people pay for <u>long-term care</u> — whether delivered at home or in a hospital, assisted living facility, or nursing home — depends on their financial situation and the kinds of services they use.

To learn more, click the red button below.

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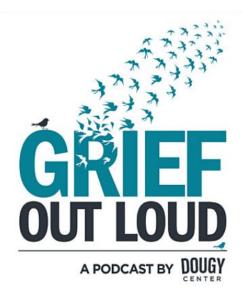
### **Taking Care of Yourself: Tips for Caregivers**

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

Caregiving, especially from a distance, is likely to bring out many different emotions, both positive and negative. Feeling frustrated and angry with everyone, from the care recipient to the doctors, is a common experience. Anger could be a sign that you are overwhelmed or that you are trying to do too much. If you can, give yourself a break: take a walk, talk with your friends, get some sleep — try to do something for yourself.

To learn more, click the red button below.

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### Podcast: Caring for a Parent at the End of Life

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

This episode of the <u>Dougy Center</u>'s podcast "Grief Out Loud" travels to a lot of places, including: What Mark learned about grief from his mother after his father died. How those lessons shaped the way he approached caring for her and grieving her death. How Mark moved into a place of acceptance with his mother for the ways she responded when he came out to her as a young adult. The ways he dealt, and continues to deal with grief, even during the height of COVID, when he was unable to access his usual outlet, travel.

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

LISTEN TO THE PODCAST



#### **Resources for Alzheimer's and Dementia Caregivers**

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

To learn more, click the red button below.

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