# THIS WEEK IN CAREGIVING



**November 23, 2022** 

**Happy National Family Caregivers Month!** 



## CAREGIVING IN THE NEWS

# Prevalence of Dementia Is Declining Among Older Americans; Inequalities Reduced but Still Persist

The prevalence of dementia in the United States is declining among people over age 65, dropping 3.7 percentage points from 2000 to 2016, according to a new RAND Corporation study.

The age-adjusted prevalence of dementia declined from 12.2 percent of people over age 65 in 2000 to 8.5 percent of people over age 65 in 2016—a nearly one-third drop from the 2000 level. The prevalence of dementia decreased over the entire period, but the rate of decline was more rapid between 2000 and 2004.

From: Rand Corporation | Published: November 7, 2022

**READ MORE** 

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# Is It Alzheimer's? Families Want to Know, and Blood Tests May Offer Answers

Joe knew something was terribly wrong when his wife, an energetic nurse and mother of three, became forgetful in her early 60s. Four years ago, Lynn was diagnosed with dementia but decided against having a spinal tap that would have shown whether the cause was Alzheimer's disease.

The couple chose to pursue a lifelong dream, buying a 40-foot camper and traveling to national parks in 35 states. "It was an adventure we could have together," Joe said.

# Caregiving When You're an Only Child

For adult children, caregiving for their parents as they age and decline is an inevitable rite of passage. But only children who have to be caregivers face a different burden compared to those who were raised in a family with one or more siblings willing to share the duties and stressors. Only children often have to do it all.

Based on interviews with several experts, all suggest that only children can benefit from preparing early for the eventuality of their parents needing caregiving assistance.

From: Washington Post | November 17, 2022

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From: nextavenue | Published: November 16, 2022

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## NAC NEWS AND UPDATES



## 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 <u>here</u>.

#### 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.







# The National Alliance for Caregiving Calls for Family Caregiver Resources

The National Alliance for Caregiving is looking for resources to populate Take Care Community. Take Care Community is a website that hosts resources created for family caregivers submitted by family caregivers and those who belong to the family caregiver community. We are looking for general resources related to any topic but, with support from Genworth, we are also looking for resources related to grief and loss in order to honor family caregivers who have lost a loved one they were caring for.

To submit a resource, click the red button below.

**SUBMIT RESOURCES** 

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It's important to recognize those with chronic pain and the family caregivers that help care for them. This second installment in the Social Innovations Spotlight Series is written by Dr. Fawn Cothran, PhD, RN, GCNS-BC, FGSA, Hunt Research Director at the National Alliance for Caregiving, and explores those caring for someone with chronic pain and the tools that are available to assist them. <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 >

### **World Carers Conversation 2022 Session Recordings**

World Carers Conversation returned May 19, 2022 as a global, virtual event with the support of EMD Serono and Embracing Carers. Innovators, researchers, policymakers and carer advocates from around the globe learned about advancements in the field, got inspired, and made connections that matter for the future of carers everywhere. These recordings cover the primary conversations and topics discussed.

To view the slide deck used in the event, click **here**. To view the recordings, click below.

VIEW RECORDINGS >

# Global Voices of Caregiving: A PhotoVoice Project

As part of the World Carers
Conversation 2022, NAC worked
with Chief Story Officer Anne Levy
and caregivers from around the
globe to help them tell their own
story through a series of photos.
These photos addressed simple
questions about being a caregiver,
such as what works, what doesn't
work, and what a world that
embraces and supports caregivers
would look like. Each one of these
stories is unique to the caregiver's

own experience and tells a diverse story of what it's like to care for others, an act which connects us all

To view and hear these stories, please click on the red button below.



VIEW STORIES



## **EVENTS & OPPORTUNITIES**

### **NOVEMBER**

### **Grow Your Resilience for Caregivers**

November 23, 2022 | 1:30 PM - 3:00 PM ET | Online

Caregivers are needed now more than ever... and face burnout at an increasing rate. We know that caring for others is an important job and to do that job well, you need to take care of yourself! Whoever you are caring for, this webinar will help you build a foundation of resilience and develop tools that will help strengthen your caregiver journey.

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



### What's My Caregiving Impact?

November 25, 2022 | 11:00 AM - 12:00 PM ET | Online

According to recent research:

- Eight in 10 (80%) family caregivers are interested in paying for products or services to help them manage
- Almost nine in 10 (87.9%) cannot identify any companies that stand out in helping them as caregivers.

Family caregivers need a local resource who can guide them, support them and encourage them.

They need someone like you.

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

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

We'll record this meeting so be sure to register even if you can't attend the live event. We'll send the archive to you after the event ends.

You can learn more about the training programs Denise has developed <u>here</u>.

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

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

REGISTER

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### **Understanding Agitation - A Responsive Behaviour**

November 28, 2022 | 2:30 PM - 4:00 PM ET | Online

Agitation is a responsive behaviour that can be seen in individuals living with Alzheimer disease and other forms of dementia. It is stressful to the person living with dementia, their families, and care providers, and can result in faster progression of the illness and even higher rate of death! Managing agitation of Alzheimer has been a major challenge with difficulty finding the right approach to improve the symptoms and reduce the risk of harm.

In this discussion hosted by the <u>Alzheimer Society of Durham</u> in Ontario, we will clarify the definition of agitation, factors that can contribute to it and describe best practices to manage it. Also, we will share information about the latest research geared towards optimizing the care for agitation of Alzheimer disease in the community, in long term care and in the hospital.

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





### **Sundowning**

### November 29, 2022 | 8:30 AM - 10:00 AM ET | Online

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

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

This session is for you if you ...

- want to gain a better understanding of the factors that may contribute to early evening agitation or sundowning
- would like to consider your own needs at this time as well as the person with dementia
- want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- would like to meet other people who are taking care of a friend or family member with dementia in a similar situation

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



# ACL Accepting Comments on the National Strategy to Support Family Caregivers

Deadline for comment submission: November 30, 2022

The Administration for Community Living (ACL) is accepting public comments regarding the National Strategy to Support Family Caregivers. Your responses to the ACL questionnaire will help the Advisory Councils identify priorities for future updates of the Strategy.

To submit a comment, click the red button below.

SUBMIT A COMMENT >

### **DECEMBER**



# **Constructing a National Vision for Family Caregiver Support**

December 1, 2022 | 11:30 AM - 12:30 PM ET | Online

On September 21, 2022, the Administration for Community Living, an agency within the U.S. Department of Health and Human Services, delivered the 2022 National Strategy to Support Family Caregivers to Congress. The strategy was created to support family caregivers of all ages, from youth to grandparents, and regardless of where they live or what caregiving looks like for them and their loved ones.

During this presentation, participants will learn about how the strategy was developed, including the formation of an innovative public/private partnership that facilitated the work, and how it can be leveraged to create a "whole of society approach" to greater recognition and inclusion of family caregivers and those they support.

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

REGISTER

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

December 1, 2022 | 2:30 PM - 3:30 PM ET | Online

It is well recognized that Parkinson's Disease affects body movement; this presentation will focuses on helping you better grasp the common emotional changes that occur in the person with PD. Learn how increasing empathy for both caregivers and their person can reduce frustration.

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

REGISTER >



# J. Levin Memorial Conference on Alzheimer's: Behavior Management Strategies

December 2, 2022 | 10:00 AM - 3:00 PM ET | Online

The Alzheimer's Family Support Center presents its annual free Zoom conference on Alzheimer's featuring Teepa Snow.

### About this event

This year's conference focuses on behavior management. Topics include:

- Managing Behavior: Start With Yourself
- Developing Activities That Have Meaning for Those Living With Dementia
- Humor and Caregiving
- Learning the Difference Between Letting Go and Giving Up

CE certification pending. Registration is required.

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

REGISTER >



### **Road Map to Acute Care Management**

December 2, 2022 | 12:00 PM - 1:00 PM ET | Online

It can be difficult to navigate Emergency Room (ER) visits for a loved one with dementia. Join us for Road Map to Acute Care Management and learn practical tips and professional advice on how to best manage these situations.

Geriatric Nurse Practitioner, Linda Pellegrini, along with Caregiver, Judy Johanson, will provide:

- Guidance on what to bring with you to the ER
- Advice on interacting with hospital staff
- Explanation of important medical forms to complete in advance

This program is part of the Massachusetts Alzheimer's Disease Research Center (MADRC) "Aging & Memory Loss Road Map Education Series." The presentation will be held via Zoom.

Registrants will receive the Zoom link via email a few days prior to the event.

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

REGISTER



## How Seasonal Decorations Might Affect a Person with Dementia

December 5, 2022 | 1:30 PM - 3:00 PM ET | Online

Decorations can be associated with a range of festivities such as Christmas, Thanksgiving, Diwali, Chinese New Year or Eid. Let's explore why decorations might be unsettling or upsetting for people with dementia and some ideas about how you might deal with this.

This session will outline some of the main considerations when decorating your house and the positive and challenging effects this may have for the person with dementia.

Our health and care professionals will explore with you a range of strategies to help you in your caring role to manage these situations.

As well as providing information and knowledge this online session offers the opportunity to share or discuss your own experiences or current challenges.

The session is for you if you would like to ...

- learn about how changes in the brain can affect how, and what the person can see and how they may interpret things in the environment
- · explore practical ways of decorating your house which will not cause stress or

- confusion to the person with dementia
- increase your awareness of the challenges which may be created which we wouldn't ordinarily think of
- spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- meet other people who are taking care of a friend or family member with dementia in a similar situation.

Sessions are all on Zoom and last approximately 1.5 hours.

To learns more about seasonal decorations can affect those with dementia, click <u>here</u>. To register for this event, click the red button below.



# Living Well With Dementia Series: Preparing the Caregiver for End of Life

### December 7, 2022 | 11:00 AM - 12:00 PM ET | Online

Understanding how people die is a difficult but necessary topic. Recognizing the signs and behaviors as persons enter into the process of Actively Dying helps us know what is normal as the body slowly ceases its function. Grief, guilt, and the reality of loss will be discussed.

On December 7th, join A Gift of Time for a presentation featuring Tam Cummings, PHD for a discussion about these topics. Dr. Cummings is the author of *Untangling Alzheimer's, The Guide for Families and Professionals*.

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



### **Conscious Caregiving**

December 7, 2022 | 1:00 PM - 2:30 PM ET | Online

The Alzheimer's Association and Juniper invite you to join us for a caregiver awareness event on December 7th.

During the holiday season, many people are visiting older relatives and friends and notice changes. Grandma missed some steps in her Thanksgiving turkey recipe that she's been making for the last 30 years. Or a brother repeatedly forgot recently shared information, like the news that someone passed away or is having a baby. What do these changes mean?

If someone in your life has Alzheimer's or another dementia, communicating with them over the disease progression can be a challenge. In this session, the Alzheimer's Association will walk through effective communication strategies for caregivers to help connect with friends and family who have Alzheimer's or another dementia. Then, Juniper will share and demonstrate the Powerful Tools for Caregivers class. Powerful Tools for Caregivers is a class that supports family caregivers to identify and reduce stress, improve communication with family and health care providers, and master caregiving decisions.

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

REGISTER



## **Understanding Compassion Fatigue and Burnout**

December 8, 2022 | 1:00 PM - 2:00 PM ET | Online

Does compassion cause suffering? When does it go too far and how can caregivers protect their own wellbeing? Learn the warning signs, who is at risk, and how to restore

your emotional energy with a licensed therapist.

On December 8th, Mindspring Mental Health Alliance will host a webinar on compassion fatigue and burnout among caregivers.

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

[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.]

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



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

December 9, 2022 | 1:00 PM - 2:00 PM ET | Online

Learn about a new model of care called the Dementia Connection Model and walk away with a number of tools for your caregiver toolbox!

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.

You can earn 1 FREE continuing education (CE) credit, after completing the webinar evaluation.

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

REGISTER >



### **Caregiver Burnout: For Caregivers of Autistic Children**

December 10, 2022 | 12:00 PM - 1:00 PM ET | Online

Parenting can be stressful, however studies have shown that parents of Autistic children score much higher on stress indicator tests.

Higher stress levels can be attributed to several factors including:

- Lack of help/support
- Lack of understanding of the child's needs
- Financial burdens
- Long waiting lists for assessments and professional support
- Dealing with judgment from society & family members
- Needing self-care & sensory needs support

And the list goes on and on....

So how can we come together to best support parents and caregivers of children with exceptional needs?

Spectrum Lingo has put together this free webinar to show caregivers how best to empower themselves and avoid experiencing burnout. How can you best serve your child if your tank is empty? So let's fill up your tank and teach you skills and strategies so that you can step into your power and keep your engine running!

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

### **Music: The Uses and Benefits**

### December 12, 2022 | 11:00 AM - 12:30 PM ET | Online

Music can provide connection and shared experience between you and the person with dementia. It is particularly useful in everyday situations when other communication or activities are more challenging.

Music can help to maintain a person's quality of life or even improve it. For carers, music can be beneficial by helping to lighten mood, helping create connections, reduce stress and bring back memories.

The webinar, presented by Dementia Carers Count in the UK, will be hosted by Alex Stirling and will explore the benefits of music and ways in which it can be used in everyday situations.

Alex is a Speech and Language Therapist who specialises in working with adults with acquired communication disabilities. Her interest in dementia has been influenced by the experience of being a part-time carer for her mother.

This session is for you if you would like to ...

- To learn about the role of music when supporting someone with dementia
- Your questions around music addressed in a safe, supportive environment by healthcare professionals with experience of supporting people with dementia and their families
- To meet other people who are supporting a friend or family member with dementia in a similar situation

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

REGISTER >

## **Understanding Psychological Wellbeing**

December 13, 2022 | 8:30 AM - 10:00 PM ET | Online

This session will explore the psychological needs for you in your caring role and also for the person who has dementia to support the well-being of you both.

This session is for you if:

- you would like to gain a better understanding of your own needs for well being and those of the person with dementia
- you would like to learn about the different factors which can contribute to a persons well being
- you want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- you would like to meet other people who are taking care of a friend or family member with dementia in a similar situation

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



### The Importance of Self-Care

December 13, 2022 | 1:30 PM - 3:30 PM ET | Online

This 2-hour webinar is one of a series of online events aimed to provide support and reassurance to parents, wherever they are on their parenting journey.

This webinar will focus on the importance of self care for parents and why we often struggle to do it. The facilitators will present some information and ideas on the topic.

This will be followed by a Q & A, during which the facilitators will respond to questions submitted by participants via the private chat.

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

REGISTER



## **Communication & Behavior: The Language of Dementia**

December 15, 2022 | 12:00 PM - 1:00 PM ET | Online

The communication changes that accompany dementia can present a host of challenges. As verbal language fades, nonverbal and behavior become more prominent methods to express thoughts, wants and needs. This webinar will review common changes that occur and learn strategies that can be easily utilized to promote understanding.

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

REGISTER >

### **Keeping the Communication Going**

December 19, 2022 | 8:30 AM - 10:00 AM ET | Online

This session aims to explain how dementia can affect language and communication. There will be an opportunity to explore the emotional impact of a breakdown in communication / relationships for a carer and the person with dementia and to identify strategies to help establish effective and meaningful interactions.

This session is for you if:

- you would like to gain a better understanding of how communication can be affected for a person with dementia
- you would like to learn about different strategies to support a persons ability to communicate and understand
- you want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- you would like to meet other people who are taking care of a friend or family member with dementia in a similar situation

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

LEARN MORE



### **Family Reactions to Mental Illness**

December 22, 2022 | 1:00 PM - 2:00 PM ET | Online

Understanding why people experience things differently can help to ease tension & increase acceptance. Discuss the caregiving experience, the stages of emotional response, and learn how to respond and cope in this one-hour seminar with a licensed therapist.

About the instructor: Jaymi Dormaier is a Licensed Master Social Worker with ten years of experience in the mental health field. In Jaymi's career as a social worker and therapist she has worked with diverse populations focusing on anxiety, depression, grief, trauma,

foster care, adoption, homelessness, and addiction. She is passionate about helping others live a life they love.

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



### **JANUARY**

### Impact of Pain in Dementia

January 5, 2023 | 8:30 AM - 10:00 AM ET | Online

Tune in on January 5th for a webinar presented by Dementia Carers Count. The session will explain how pain may be experienced by a person with dementia and the impact it may have on both the person you care for and you as a carer.

There will be an opportunity to explore the impact and consequences of pain for a person with dementia and how taking different approaches may improve pain management and wellbeing.

This session is for you if you would like to:

- Gain a better understanding of pain and the implications for someone with dementia
- Understand the risk factors and consequences for both you and the person you care for
- Learn how pain can be identified and managed effectively with tips and strategies
- Discuss the emotional impact of pain for both yourself and the person with dementia
- Spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- Meet other people who are looking after a friend or family member with dementia in a similar situation

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

REGISTER



### Relationships, Family, and Mental Health

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

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

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

REGISTER >

# 10 WARNING SIGNS OF ALZHEIMER'S



### **ALZHEIMER'S PROGRAM: 10 Warning Signs**

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

Memory loss that disrupts daily life may be a symptom of Alzheimer's or other dementias. Alzheimer's is a brain disease that causes a slow decline in memory, thinking and reasoning skills. This webinar will discuss 10 warning signs and symptoms.

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

REGISTER

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# Sustainable Caregiving for Care Partners of People with Neurologic Illness

Tuesdays, January 10 - February 28, 2023, 5:00 PM - 6:30 PM ET | Online

This course will meet weekly for eight session, online workshop to learn evidence-based skills to make your caregiving sustainable.

This is a live-online program of eight weekly 90-minute classes. In each class, you will learn evidence-based skills to help make your caregiving sustainable.

Teaching methods include brief lecture periods mixed with experiential exercises. You will also have opportunities to speak with others in structured break-out groups (pairs or triads) as well as in the larger group.

Each class will have its own theme and the opportunity to practice new skills in a safe place, so that they're more available during the days ahead. Themes include:

- Attentional balance and grounding
- Repertoire of stress responses and meeting difficult emotions
- Positive intention setting
- Mindful self-compassion
- Challenging relationships and patients' concerns around "being a burden"
- · Re-framing chronic sorrow
- Balance and growth in adversity
- 'What works for me?' -- wellness practice -journals to cultivate a positive mindset

If you have questions about this program, contact Program Manager Gayle Kojimoto at 415.509.8645 or <a href="mailto:gayle.kojimoto@ucsf.edu">gayle.kojimoto@ucsf.edu</a>.

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

REGISTER

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## **CONFIDENCE Financial Education Program**

Thursdays, January 19 - February 16, 2023, 5:00 PM - 7:00 PM ET | Online

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

Sessions will take place over Zoom video conference.

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



### **Managing Changes in Movement and Sensation**

January 23, 2023 | 8:30 AM - 10:00 AM ET | Online

This Zoom meeting presented by Dementia Carers Count on January 23rd (8:30 AM) will explore how changes in the brain affect everyday tasks

It will be an opportunity to focus specifically on some of the motor and sensory challenges which can occur for a person with dementia alongside support strategies which can really impact on the well-being of the person and your ability to cope with the challenges. These challenges may include sequencing everyday tasks such as getting dressed, eating a meal, sensations, and spatial awareness. By understanding the challenges for the person with dementia, this session will provide you with the knowledge that you have the ability and skills to support some of these challenges.

This session is for you if:

- you would like to learn about how changes in the brain can affect what the person senses and the complexity of the everyday tasks we complete daily
- you would like some ideas for simplifying tasks and help the persons sensory awareness
- you want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- you would like to meet other people who are taking care of a friend or family member with dementia in a similar situation

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

REGISTER >

### **Meaningful Activity**

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

Why is meaningful activity important for people with dementia? Meaningful activity is important to help us all maintain a good quality of life, whether we are living with dementia or not. It is particularly important for people with dementia as it:

- Helps maintain skills and independence
- Helps maintain brain (cognitive) function
- Builds and preserves self-esteem and self-confidence
- Gives an outlet for self-expression
- Provides social and emotional connection

The type of meaningful activity a person with dementia will be able to engage in will depend on their interests, strengths and abilities.

Meaningful activity can vary from daily tasks such as cooking and cleaning, to art classes, watching films, exercise and spending time with family and friends.

Why join this session?

It is an opportunity to consider activities and why they are important to someone with dementia. The session explores different sorts of activities might meet the different needs of an individual. There will be some practical advice and strategies about how to engage someone in activities.

The course is for you if you would like to ...

- Know more about why activities are important
- Consider the different needs an individual has and how activities might meet these
- Learn some hints and tips about how to get someone involved in activities
- Spend time with experienced healthcare professionals who will answer your questions in a safe and supportive environment
- Meet other people who are taking care of a friend or family member with dementia in a similar situation

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

**REGISTER** 

**PATIENT AND CAREGIVER STUDIES** 



### The Trial-Ready Cohort -- Down Syndrome (TRC-DS)

Because people with Down syndrome have the same brain changes as those with Alzheimer's disease, they are at very high risk for Alzheimer's disease dementia and are an important population to consider as we develop therapies for Alzheimer's research.

Participants are needed to support new research into the connection between Alzheimer's and Down syndrome. The Trial-Ready Cohort -- Down Syndrome (TRC-DS) needs healthy adults between the ages of 25 and 55 with Down syndrome to participate and become part of a larger movement advancing Alzheimer's disease therapies and potential cures for people with Down syndrome.

To learn more about the study, click here. To enroll, click on the red button below.





## LGBTQIA+ & Non-LGBTQIA+ Caregivers Needed: Parkinson's Research

Are you 18+ and a caregiver for someone living with Parkinson's?

The UNLV School of Public Health and the Michael J. Fox Foundation for Parkinson's Research just launched an exciting research study – and we need your help! Parkinson's Research with Inclusion, Diversity, and Equity ("PRIDE") explores the health and health care needs of people living with Parkinson's disease.

Little is known about the LGBTQIA+ community because questions about us are not often asked in research. This one time, 45-minute phone study measures the unique needs and struggles of LGBTQIA+ individuals with Parkinson's and their caregivers. It will answer

some of the following questions: What problems do LGBTQIA+ individuals with Parkinson's disease experience when using health care services? Would the community benefit from additional support and services? How do LGBTQIA+ people find the services they need?

Participation is voluntary and all information will be kept private. Participants will receive a \$25 Visa E-gift card.

All questions can be directed to primary investigator Jason Flatt, PhD at 702-895-5586 or Jason.Flatt@unlv.edu. Please note that we unfortunately cannot accept Google phone numbers.

Complete the survey today by calling **1-888-709-7689!** To learn more about the study, click on the red button below.



### Life Enhancing Activities for Family Caregivers (LEAF)

Researchers at Northwestern University and the University of California San Francisco are testing a program for family caregivers of individuals with Alzheimer's Disease. Six positive emotion based skill-building sessions are delivered either one-on-one via Zoom videoconferencing with one of our facilitators or via a self-guided platform online. Participants will be supplied with tablet computers, so caregivers can take part from anywhere in the USA. The study consists of one hour long session per week for six weeks to learn the skills, nightly home practice, and online surveys. To be eligible, you must be the primary caregiver of someone with Alzheimer's Disease, and you must have consistent access to a reliable Wi-Fi connection for your weekly sessions.

We know that caregiving for your loved one can be stressful, especially in these uncertain times. By sharing these skills, we are not saying that positive emotion will magically make everything better or easier. Instead, the program is based on the fact that even in the midst of challenging and stressful circumstances, positive emotion can occur, and there are things you can do to notice, create, and savor the good things to increase your own experience of positive emotion.

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



### The Alzheimer Prevention Trials (APT) Webstudy

Start: December 20, 2017 End: April 30, 2023

Enrollment: 20,0000

The Alzheimer Prevention Trials (APT) Webstudy is an online registry designed to accelerate enrollment for Alzheimer's disease clinical trials by identifying and tracking individuals who may be at higher risk for developing Alzheimer's dementia.

The APT Webstudy monitors volunteers who are 50 and older for changes in their memory through a series of quarterly, no-cost memory tests. It takes place online, without any inperson visits required. APT Webstudy researchers use the results to track volunteers' memory and, based on potential risk level, invite select volunteers to participate in other Alzheimer's research studies.

Participants in the Webstudy, will receive:

- Access to secure, web-based tools to assess your brain's cognitive function over time:
- A personalized dashboard with insights into your own memory based on test results;
- The potential opportunity to participate in comprehensive memory evaluations at one of our nationwide clinical sites; and
- The potential opportunity to participate in clinical trials to prevent Alzheimer's disease.

To learn more or sign up, click on the red button below.



## **Mindcrowd Memory Test**

MindCrowd is an online research study to understand the factors that influence how the human brain functions. Specifically, MindCrowd researchers want to know how the way people remember things might change as they age. If researchers better understand the way memory changes as people age, they may be able to understand what changes occur in people who have an age-related brain disease that affects their memory (like Alzheimer's disease and other dementias).

Participants will take one attention test and one memory test, and answer a few study-related questions. The online memory test takes approximately 10 minutes to complete.

Participant test results show how they performed compared to all of those who have taken the MindCrowd memory and attention test so far. MindCrowd is testing only a small fraction of each participant's overall cognitive performance. The MindCrowd test results reflect each individual's performance for that specific cognitive domain and do not indicate overall ability or intelligence.

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

PARTICIPATE >



**AHEAD Study** 

Start: July 13, 2020 End: October 25, 2027 Enrollment: 1400

The AHEAD Study is an exciting step in the fight against Alzheimer's disease. This trial, funded by the National Institutes of Health (NIH) and Eisai Inc., aims to help prevent Alzheimer's disease by testing an investigational treatment aimed at delaying memory loss before noticeable signs of Alzheimer's disease begin.

The AHEAD Study tests whether an investigational treatment can slow or stop the earliest brain changes due to Alzheimer's disease in people with a higher risk of developing the disease later in life. It is an opportunity to work with world-renowned experts to carefully monitor your brain health at no cost and take advantage of the latest advances made in treatment.

### The AHEAD Study is the first of its kind to:

- Enroll participants as young as 55 years old who are at risk of developing symptoms of Alzheimer's disease as they get older;
- Use a blood test to rule out people not likely to be eligible based on amyloid PET imaging;
- Target the earliest changes in the brain due to Alzheimer's disease by enrolling participants with intermediate levels of brain amyloid;
- Use an approach that tailors dose levels of the investigational treatment to study participants' brain amyloid levels;
- Test an investigational treatment that has been shown to lower brain amyloid in people with symptoms of Alzheimer's.

To see if you're eligible to participate, click on the red button below.

PARTICIPATE >

## Brain Stimulation Through Smell for People With Early-Stage Alzheimer's Disease

Start: November 8, 2021 End: April 30, 2023 Enrollment: 200 Preliminary research suggests that stimulating the parts of the brain that sense smell, called the olfactory regions, may help reduce some brain changes associated with Alzheimer's disease. This study will test whether daily treatment with computerized olfactory training (COT), which uses a portable device to deliver task training along with timed exposure to the scent of essential oils, improves cognitive and daily functioning. Potential participants will be screened for amyloid, a protein associated with Alzheimer's disease, using a PET brain scan or a cerebral spinal fluid test.

Amyloid-positive participants will be randomly assigned to receive COT using either the therapeutic essential oils or a placebo scent. The participant's caregiver will administer COT to the participant at home for 45 minutes each day for six months. Researchers will assess changes in memory and cognitive function, brain structure, smell sensitivity, and other measures related to the participant's quality of life and daily functioning at the start of the study, and after six and nine months.

Minimum Age: 65 Years Maximum Age: 85 Years

#### Must have:

- Probable mild Alzheimer's disease with:
  - Mini-Mental State Examination score of 21 to 27
  - Clinical Dementia Rating score of 1
  - Presence of amyloid deposits, based on analysis of the cerebral spinal fluid or a PET brain scan
- Females must be postmenopausal for at least two years
- Available study partner with normal cognitive function

### **Must NOT have:**

- Any significant neurologic disease other than Alzheimer's disease
- MRI evidence of infection or blood vessel damage
- Significant nasal disease
- Any unstable medical condition
- Major psychiatric disorder or substance use disorder within the past two years
- Any condition that may make having an MRI unsafe (e.g., metal implant, cardiac pacemaker, epilepsy, severe claustrophobia, morbid obesity)
- Treatment with any drug designed to slow the progression of Alzheimer's disease in the past six months
- Use of prohibited medications, including antipsychotics, anticholinergics, anticonvulsants, other antidepressants, benzodiazepines or other psychotropic medications, and blood thinners (a low dose of aspirin is acceptable)

To learn more or sign up, contact Evaristus Nwulia, MD, by clicking on the red button below.

LEARN MORE OR ENROLL

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# Health and Cognitive Effects of Dementia Caregiving in Black Male Caregivers

This study will examine the effects of dementia caregiver burden on cognitive function and physical health in Black American male caregivers. Participants will complete questionnaires, surveys, and memory and thinking tests. Researchers will also collect saliva samples to measure stress levels. Many of the research activities will be completed over the telephone. The results of this study will inform the development of support measures and treatment options for Black American men as primary caregivers of a person with dementia.

Minimum Age: 30 Maximum Age: 85

#### Must have:

- Living with a close family member, friend, or other person with dementia and providing more than 10 hours of care each week
- Care recipient has a diagnosis of progressive dementia
- Able to speak, read, and write English

#### Must NOT have:

- Paid professional caregiver
- Significant medical or neurological disease (e.g., major organ failure, insulindependent diabetes, alcoholism, or sleep disorder)
- Significant, untreated depression; stable dosing with serotonin reuptake inhibitors is acceptable
- Use of medications that may interfere with the study, particularly those that may affect central nervous system function or physical measurements (e.g., antipsychotics or steroids)
- Significant visual impairment

To learn more or sign up, contact Robert Turner by clicking on the red button below.

LEARN MORE OR ENROLL

### IN CASE YOU MISSED IT...

# Caregiving Today: A Look at This Vital Role and What it Takes with the All of Us Research Program



This virtual discussion about Caregivers was held on November 17, 2022. Whether professionals, family members, or friends, they give so much for the well-being of those in their charge, but who cares for the Caregivers? This program focused on the health of the caregiver, needed resources, and how data and experience can help drive needed research.



## RESEARCH & RESOURCES



### **Getting Started Guide for New Caregivers**

When many people hear the word caregiver, they tend to think of someone who takes care of a disabled relative and acts almost like a home nurse while also taking care of finances, cooking, and cleaning. That's not wrong, but not all caregivers play such an involved role. Being a caregiver can mean a lot of things.

<u>Mental Health America</u> (MHA) has released a guide for new caregivers. Its specific focus is on people who care for someone who has been recently diagnosed with a mental health condition.

To view the MHA guide, click the red button below.

### **VIEW THE GUIDE**

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## Saving Money with the Inflation Reduction Act

The Inflation Reduction Act will save money for people with Medicare by improving access to affordable treatments and strengthening the Medicare program.

The cost of a month's supply of each Part D-covered insulin will be capped at \$35, and you won't have to pay a deductible for insulin, starting on January 1, 2023.

If you have drug costs high enough to reach the catastrophic coverage phase in your Medicare drug coverage, you won't have to pay a copayment or coinsurance, starting in 2024.

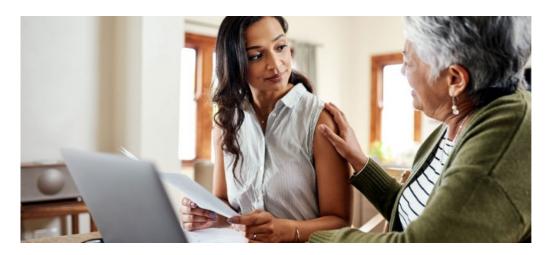
To learn more, click the red button below.



## **Legacy Lessons from the Sages of Aging**

Curated from twelve hours of interviews with 12 of the diverse set of legendary pathfinders in the fields of aging, Legacy Lessons from the Sages of Aging is a 90-minute powerful and inspirational documentary for students and professionals in gerontology, social work, healthcare, medicine, nursing, law, housing, psychology, and other professions who work to meet the needs of older adults.

**VIEW THE VIDEO** 



## Planning for the Future After a Dementia Diagnosis

If you or a loved one has been diagnosed with Alzheimer's disease or a related dementia, it may be difficult to think beyond the day to day. However, taking steps now can help prepare for a smoother tomorrow.

Over time, the symptoms of Alzheimer's and related dementias will make it difficult to think clearly. Planning as early as possible enables you to make decisions and communicate those decisions to the right people.



# 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.

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. This is best done when there is not an emergency. A calm conversation about what kind of care is wanted and needed now, and what might be needed in the future, can help avoid a lot of confusion.

Decide who will be responsible for which tasks. Many families find the best first step is to name a primary caregiver, even if one is not needed immediately. That way the primary caregiver can step in if there is a crisis.

Agree in advance how each of your efforts can complement one another so that you can be an effective team. Ideally, each of you will be able to take on tasks best suited to your skills or interests.

LEARN MORE



### **Look for the Helpers: Providing Support to Older Adults**

People age 50 and above commonly provide health, personal, and other types of care and support to other older adults living with chronic conditions or disabilities. This support is often essential for aging in place and managing chronic conditions. In July 2022, the University of Michigan National Poll on Healthy Aging asked a national sample of U.S. adults age 50–80 about their experiences helping an adult age 65 or older with health, personal, and other types of care needs.

To learn more about the poll's findings, click the red button below.

**LEARN MORE >** 

### PREVIOUSLY APPEARED



# Medicaid Structured Family Caregiving: Enabling Family Members to Make Caregiving Their Primary Focus

Family caregivers play an important role in states' efforts to help Medicaid beneficiaries safely remain in their communities. And, as of August 2022, at least seven states (Connecticut, Georgia, Indiana, Louisiana, Missouri, North Carolina, and South Dakota) covered structured family caregiving (SFC) services provided to older adults and/or people with physical disabilities under their Medicaid programs. Coverage of SFC services results in Medicaid payments and other support to family caregivers, usually including spouses and others who are legally responsible for the beneficiary. This brief, which is based on research and interviews with state staff, examines how Georgia, Missouri, and South Dakota are using Medicaid-funded SFC services to help older adults remain in the homes they share with their loved ones.

SFC services consist of a package of services that support home and community-based services (HCBS) waiver participants' primary caregivers and includes payment, individualized training based on the needs of the waiver participant, coaching, back-up or respite care, and other supports. All interviewees emphasized that they valued SFC services because they enabled HCBS waiver participants who do not self-direct services to receive the personal care they need in their homes from people they know and trust.

Georgia and South Dakota offer SFC services to both older adults and people with disabilities enrolled in Medicaid. Missouri, however, offers the services only to Medicaid beneficiaries with Alzheimer's or a related diagnosis. In all three states, Medicaid beneficiaries must be enrolled in an HCBS waiver to qualify for SFC services. As of July 2022, Missouri was providing SFC services to 62 waiver participants, and South Dakota was providing them to 217 participants. Also, all three states administer their SFC services through agencies, which are entities (usually home health providers) that have agreed to provide the services. Interviewees reported that approach enabled their states to implement the service without new staff resources and helped ensure appropriate oversight of the care delivered to Medicaid beneficiaries.

To learn more about Medicaid structured family caregiving, click the red button below.



### The COPD Caregiver's Toolkit

Caring for someone with chronic obstructive pulmonary disease (COPD) might be new for you. It is a condition that can be hard to understand and manage. COPD is a group of lung diseases including emphysema and chronic bronchitis, or both — that block airflow in the lungs. This makes breathing difficult for people living with COPD.

Caregivers who feel confident about what to do often provide better care for their loved ones. "The COPD Caregiver's Toolkit" offers advice on a variety of topics for patients and caregivers, including how to prepare for doctors' appointments, navigate changes in home life, provide help after a COPD flare-up or hospital stay and stay mentally and physically healthy through it all.

To view the toolkit, click the red button below.

VIEW THE TOOLKIT



### **Acceptance & Letting Go**

We cannot control everything; we can only control our responses. On our caregiver journey, we often want to assert control over situations in order to show love or support.

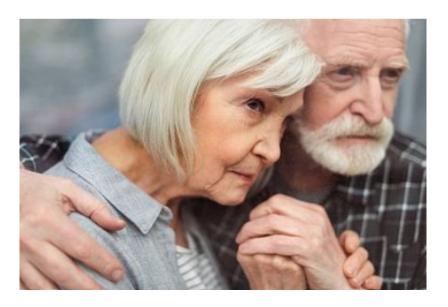
Sometimes the best way to provide care to our loved ones is to practice radical acceptance and letting things go.

Letting go is hard for everyone at first. Courage to Caregivers has put together some tips and philosophies on acceptance.

To learn more, click the red button below.

**LEARN MORE** 

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## Potential Contributor to Sex Differences in Alzheimer's Risk

Alzheimer's disease, which can destroy the ability to think, learn, and remember, is more common in women than men. The reasons for this disparity between the sexes are not well understood.

Women are known to have greater levels of tau protein abnormally build up in brain cells over their lives. The structures that form, called tau tangles, are one of the hallmarks of Alzheimer's disease.

To learn more, click the red button below.

**LEARN MORE** 

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

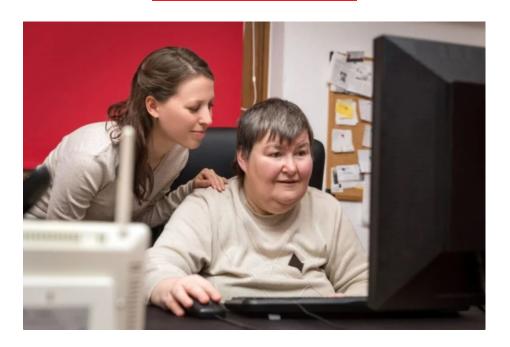
Many older adults and caregivers worry about the cost of medical care and other help they may need. These expenses can use up a significant part of monthly income, even for families who thought they had saved enough.

At first, many older adults pay for care in part with their own money. Initially, family and friends may provide personal care and other services, such as transportation, for free. But as a person's needs increase, paid services may be needed.

Older adults may be eligible for some government health care benefits. Caregivers can help by learning more about possible sources of financial help and assisting older adults in applying for aid as appropriate.

To learn more about options for paying for long-term care, click the red button below.

LEARN MORE



# Caring for a Person Who Has Intellectual Developmental Disabilities

An intellectual or developmental disability affects a person's ability to live, attend school, and work independently. A person may need support with cooking, banking,

transportation, social situations, health care visits, and jobs. Three of the best-known intellectual or developmental disabilities are Down syndrome, autism, and traumatic brain injury (TBI). Many families care for a person who has an intellectual or developmental disability. It could be a young child, an adult child who lives at home with their parents, or even an adult sibling.

To learn some tips about caring for someone with intellectual developmental disabilities, click the red button below.

LEARN MORE



## **Holiday Hints for Alzheimer's Caregivers**

Holidays can be meaningful, enriching times for both the person with Alzheimer's disease and his or her family. Maintaining or adapting family rituals and traditions helps all family members feel a sense of belonging and family identity. For a person with Alzheimer's, this link with a familiar past is reassuring.

However, celebrations, special events, or holidays, which may include other people, can cause confusion and anxiety for a person with Alzheimer's. He or she may find some situations easier and more pleasurable than others.

To learn some tips that will help you balance busy holiday activities with everyday care for a person with Alzheimer's disease, click the red button below.

LEARN MORE

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## **Daily Multivitamin May Improve Cognition in Older Adults**

Alzheimer's disease and related dementias affect more than 46 million people worldwide. Safe and affordable treatments to prevent cognitive decline in older adults are urgently needed. In response to this need, certain dietary supplements have been touted as having protective effects on cognition.

To learn more, click the red button below.



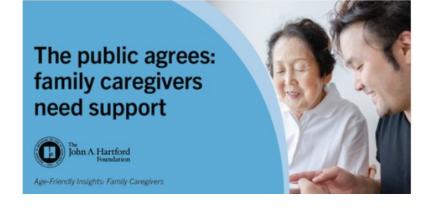


#### **Fall Prevention Partner Toolkit**

There's so much about life to enjoy as we age. We need to stay healthy and take steps to prevent falls so we can enjoy our family, friends, and the things we love. Falls are the number one cause of injury in adults aged 65 and older and can lead to serious health problems. Many of these falls are preventable. You can take control by assessing your fall risk.

Take the Falls Free CheckUp by clicking on the red button below, and discuss the results with your doctor.

TAKE THE FALLS FREE CHECKUP



# Age-Friendly Insights Poll: Broad Political Support for Policies to Help Family Caregivers

In a recent poll, the John A. Hartford Foundation recently asked adults living in the U.S. for their opinions on policies to help family caregivers, including those recommended in the 2022 National Strategy to Support Family Caregivers. Agreement is near-universal: Action is needed to support family caregivers.

To learn more about the poll's findings, click the red button below.

LEARN MORE

# MAKE YOURSELF A PRIORITY, TOO [TIPS FOR CAREGIVERS]

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

Being a caregiver can be extremely rewarding, but it can also be overwhelming. It's not uncommon to feel lonely or frustrated with everyone around you, from the care recipient to the doctors. That's why taking care of yourself is one of the most important things you can do as a caregiver. Here are a few things you can do to care for yourself:

- Stay physically active. Try doing yoga or going for a walk.
- Eat healthy foods. Nutritious food can help keep you healthy and give you energy.
- Join a caregiver support group online or in person. Meeting other caregivers will give you a chance to share stories and ideas.

To learn more self-care tips for caregivers, click the red button below.

LEARN MORE



## **Doctor's Appointments: Tips for Caregivers**

Working with doctors and other healthcare professionals can be an important part of being a caregiver. Some things caregivers may find especially helpful to discuss are: what to expect in the future, sources of information and support, community services, and ways they can maintain their own well-being.

For suggestions that can help caregivers be an ally and an advocate for those they care for, click the red button below.

**LEARN MORE** 



- I am a caregiver
  - () I access care
  - I am a care I support caregivers provider and care providers



#CdnCaregiving

## Giving Care: An Approach to a Better **Caregiving Landscape in Canada**

Unpaid caregivers and paid care providers make up the largest part of Canada's healthcare and social supports systems. Research shows that they provide approximately three hours of care for every hour provided through the rest of our systems. They help seniors living in the community or in long-term care settings; children and adults with physical, intellectual, or developmental disabilities; people with medical conditions; people experiencing mental illness; and people with changing support needs related to aging.

On November 7, 2022, the Canadian Centre for Caregiving Excellence released it's first policy white paper - Giving Care: An approach to a better caregiving landscape in Canada. The report aims to ignite a public conversation on the state of caregiving and

offer potential policy solutions to address the many challenges and systemic issues experienced by Canada's 8+ million caregivers and care providers across the country.

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

## VIEW THE WHITE PAPER



## **Understanding and Treating Depression**

It's normal to feel sad, down, or low at times. But these feelings can sometimes linger. They can get worse, too, eventually making it hard to do basic daily tasks. If you've had a depressed mood or a loss of interest or pleasure in most activities for at least two weeks, you may be experiencing depression.

Depression is a serious disorder. "It's not some-thing that you can just 'push through,' or get through without help," says Dr. Kymberly Young, a mental health researcher at the University of Pittsburgh.

Depression isn't caused by a single thing. Some people's genes put them at risk for depression. Stressful situations may trigger depression. Examples include money problems, the loss of a loved one, or major life changes. Having a serious illness like cancer or heart disease can also lead to depression. And depression can make such illnesses worse.

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

**LEARN MORE** 

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## Feeling Fatigued?

Exhaustion seems to be on the rise. Fatigue is one of the symptoms most often reported by people with COVID-19, and their tiredness can linger. Add this to the many other causes of fatigue that existed before the pandemic—such as lack of sleep, mental health concerns, and health conditions like anemia or heart disease. Overall, it seems, we are one weary nation.

Fatigue can be helpful. It can be a warning sign that you need to ease up after strenuous exercise. Or it can make you rest if you get sick. But more often, fatigue creates problems. It can be an overwhelming and lasting feeling of exhaustion that makes it hard to do everyday tasks.

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



## Medicare Open Enrollment Period Outreach & Media Materials

October 15 to December 7 is when all people with Medicare can change their Medicare health plans and prescription drug coverage for the following year to better meet their needs.

The U.S. Centers for Medicare & Medicaid Services (CMS) have provided partner

organizations with outreach and media materials for <u>English-speaking</u>, <u>Spanish-speaking</u>, and <u>other audiences</u> that can help them to help others with Medicare open enrollment.

To learn more about Medicare outreach resources, click the red button below.





## engAGED Year Three Poll

The National Resource Center for Engaging Older Adults (engAGED) would like to learn about programs offered by caregiving organizations that specifically address social isolation, loneliness or social engagement. To this end, engAGED is conducting a poll from November 1 to December 2 to learn more about social engagement programs currently offered by Aging Network and partner organizations. This is part of our Year Three project workplan, and builds upon an engAGED poll conducted in 2020.

Responses to this poll will help engAGED learn more about social engagement programs currently offered by Aging Network and partner organizations, including types of programs, partners involved, populations and communities served and outcome measurements. The results from this poll will be used to develop a fact sheet depicting social engagement program trends across the Aging Network and partner organizations.

engAGED is asking partner organizations to promote the poll widely to their networks and have provided a dissemination toolkit that contains sample social media and newsletter language along with sample images. To access the toolkit, click <u>here</u>.

Questions? Contact info@engagingolderadults.org.

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

PARTICIPATE IN THE POLL



## **Serious Illness Messaging Toolkit**

Capture public interest, bypass misconceptions, and increase demand for your services with better messaging. This toolkit will show you easy ways to improve your messaging about care for serious illness.

This toolkit is the product a joint endeavor funded by The John A. Hartford Foundation and Cambia Health Foundation. Its launch will take place on November 2.

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

ACCESS THE TOOLKIT >



## **Vitality Arts**

Next Avenue's special series, Vitality Arts, shows the powerful effect that participating in the arts can have on our minds, bodies and souls. Look to this page for information, resources and inspiration that will help you age better through the arts and show that creativity has no age limit.

To learn more, click the red button below.

**LEARN MORE** 

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## **Long-Distance Caregiving**

Anyone, anywhere, can be a long-distance caregiver, no matter your gender, income, age, social status, or employment. If you are living an hour or more away from a person who needs your help, you're probably a long-distance caregiver. This kind of care can take many forms—from helping with money management and arranging for in-home care to providing respite care for a primary caregiver and planning for emergencies.

The U.S. National Institute on Aging provides a number of resources for long-distance carers. To learn more, click the red button below.





## If You're About to Become a Cancer Caregiver

Today, most <u>cancer treatment</u> is given in outpatient treatment centers – not in hospitals. This means someone is needed to be part of the day-to-day care of the person with cancer and that sicker people are being cared for at home. As a result, <u>caregivers have many roles</u>. These roles change as the patient's needs change during and after cancer treatment.

To learn more about cancer caregiving, click the red button below.



## **Adult Day Care**

Adult Day Care Centers are designed to provide care and companionship for older adults who need assistance or supervision during the day. Programs offer relief to family members and caregivers, allowing them to go to work, handle personal business, or just relax while knowing their relative is well cared for and safe.

The goals of the programs are to delay or prevent institutionalization by providing alternative care, to enhance self-esteem, and to encourage socialization. Adult day health care offers intensive health, therapeutic, and social services for individuals with serious medical conditions and those at risk of requiring nursing home care.

To learn more about adult day care, click the red button below.





## What Are the Caregiver's Rights?

Caring for someone you love after a heart or stroke event can be hard. The responsibilities and the emotional stress of being a caregiver can cause you to forget to take care of yourself.

These rights can help you reaffirm that you have a right to health and happiness, even when you're caring for someone else. They'll help you realize that the emotions and pressures you may be feeling are normal

To learn more about caregivers' rights, click the red button below.

LEARN MORE



# Hospital Discharge Planning: A Guide for Families and Caregivers

A trip to the hospital can be an intimidating event for patients and their families. As a caregiver, you are focused completely on your family member or friend's medical care, and so is the hospital staff. You might not be giving much thought to what will happen when

your friend or family member leaves the hospital.

Everything about this transition – whether the discharge is to home, a short-term rehabilitation ("rehab") center, or a residential nursing facility – is critical to the health and well-being of the person you care for. Yet, while it's a significant part of the overall care plan, there is a surprising lack of consistency in both the quality and process of discharge planning across the health care system.

To learn more, click the red button below.



# One Way to Help Family Caregivers: Caregiving Navigators

In early 2022, Nexus Insights brought together long-term care providers, caregiver advocates, tech-driven start ups and policy experts to discuss how to help older adults and their caregivers better navigate the complex and fragmented array of long-term care and aging services. The resulting report, "Where Am I, Where Do I Go: The Missing Entry Point to Long-Term Care Solutions for Older Adults and Their Caregivers," details the challenges older adults and their families face and the need for navigational centers, or hubs, to support these individuals as they make critical decisions, often under stressful conditions, about their care needs.

To learn more about the benefits of navigation hubs, click <u>here</u>. To view the report itself, click the red button below.



# Alzheimer's Disease Research Centers: National Research Centers, Local Resources

The Alzheimer's Disease Research Centers (ADRCs) offer local resources, support, and opportunities to participate in research on Alzheimer's disease and related dementias. These centers are dedicated to developing and testing new ways to detect, diagnose, treat, and prevent dementia and to improving care for people with these diseases and their families. The National Institute on Aging (NIA) at the National Institutes of Health (NIH) funds more than 30 ADRCs at medical institutions across the country. Each center has specific scientific and population areas of focus.

For families affected by Alzheimer's and related dementias, ADRCs offer:

- Help with obtaining diagnosis and managing your care
- Information about the diseases, services, and resources
- Opportunities for volunteers to participate in clinical trials and studies that contribute to improved understanding of dementia, which may lead to new treatments and better care

Support groups and other special programs for volunteers and their families

To learn more about resources offered by ADRCs, click the red button below.



# Caring for the Caregiver: Balancing Work While Caring for Others

Caregiving is a selfless act, but for most caregivers finding the right balance between employment and their personal well-being can be difficult. It may seem counterintuitive for caregivers to think of themselves, but for a caregiver to effectively manage working while providing care, self-care is essential.

To improve the work-life balance and well-being of caregivers, there are actions they can take and employer-sponsored benefits that may provide some help.

To learn more, click the red button below.



## Navigating the Journey: Caregiving for a Loved One With Autism Spectrum Disorder

Autism Spectrum Disorder (or simply Autism) is a mental difference characterized by a spectrum of non-typical social, sensory, and cognitive traits. Autism is not a disease, but rather a form of neurodivergence with its own type of normality. Still, your loved one might be going through a lot.

Courage to Caregivers has compiled a list of resources available for caregivers supporting a loved one with autism. To learn more, click the red button below.





## **One-to-One Caregiver Peer Support**

Courage to Caregivers is accepting registrations for volunteers (caregiver providing support) and participants (caregivers seeking support) for its virtual One-to-One Caregiver Peer Support program.

This program connects caregivers with volunteers who have experience caring for someone with a mental illness. The purpose of the program is to provide participants with support and resources so they are better able to take care of someone else.

Volunteers are trained through a series of online webinars and monthly ongoing training opportunities. Courage to Caregivers has an onboarding process with your privacy and confidentiality in mind.

To learn more, click the red button below.

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## **Financial Caregiving Hub**

The Women's Institute for a Secure Retirement (WISER) has produced a new tool designed to serve as a one-stop clearing house for financial caregivers and care recipients. The online tool offers an easily accessible suite of vetted and trusted educational materials focused on caregiving, aimed at helping caregivers for their spouses, parents, children, and other family members access vetted content including podcasts, videos, and blog posts from experts along with links to community-based programs supporting caregivers.

To explore the Financial Caregiving Hub, click the red button below.

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# My Health Priorities: A Guide for Older Adults and Care Partners

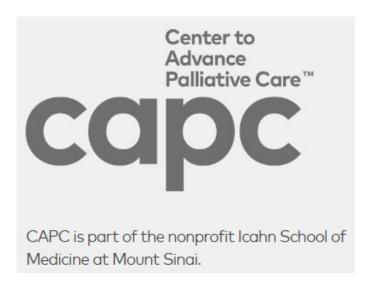
What matters most in life and health is different for everyone. Managing your health may be particularly difficult if you have multiple chronic conditions.

The more you and your health care team know about what matters most to you, the better you can work together to line up your health care decisions with your Health Priorities.

Patient Priorities Care has come up with a new tool designed to help older adults determine their health and life priorities. The aim of the tool is that knowing your health priorities will help you to communicate what matters most to you to your health care team, family and care partners.

To explore the online tool, click <u>here</u>. To view a printable version, click the red button below.

VIEW THE GUIDE >



## **MOTIVATE: Marketing and Messaging Palliative Care**

The Center to Advance Palliative Care (CAPC) has developed the MOTIVATE toolkit about marketing and messaging palliative care.

Due to low public awareness and consistent misconceptions, how you frame palliative care and its benefits is vitally important. Marketing, supported by sound messaging, helps patients, families, referral sources, and service partners understand the work that you do. Palliative care is about quality of life. When done well, proper messaging and marketing

can clarify this and motivate patients, families, and clinicians to take advantage of it.

Use the MOTIVATE toolkit to refine your program's marketing strategy, and your messaging.

To explore the online toolkit, click the red button below.





## Join The ALL IN® Community

Aurinia Pharmaceuticals is committed to supporting the lupus nephritis community. That's why it launched the ALL IN® program, a source of information, resources, and support for those affected by or at risk for lupus nephritis and their care partners. Caring for someone with lupus nephritis can be overwhelming, but you're not alone. The Lupus Nephritis Awareness Kit offers support for both individuals living with LN and their loved ones, along with other helpful resources.

To learn more, click the red button below.





## **Engaging Older Adults Through Virtual Communities**

Due the COVID-19 pandemic, efforts to address social isolation and loneliness are more important than ever.

To highlight how such efforts have supported older adults and caregivers who may be facing social isolation, USAging has produced a new video vignettes—"Engaging Older Adults Through Virtual Communities"—showcasing the unique ways AAAs and Title VI Native American Aging Programs have engaged older adults through high and low-tech methods.

To view the video, click the red button below.

**VIEW THE VIDEO** 

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## Just released: 2022 National Strategy to Support Family Caregivers





## **2022 National Strategy to Support Family Caregivers**

The National Alliance for Caregiving – a coalition of 67 national organizations – applauds the release of the 2022 National Strategy to Support Family Caregivers developed by the U.S. Department of Health and Human Services but urges strong accountability and implementation efforts to turn the strategy into action.

The strategy details more than 350 federal actions and 150 measures that state and local governments, public health departments, philanthropies, and community-based, faith-based, and nonprofit organizations can take immediately to support the nation's 53 million family caregivers who make up 21% of the population.

The National Strategy includes potential government actions that address issues that family caregivers say are most important, including:

- 1) Access to Respite Services
- 2) Support with Day-to-Day and Complex Medical Tasks
- 3) Inclusion of Caregivers in Care Teams
- 4) Financial Education on Caregiving Costs
- 5) Better Identification of Family Caregivers
- 6) Research on the Needs of Family Caregivers

NAC was integral to mobilizing the caregiving community in support of the RAISE (Recognize, Assist, Include, Support, and Engage) Act, which established the council and process for developing the 2022 National Strategy to Support Family Caregivers. NAC also worked with The John A. Hartford Foundation and the National Academy for State Health Policy to ensure family caregivers were centered in the development of the recommendations and that the strategy reflected the lived experiences of this diverse community.

We encourage individuals and organizations to **provide public comment** on the National Strategy. The Strategy will be updated biennially, informed in part by public feedback, ensuring it continues to meet the needs of family caregivers and those they care for as they evolve.

To learn more, click the red button below.

**LEARN MORE** 



## **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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## **Frequently Asked Questions About Palliative Care**

Palliative care is specialized medical care for people living with a serious illness. Palliative care can be received at the same time as your treatment for your disease or condition. It focuses on providing relief from the symptoms and stress of serious illness. The palliative care team works to prevent or ease suffering, improve quality of life for both the patient and their family, and help patients and their families make difficult health care decisions. When a patient decides to forgo treatment for their serious illness or is near the end of life, they may decide to enter hospice care.

To learn more, click the red button below.

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## **Keep Your Mind Active**

Being intellectually engaged may benefit the brain. People who engage in personally <u>meaningful activities</u>, such as volunteering or hobbies, say they feel happier and healthier. Learning new skills may improve your thinking ability, too. For example, <u>one study</u> found that older adults who learned quilting or digital photography had more memory improvement than those who only socialized or did less cognitively demanding activities. <u>Some of the research</u> on engagement in activities such as music, theater, dance, and creative writing has shown promise for improving quality of life and well-being in older adults, from better memory and self-esteem to reduced stress and increased social interaction.

To learn more, click the red button below.





## Tips for Managing Agitation, Aggression, and Sundowning

Download or order this one-page tip sheet that caregivers can use during difficult situations to help deal with agitation, aggression, and sundowning behaviors in people with Alzheimer's disease. Hang the publication in your home or office for quick access to the tips.

To view the tip sheet, click the red button below.

VIEW THE TIP SHEET >

## Making Decisions for Someone at the End of Life

It can be overwhelming to be asked to make health care decisions for someone who is dying and is no longer able to make their own choices. It is even more difficult if you do not have <u>written or verbal guidance</u>. Even when you have written documents, some

decisions still might not be clear.

To learn more, click the red button below.





## **Understanding the Options**

FAIR Health created a new consumer website for older adults and family caregivers with decision-making and treatment cost tools to help them make informed choices and navigate the health care system. The tools assist in answering questions like "should I have a hip replacement?" and estimating costs of care for conditions such as Alzheimer's disease.

To view the website, click the red button below.

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#### **Vaccinations and Older Adults**

When fall arrives, many of us know it's time to get the annual flu, or influenza, shot. It's also a good time to consider what other vaccines or boosters to get to protect your health.

Staying up to date on vaccines is especially important for older adults. Our immune system helps the body fight infection, but it gets weaker as we age. Vaccines help to strengthen the immune system.

Other vaccines that are important to older adults include COVID-19, pneumonia, shingles, and TDP (tetanus, diphtheria, and pertussis).

To learn more about vaccinations and older adults, click the red button below.

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## **Hearing Loss and Older Adults**

Hearing loss is a sudden or gradual decrease in how well you can hear. It is one of the most common conditions affecting older and elderly adults. Approximately one in three people between the ages of 65 and 74 has hearing loss and nearly half of those older than 75 have difficulty hearing. Having trouble hearing can make it hard to understand and follow a doctor's advice, to respond to warnings, and to hear doorbells and alarms. It can also make it hard to enjoy talking with friends and family. All of this can be frustrating, embarrassing, and even dangerous.

To learn more hearing loss, click the red button below.

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## **How Biomarkers Help Diagnose Dementia**

Biomarkers are measurable indicators of what's happening in the body. These can be found in blood, other body fluids, organs, and tissues. Some can even be measured digitally. Biomarkers can help doctors and researchers track healthy processes, diagnose diseases and other health conditions, monitor responses to medication, and identify health risks in a person. For example, an increased level of cholesterol in the blood is a biomarker for heart attack risk.

Before the early 2000s, the only sure way to know whether a person had <u>Alzheimer's</u> <u>disease or another form of dementia</u> was after death through autopsy. But thanks to advances in research, tests are now available to help doctors and researchers see biomarkers associated with dementia in a living person.

To learn more, click the red button below.

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## CONVERGENCE



# Convergence Dialogue on Reimagining Care for Older Adult Adults

In a new report, Convergence Center for Policy Resolution released recommendations from its Convergence Dialogue on Reimagining Care for Older Adults. The report offers consensus solutions produced by leaders and experts who participated from across the political spectrum in a multi-stage convening. These unlikely allies propose changes to America's systems of care that reflect the unique needs and realities of aging adults today and in the future.

To review the report, click the red button below.



## **Brain Stimulation Can Affect Memory in Older Adults**

The number of older adults worldwide is rising, along with an increase in age-related memory decline. Researchers have long sought ways to prevent or reverse memory impairment. They've been able to pinpoint specific brain circuits and networks that underlie learning and memory. But effective and lasting interventions to improve memory have remained elusive.

To learn more about brain stimulation and memory, click the red button below.

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# Genetic Risk Factors that Underlie Depression May Also Drive Alzheimer's Disease

Some cases of Alzheimer's disease may be driven by the genetic risk factors that can underlie depression, according to an NIA-supported data-mining study by researchers at Emory University School of Medicine. The results, published in Biological Psychiatry,

suggest that the activity of at least seven genes may help explain why depression appears to increase the chances one may experience Alzheimer's.

To learn more about the connection between depression and Alzheimer's disease, click the red button below.

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## **Exposure to Green Space May Boost Cognitive Health**

Residential areas with more green space were associated with faster thinking, better attention, and higher overall cognitive function in middle-aged women, according to an NIA-funded study. Published in JAMA Network Open, the findings suggest that green space — such as trees, flowers, grass, gardens, and parks — could be explored as a potential community-based approach to improving cognitive health.

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

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Memory, Forgetfulness, and Aging: What's Normal and What's Not?

Many older adults worry about their memory and other thinking abilities. For example, they might be concerned about taking longer than before to learn new things, or they may sometimes forget to pay a bill. These changes are usually signs of mild forgetfulness — often a normal part of aging — not serious memory problems.

Click <u>here</u> to view a brief, animated video explains the difference between normal and serious memory problems.

To learn more about issues related to memory and forgetfulness, click the red button below.

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## What Is Frontotemporal Dementia?

Frontotemporal dementia is caused by a group of disorders that gradually damage the brain's frontal and temporal lobes. These damages cause changes in thinking and behaviors. Symptoms can include unusual behaviors, emotional problems, trouble communicating, challenges with work, and difficulty with walking.

Frontotemporal dementia (FTD), sometimes called frontotemporal disorders, is rare and tends to occur at a younger age than other dementias. About 60% of people with frontotemporal dementia are 45 to 64 years old.

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

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# Get Fit So You Can Do More!

**Exercise and Older Adults Toolkit** 

Physical activity is an important part of healthy aging. NIA has developed a toolkit to help raise awareness about the importance of exercise as you age.

To view the NIA toolkit, click the red button below.

LEARN MORE >



## What Is Dementia? Symptoms, Types, and Diagnosis

Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of living.

Dementia is more common as people grow older (about one-third of all people age 85 or older may have some form of dementia) but it is not a normal part of aging. Many people live into their 90s and beyond without any signs of dementia.

To learn more, click the red button below.

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# Partnering with Your Healthcare Provider: A Resource for People Living with Memory Problems and Their Care Partners

The University of Washington Dementia Palliative Education Network and the WA State Dementia Action Collaborative have created a new free toolkit for family/friend care partners of people living with dementia.

The goal of this toolkit is to:

- Explain how to form a working partnership with healthcare providers
- Show hot to organize, streamline tasks, and communicate about the care needs of the person living with dementia
- Reduce chances of avoidable care transitions

#### The toolkit includes:

- Easy-to-navigate narrated presentation
- Video scenario demonstrations
- · Care, medication, and appointment log sheets

For more information about the toolkit, click <u>here</u>. To view the flyer, click the red button below.

**VIEW THE FLYER** 

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## **Investing in Caregiving Podcast**

The Grantmakers In Aging Investing in Caregiving podcast series is an initiative of the Family Caregiving Funders Community, network of over 40 funders working to mobilize intellectual and financial capital to improve the caregiving experience.

In this episode, the National Alliance for Caregiving's <u>Mike Wittke</u> talks about public health partnership and discusses NAC's advocacy collaborative.

To listen the podcast, click the red button below.

LISTEN TO THE PODCAST



# New Report on Impact of Caregiver Shortages on Older Adults, Area Agencies on Aging

New data from USAging shows that existing shortages in the caregiving workforce have grown during the COVID-19 pandemic—posing a significant threat to the ability of older adults to age well in their homes.

Caregiver Needed: How the Nation's Workforce Shortages Make It Harder to Age Well at Home, a new report from USAging, reveals that many AAAs and their direct care provider partners across the country are facing workforce shortages which threatens their ability to provide home and community-based services to older adults who depend on them.

To view the report, click the red button below.

**VIEW THE REPORT** 

NATIONAL Sciences
ACADEMIES Medicine

Medicine

## **Caring for People with Serious Illness**

The COVID-19 pandemic has highlighted existing weaknesses in the United States health care system, while creating a new set of challenges related to caring for people with serious illness. The National Academy of Sciences, Engineering, and Medicine's Roundtable on Quality Care for People with Serious Illness hosted a three-part workshop to explore the initial responses to the pandemic by health care teams providing care to people with serious illness, the impact of the pandemic on the health care workforce, the use of telehealth, issues related to clearly communicating with the public about health emergencies, and policy opportunities to improve care for people with serious illness.

To view the workshops' results, click the red button below.

VIEW THE RESULTS

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