Caregiving for a Spouse After a Traumatic Injury

In the evening of May 12, 2015, Geralyn Ritter, 54, was eager to get home to her husband, Jonathan, 56, and three sons in New Jersey after a meeting in Washington, D.C. As an executive at Merck & Co., Geralyn loved traveling the globe as part of her role in the humanitarian health care arena.

As Amtrak train 188 approached Frankford Junction, the sharpest rail curve in the Northeast Corridor in Philadelphia, it began to speed up instead of slowing down. By the time the conductor pulled the emergency brake, it was too late. The train broke free from the rails, going 106 miles per hour on a curve designed for a maximum of 50. Geralyn was thrown from the train’s first car with such force that her organs were rammed up into her chest, rupturing her diaphragm and bladder, collapsing her lungs, destroying her spleen and lacerating her intestines. Her pelvis was broken in half, ribs were broken and there were multiple fractured vertebrae in her neck and back.

From: AARP | Published: December 15, 2022

Teaching Caregiving to Dementia Patients' Families

Though Gloria Krzywiec would repeat herself in conversation the last couple years, her son Carl didn’t think much of it. Then one day in November 2020, she got a flat tire and walked three miles on US Route 30 to their home in North Huntingdon.

“She just told me she parked her car and she didn’t feel like driving anymore,” her son said.

Understanding Temperament and Caregiver-Child Mismatches

When adults caring for young children have basic knowledge about temperament and how it affects behavior, they have an edge! While personality is understood as something that develops over time, temperament is believed to be innate. Practitioners can share with caregivers that temperament considers a range of behavior in nine areas: activity
Concerned that she had crashed her car and suffered a stroke, he and his wife, Jeanie Krzywiec, took his mother to the hospital where the doctors diagnosed Binswanger's disease, which causes blood vessels in the brain to narrow and tissues to die.

From: Pittsburgh Post-Gazette | December, 18, 2022

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From: Psychology Today | Published: December 15, 2022

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 level, distractibility, intensity, regularity, sensitivity, approach and withdrawal, adaptability, persistence, and mood. The constellation of these areas makes up each human’s unique temperament, a key predictor of how they experience the world.

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

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

If you're a family caregiver or have cared for someone in the past, call 1-888-665-2190 to share your caregiving story and the feelings associated with it.
If you would prefer to write out your response rather than leave an audio message, you may do so here.

We want to know:

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

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

To learn more, click the red button below.

LEARN MORE

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

To read the report, click the red button below.

VIEW THE REPORT

The 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.

**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.
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.

EVENTS & OPPORTUNITIES

DECEMBER

Family Reactions to Mental Illness
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.

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**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.
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.
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 gayle.kojimoto@ucsf.edu.

To register for this event, click the red button below.
How Trauma Effects Children, for Parents and Caregivers

January 11, 2023 | 6:00 PM - 8:00 PM ET | Online

This workshop is designed to provided introductory information about the impact of trauma and the power of relationships to help children heal. The more parents and caregivers understand how trauma effects children, the more they will understand the reasons for kids’ behaviors and emotions, and the more they will be able to help them cope.

FOR MORE INFORMATION:
(717) 270-6972 x360 or Clockard@sarccheals.org

To register for this event, click the red button below.
How do we elevate national recommendations to public health action when supporting dementia caregivers? Join the BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC) for a webinar on January 12th, the RAISE National Strategy to Support Family Caregivers," that will discuss how public health agencies and professionals can help to implement the RAISE National Strategy to Support Family Caregivers. Attendees will learn how other states are adopting RAISE recommendations, and how your agency's work can align with this unprecedented national strategy to support family caregivers of people living with dementia.

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

A Fresh Approach to Living Well with Dementia - Virtual Fair by LifeCircles

Living with dementia can be very challenging, but there are ways to bloom at every stage. Life is better when we are amplifying our stories, valuing our experiences and learning to live well with dementia.

This free event on January 12th includes presentations from people living well with dementia, tips on positive brain-change approaches, and takeaways for medical professionals to make our community more dementia friendly and inclusive.

This virtual event is for everyone: people living with brain change or dementias, people curious about dementia, caregivers, family and friends of people living with dementia, and for professionals who work with people living with brain change.

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

Visual Changes

An opportunity to focus specifically on the visual changes that can occur for a person with dementia and the support strategies which can really impact on the well-being of the person and your ability to cope. 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 how and what the person can see and how they may interpret things in the environment
- 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.
Home Care, Palliative Care, and Hospice: Making the Right Choice

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

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

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

To register for this event, click the red button below.
Health challenges can be daunting. The disorienting and confusing nature of a health issue tends to put a strain on relationships; conflicts, changing roles, shifting expectations, sensitive and uncomfortable topics can all add to the messy mix. Whether in a caring dynamic at home, in a clinical or organizational setting, we may find ourselves having difficult conversations. Many relationships, familial and professional alike, snap under the pressure of disagreement.

Tune in on January 18th for a workshop led by Joe Weston that will guide participants through the murky waters of how to have difficult conversations - how does one bend rather than break in tense confrontations? Whether you’re dealing with, or caring for someone with a health challenge, working in a caring profession and trying to understand how to better relate to peers, or even working towards a shift in your organizational culture, Joe will offer tried and true insights about how to transform hardship into healing relationships.

Joe Weston is an author, educator, and guide. With a career spanning 30+ years in the fields of conflict prevention, leadership, stress management, and communication, he is a highly sought-after facilitator for individuals, as well as corporations, government agencies, and nonprofits around the world.

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

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**Powerful Tools for Caregivers Six-Week Course**

**Thursdays, January 19 - February 23, 2023, 1:00 PM – 3:00 PM ET | Online**

Powerful Tools for Caregivers is a six-week educational program designed to help family caregivers. You will learn how to take care of yourself while caring for a relative or friend, wherever they live: at home, in a nursing home or across the country. Note: Class is not designed for professional caregivers.

To register for this class, click the red button below.
Looking Ahead: A Road Map for Caregivers in Times of Need

January 19, 2023 | 1:00 PM - 2:30 PM ET | Online

Caregiving is a labor of love that many perform willingly. We know that life is full of surprises and despite their best intentions, there may be times that caregivers may need to step back from their role to care for themselves. If you are a caregiver, do you have a plan for your loved one in the event that you need to take a break from caregiving?

Join Acclaim Health and Regional Learning Centre for this 1.5 hour webinar where we will discuss:

• How to identify your circle of support
• Important documents to have in place
• Community resources
• How to create an emergency plan

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

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
Understanding Aggression Toward Family/Caregivers in Childhood Adolescence

January 19, 2023 | 7:00 PM - 8:30 PM ET | Online

AFCCA refers to Aggression towards Family/Caregivers in Childhood & Adolescence. AFCCA can be a difficult subject to talk about, and parents/caregivers often share they feel shame, stigma, and isolation when they do seek help. Everyone involved—including the youth themselves—is at risk of physical and/or psychological harm, as well as family instability and possible breakdown.

We know that families need understanding, and we offer a welcome, accepting community who are walking similar paths. Please join us for an evening with Adopt4Life’s AFCCA Family Supports Program Team as we explore the complexities of AFCCA including common challenges and promising interventions to improve safety and strengthen families including non-violent resistance (NVR), de-escalation techniques, and building circles of support.

To learn more about Adopt4Life’s AFCCA Family Support Program, visit https://www.adopt4life.com/afcca

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

REGISTER >

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 person's 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.

**Essentials of Caregiving: Advance Directives**

**January 25, 2023 | 11:30 AM - 1:00 PM ET | Online**

This presentation will provide a broad overview of the steps you can take to prepare for your future care and the care of your family member(s) living with dementia. We will cover Medical Power of Attorney (MPOA), living wills, and out-of-hospital DNRs.

Communicating your wishes to your family and providers is critical in ensuring you are provided care that aligns with your values and preferences. We can never anticipate what might happen and the possibility that we may be unable to communicate our wishes one day. Hosted by the Caring for the Caregiver program at the School of Nursing at UT Health San Antonio, this presentation will help you proactively prepare for your future and communicate what matters to you in terms of care.

Our presenter, Alaina Kuhn, RN, BSN, is completing her Doctorate of Nursing Practice at UT Health San Antonio. She has experience working across settings including critical care and has seen firsthand the importance of having advance directives in place. She will be joined by Stett Jacoby from the Law Offices of Carol Bertsch, who will be available to support discussion and answer questions.

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

**Carers' Rights and Benefits**

**January 27, 2023 | 8:30 AM - 10:00 AM ET | Online**

Caring for a family member or friend with dementia can be financially challenging. There is a range of financial support available, but getting to grips with the system can be tricky.

This session explores the range of carers’ rights and benefits and the types of assessments and support available.
The various benefits will be described, and there will be an opportunity to reflect and apply this to your own situation.

This session is for you if you would like to …

- Gain a better understanding of the rights and benefits available to you and the person you care for
- Spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- Meet other people who are taking care of a friend or family member with dementia in a similar situation

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

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

FEBRUARY
Relationships and Feeling Secure

February 2, 2023 | 8:30 AM - 10:00 AM ET | Online

This session aims to explore the types of relationships and bonds we have with important people in our lives, including the person with dementia that you care for. There will be an opportunity to discuss how attachment affects a person with dementia and what can help them feel more secure in relationships.

This session is for you if:

- you would like to gain a better understanding of the influences the ability of a person with dementia to feel secure
- you would like to learn about the different strategies which can contribute to a person feeling secure
- 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

Advance Directives: What Families Should Know

February 7, 2023 | 1:00 PM - 2:00 PM ET | Online

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

This workshop is part of a series designed to provide education, support, and resources for those caring for loved ones with an illness. There will be time for Q&A following each presentation. Please note, all times are Eastern Time (U.S.).

Questions? Contact us at CommunityEducation@HopeHealthCo.org

To register for this event, click the red button below.
Family caregivers play an invaluable part in supporting people living with heart failure. However, this role can be stressful and overwhelming, and it may be difficult for caregivers to balance their needs with their care recipient.

In recognition of Heart Month, join the Ontario Caregiver Organization on February 9th for a presentation given by two heart failure caregivers, Cindy Yip and John Yudelman, who will share their challenges, experiences, and helpful supports they found on their caregiver journeys. You will also hear from Dr. Phyllis Billia, cardiologist at UHN’s Peter Munk Cardiac Centre. Dr. Billia specializes in heart failure, focused on patients undergoing advanced therapies. She will provide practical resources and explain care strategies and support for caregivers.

To register for this event, click the red button below.
Caregiver Learning Workshop: Estate and Elder Law Planning

February 16, 2023 | 1:00 PM - 2:00 PM ET | Online

Join Rebecca L. Wilson (Attorney, Myers Billion LLP Law Firm) on February 16th that will cover estate planning and elder law tools that can help you get your ducks in a row. She will focus on tools that enable caregivers to handle issues that arise, from paying bills to making medical decisions. We will discuss ways to create a plan that ensures an individual's wishes are carried out, both during any incapacity and on death. We will also cover the consequences of failing to put together a plan ahead of time and the options that remain when emergencies arise.

For more information, contact Leacey Brown, SDSU Extension Gerontology Field Specialist, at 605-394-1722 or leacey.brown@sdstate.edu.

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

REGISTER>

Why Dementia is Different for Everybody

February 22, 2023 | 8:30 AM - 10:00 AM ET | Online

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

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

Presented by Dementia Carers Count in the UK, this introductory course on February 22nd, looks at the different factors that affect a person's experience of dementia and how these might influence the role of the carer.

Why join this session?

Whether the person you care for has a formal diagnosis or not, this session is for you. By better understanding dementia, you will be better equipped to deal with the challenges you both might have to face.

The course is for you if you would like to …

- Gain a better understanding of your friend or family member
- Learn about the different factors which can contribute to a person's experience of having dementia
- Understand why no two people with dementia have the same experience
- Spend time with experienced healthcare professionals who will answer your questions in a safe and supportive environment.
- Meet other people who are taking care of a friend or family member with dementia in a similar situation

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

REGISTER >
Information for Caregivers of People on Kidney & Liver Transplant Waitlist

February 22, 2023 | 12:00 PM - 1:00 PM ET | Online

If you are caring for someone who was recently diagnosed with end stage kidney or liver failure or is currently on the kidney or liver transplant waitlist this interactive webinar session may help.

We will provide an overview of the referral process, pathways to transplant, resources for caregivers and an opportunity for questions and answers.

Pre-registration is required. A follow-up email containing webinar login/call-in details will be sent to all registrants.

If you have questions or would like more information about these sessions, please email livingorgandonation@uhn.ca.

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

REGISTER

MARCH

Comfort for Caregivers: Strategies for Dealing with Caregiver Stress

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

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

This workshop is part of a series presented by HopeHealth Hospice & Palliative Care designed to provide education, support, and resources for those caring for loved ones with an illness. There will be time for Q&A following each presentation.
Health and Aging Policy Fellowship 2023-2024
Call for Applications
Deadline to apply: April 17, 2023

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

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

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

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

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

PATIENT AND CAREGIVER STUDIES
Alzheimer's Disease Research Study

Are you currently caring for a loved one with Dementia?

The Ohio State University is looking for people with dementia and their caregivers to be part of a research study to better understand how people with dementia experience pain.

This study can be completed over the phone with the option of 1 in-person session. Our team is looking forward to talking with you!

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

LEARN MORE

Co-Designing a Stress Management Toolkit for Families Living With Dementia

Researchers at Duke University would like to learn more about stress experienced by people living with dementia and their care partners, as well as about how families manage stress at home.

The goal of the project is to develop a toolkit of different things that people with dementia and their care partners can use on a daily basis to manage stress at home.

Focus groups will be held with dyads of people with dementia and their care partners together, and with care partners only. Groups will be held remotely using Zoom and are anticipated to last about 60-90 minutes. Participants will be compensated for their time.

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

LEARN MORE
Care2Sleep Education Program

Are you a care partner for a person with memory problems? Do you have problems sleeping?

Researchers at the University of California are testing an education program that teaches simple strategies to help care partners and people with memory problems sleep better.

Our research study involves:

- An initial health and sleep evaluation.
- 5 education sessions provided by a trained sleep educator.
- 2 follow-up evaluations.
- Optional collection of blood samples from care partners only.

Care partners may receive up to $450 and care-receivers may receive up to $300 for participating in this study.

This is not a medication study. You will not be asked to stop or begin taking any new medication.

This research study only applies to California residents.

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

DC Longitudinal Study on Aging and Specimen Bank

Start: January 1, 2007
End: January 2027
Enrollment: 1000

Where Is This Study Located? District of Columbia

What Is This Study About?

This study will examine the usefulness of various diagnostic tests for Alzheimer's disease, mild cognitive impairment, and other neurodegenerative disease. The study also aims to
assess changes in biological, lifestyle, and cognitive assessments collected from individuals over time. The researchers will collect test information from participants either once in a single study visit or if the participant chooses, multiple times over several years. Participants will complete cognitive testing, lifestyle questionnaires, and provide blood and/or spinal fluid (optional) samples for biochemical and genetic testing. Test results will not be shared with participants, but the information will help improve diagnostic tools. Blood and spinal fluid samples will be also be stored in a specimen bank, without any information that would identify the participant, to be available to other researchers.

Do I Qualify To Participate in This Study?

Minimum Age: 45 Years
Maximum Age: N/A

Must have:

- Individuals with normal cognition or diagnosis of a neurodegenerative disorder (e.g., mild cognitive impairment, Alzheimer's disease or a related dementia)
- Participants ages 45-50, must have a first-degree relative with a neurodegenerative disease

To learn more about the study, contact Kelly McCann at (202)687-0413 or email her by clicking on the red button below.

LEARN MORE >

Metformin for Alzheimer's Dementia Prevention

Start: April 23, 2021
End: April 30, 2026
Enrollment: 370

Where Is This Study Located? District of Columbia

What Is This Study About?

This study will test the effects of metformin, an FDA-approved medication to treat diabetes, on memory and other indicators of Alzheimer’s disease in older adults who are overweight or obese and have mild cognitive impairment but do not have diabetes. Participants will be randomly assigned to take a placebo or extended-release metformin medication, by mouth, daily for two years. Researchers will conduct a physical exam and neuropsychological testing at the start of the study and every six months. Approximately half of participants will undergo MRI and amyloid PET brain scans at the start and end of the study.

Do I Qualify To Participate in This Study?

Minimum Age: 55 Years
Maximum Age: 90 Years

Must have:

- Diagnosis of amnestic mild cognitive impairment
- Fluency in English or Spanish
- No known history of diabetes
- No evidence of dementia based on general cognition and functional performance
- Vision and hearing sufficient to complete testing procedures
- Study partner to come to all appointments or be available by telephone at follow-up
Participants who have a condition that prevents them from safely having an MRI (e.g., metal implants or devices, morbid obesity, claustrophobia, epilepsy, etc.) will still be able to participate in the study but will not undergo MRI procedure.

Must NOT have:

- Current use of metformin
- History of intolerance to metformin
- Evidence of kidney or liver disease, congestive heart failure, and/or alcohol abuse
- History of cerebrovascular event (e.g., stroke) that resulted in neurological impairment

To learn more about the study, contact Katie Seidenberg at (202) 687-5338 or email her by clicking on the red button below.

**Study of Caregiving Couples**

**Start:** April 19, 2021  
**End:** August 1, 2025  
**Enrollment:** 600

**Where Is This Study Located? Massachusetts**

**What Is This Study About?**

This longitudinal study will gather information about the characteristics of couple relationships in which one member identifies as a caregiver for their partner. The researchers will also evaluate how changes in mental health and cognition affect the health and well-being of both partners. The study couple will first complete a series of questionnaires to provide information about their health (physical, mental, and emotional), personality, social supports, and self-sufficiency. The caregiving partner will complete a second set of questionnaires. Questionnaires will be given again every six months for a total of three years. Each person will also be screened for cognitive impairment every six months, and those in the middle to advanced stages of dementia will no longer be able to participate in the study.

All study meetings will be conducted online using videoconferencing.

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

**Minimum Age:** 65 Years  
**Maximum Age:** N/A

**Must have:**

- In a committed relationship; all couples, regardless of sexual orientation or gender preference, are eligible to participate
- Both members of the couple must live together at the time of enrollment
- Stable internet connection and ability to stream video with sound
- Willing to have the audio of study comments recorded
- Speak English
- Live in the New York City or Boston metropolitan areas

**Must NOT have:**

- Prior diagnosis of schizophrenia or other psychotic disorder
- Prior diagnosis of a chronic, disabling medical condition that would make it
impossible to participate in an online focus group
- Living in a nursing home or other long-term care facility

To participate in the study, call Rebecca Salant at (646)754-2249 or email her by clicking on the red button below.

**LEARN MORE >**

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**Bowel Health Survey**

For the past 3 years, the National Association For Continence has conducted a nationwide survey to learn more about bladder health and all of the physical, financial and emotional challenges that come along with it. However, incontinence isn’t only a condition of the bladder – bowel problems can be just as troubling, if not more so. That’s why this year NAFC is focusing its efforts on learning more about bowel health and how digestive conditions affect you.

NAFC is seeking participants who will complete the survey in order to provide important insight on the symptoms you deal with, your management strategies, your experience with physicians, the products you use, the mental impact it has, and the ways it can influence your relationships. Most of all, we want to learn how we can help make your life a little easier – after all, that’s our first and most important priority.

To participate in the survey, click on the red button below.

**LEARN MORE >**

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**Atorvastatin for Mild Cognitive Impairment**

Start: May 21, 2021
End: Dec 31, 2023
Enrollment: 20

**Where is this Study Located? Maryland**

**What Is This Study About?**

This Phase 2 clinical trial will test the ability of the FDA-approved drug atorvastatin to
improve brain blood flow and cognition in older adults with mild cognitive impairment. After answering questions over the phone to determine eligibility, all participants will take an atorvastatin pill once every evening. At the start and end of the three-month study, participants will undergo MRI brain imaging, provide blood samples, and complete thinking and memory tests. Researchers will measure changes in cognitive function and blood vessel flow around the brain.

Do I Qualify To Participate in This Study?

Minimum Age: 60 Years
Maximum Age: 95 Years

Must have:

- Diagnosis of mild cognitive impairment, with:
  - Clinical Dementia Rating score of 0.5 or 1.0
  - Cognitive scores (memory, processing speed, executive function, and language) > 1.5 standard deviations below the average of others with similar education and age

Must NOT have:

- History of dementia or any other neurological disease that could cause cognitive impairment
- Currently taking a statin medication, or have taken one in the last six months
- Known allergy or other adverse reaction to a statin
- Currently taking cyclosporine following organ transplant surgery
- Any condition that may make having an MRI brain scan unsafe (e.g., metal shrapnel, heart pacemaker, severe claustrophobia, epilepsy, body size and shape that prevents comfortable fit in scanners)
- Current diagnosis of substance abuse
- History of stroke or heart attack in the past six months
- History of HIV

To learn more about the study, contact Samantha Horn at (410)550-9020 or by clicking on the red button below.

LEARN MORE

Effects of Vascular Health on Changes Linked Alzheimer's Disease

Start: Sept. 17, 2012
End: Dec. 31, 2026
Enrollment: 850

Where Is the Study? Tennessee

What Is This Study About?

The Vanderbilt Memory and Aging Project is a long-term observational study to
understand the relationship between heart and blood vessel health, called vascular health, to the biological markers of early Alzheimer's disease. In an earlier part of the study, scientists found that changes in vascular health were associated with changes in cognition, brain size, and other biological changes associated with early Alzheimer's. The current study will examine the effects of vascular health on the same measures in people with normal cognition. All participants will attend a four-hour study visit to complete memory and thinking tests, undergo an MRI, an echocardiogram, and provide blood and cerebrospinal fluid samples. Every 18 to 24 months for up to five years, participants will return to repeat the same tests and procedures. Information gathered in this study will help develop new tools for the early detection of Alzheimer's.

Do I Qualify To Participate in This Study?

Minimum Age: 60 Years
Maximum Age: N/A

Must have:

- Normal cognition
- English as primary language
- Availability of a reliable study partner who knows the participant well enough to complete questionnaires and interviews about the participant's general memory, health, and thinking

Must NOT have:

- History of brain disease that could affect brain structure or function, including:
  - Major psychiatric illness (e.g., schizophrenia, bipolar)
  - Neurological illness (e.g., stroke, epilepsy, multiple sclerosis, Parkinson's disease, dementia)
  - Head injury that resulted in loss of consciousness
- Diagnosis of congestive heart failure, atrial fibrillation, or other heart arrhythmia
- Diagnosis of chronic obstructive pulmonary disease
- Current diagnosis of cancer
- History or current serious alcohol or drug abuse
- Any condition that may make having an MRI brain scan unsafe (e.g., metal shrapnel, heart pacemaker, severe claustrophobia, epilepsy, body size and shape that prevents comfortable fit in scanners)
- Living in a nursing home or other long-term care facility

To learn more about the study or enroll, contact Paige Crepezzi at (617)643-6348 or by clicking on the red button below.
What Is This Study About?

Primary progressive aphasia (PPA) involves changes in the ability to use language to speak, read, write, and understand what others are saying. This study will evaluate the effectiveness of noninvasive brain stimulation to improve language performance in people with PPA. Participants will be randomly assigned to receive either the intervention or a sham treatment once a day on weekdays for two weeks. At the start and end of the study, participants will complete language performance tests and undergo MRI brain imaging. Researchers will measure changes in language skills and brain connectivity.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years
Maximum Age: 90 Years

Must have:

- Diagnosis of PPA
- Observed for at least one year by a specialized clinician
- Mild to moderate language impairment
- Native English speaker
- Availability of a study partner (e.g., spouse, sibling, or adult child) who can accompany participant to every study visit

Must NOT have:

- History of seizures, unexplained fainting, or an immediate family member with epilepsy
- History of serious neurological illness unrelated to neurodegeneration associated with PPA (e.g., multiple sclerosis)
- History of serious medical problems (e.g., poorly controlled diabetes, uncontrolled high blood pressure, cancer within the last five years)
- Symptoms of major depressive disorder, bipolar disorder, schizophrenia, substance use disorder, or intellectual disability
- Evidence of significant brain disorder, including cerebrovascular disease, hydrocephalus, or brain tumor, as determined by MRI brain imaging
- Any condition that may make having an MRI brain scan unsafe (e.g., metal shrapnel, heart pacemaker, severe claustrophobia, epilepsy, body size and shape that prevents comfortable fit in scanners)
- Pregnant or breastfeeding

To learn more about the study or enroll, contact Alexandra Touroutoglou at (615)322-8676 or by clicking on the red button below.
Memory Training to Improve Cognitive Function in Older Adults

Start: April 7, 2022  
End: Feb. 28, 2023  
Enrollment: 30

Where is this study located? Michigan

What is this study about?

Working memory allows a person to remember and access information in the mind without losing track of what they are doing, such as a task. This study will test whether working memory training can improve learning and memory in people with mild cognitive impairment or normal cognition. Participants will receive online or in-person working memory training for 10 training sessions. At the start, end, and one month after the two-week training period, participants will take memory tests and undergo MRI brain imaging. Researchers will evaluate changes in task performance, memory, and cognition, and brain activity.

Do I Qualify To Participate in This Study?

Minimum Age: 60 Years  
Maximum Age: N/A

Must have:

- Diagnosis of mild cognitive impairment
- Right-handed

Must NOT have:

- History of a neurological or medical condition known to affect cognitive functioning, other than mild cognitive impairment
- Serious mental illness
- Significant vision, hearing, or other impairment that limits the ability to participate
- History of alcohol or drug abuse
- Any condition that may make having an MRI brain scan unsafe (e.g., metal shrapnel, heart pacemaker, severe claustrophobia, epilepsy, body size and shape that prevents comfortable fit in scanners)

To learn more about the study or enroll, contact Alexandru Iordan at (734)647-3704 or by clicking on the red button below.
IN CASE YOU MISSED IT...

Conscious Caregiving Mini Conference

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.
Does Exercise Really Help Aging Brains?
New Study Raises Questions

Exercise and mindfulness training did not improve older people’s brain health in a surprising new study published this week in JAMA. The experiment, which enrolled more than 580 older men and women, looked into whether starting a program of exercise, mindfulness — or both — enhanced older people’s abilities to think and remember or altered the structure of their brains.

To learn more, click the red button below.

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Alzheimer's Tied to Cholesterol, Abnormal Nerve Insulation

The protein apolipoprotein E (APOE) plays a key role throughout the body. It helps to transport cholesterol and other fatty molecules, or lipids. The gene that produces APOE comes in a few different varieties. The most common is called APOE3.

The most notorious is APOE4, which has long been linked to an increased risk of dementia in Alzheimer’s disease. People who inherit one copy of the APOE4 gene have up to a fourfold greater risk of developing Alzheimer’s disease dementia.

To learn more, click the red button below.

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Vascular Dementia: Causes, Symptoms, and Treatments

Vascular dementia refers to changes to memory, thinking, and behavior resulting from conditions that affect the blood vessels in the brain. Cognition and brain function can be significantly affected by the size, location, and number of vascular changes.

People with vascular dementia almost always have abnormalities in the brain that can be seen on MRI scans. These abnormalities can include evidence of prior strokes, which are often small and sometimes without noticeable symptoms. Major strokes can also increase
the risk for dementia, but not everyone who has had a stroke will develop dementia.

To learn more, click the red button below.

LEARN MORE

What Are the Signs that an Aging Parent Needs Help?

When caring for an aging parent or relative from afar, it can be hard to know when your help is needed. Sometimes, your parent will ask for help. Or, the sudden start of a severe illness will make it clear that assistance is needed. But, when you live far away, some detective work might be necessary to uncover possible signs that support or help is needed.

To learn more, click the red button below.

LEARN MORE

Can a Hobby Keep Dementia at Bay? Experts Weigh In
To many, the word “hobby” signifies something lightweight or trivial. Yet taking on a new hobby as one ages might provide an important defense against dementia, some experts say.

About 5.8 million adults over 65 in the United States live with Alzheimer’s disease or other dementia disorders, according to the Centers for Disease Control and Prevention. One in 9 Americans over 65 has Alzheimer’s, according to the Alzheimer’s Association. And although the rate of dementia may be falling thanks to lifestyle changes, more of us are living longer, which means the societal burden of dementia is rising.

To learn more, click the red button below.

PREVIOUSLY APPEARED

Know Your Rights: Caregivers and Nursing Home Debt

Helping someone you love to move into a nursing home can be stressful enough. Nursing homes should not try to make you personally responsible for a loved one’s bill as a condition of admission.

To learn more, click the red button below.

Finding Dementia Care and Local Services

A person with dementia will need more care as symptoms worsen over time. Problems with memory, thinking, and behavior often present challenges for those with dementia as well as for their family members. Whether the disease is in early or late stages, there are support systems, resources, and services that can help.
While it can be difficult for some to admit they need assistance with care or caregiving, it is okay to ask for help. Alzheimers.gov has provided a set of tips and resources for finding assistance in your local area.

To learn more, click the red button below.

Caring for the Caregivers is Part of Optimal Age-Friendly Care

Recently, the Institute for Healthcare Improvement has deepened its commitment to supporting caregivers of older adults. The John A. Hartford Foundation has provided funding for Rush University Medical Center to partner with IHI on the Caregiver Intervention (4Ms-CGI) program, which has two goals: 1) transform how the staff of health systems think about and interact with family caregivers; and 2) provide programs and services for family caregivers to address their own needs and help them provide a reasonable amount of care for the older adult in their lives.

To learn more, click the red button below.
When Should Family Caregivers Apply for Medicaid for a Loved One?

Imagine your parent or spouse has had a fall or a stroke and is hospitalized. Usually, the following days and weeks are spent getting him or her stable, talking to family and doctors, and wrapping your mind around the incident that happened. It can be a shocking and overwhelming time. Often, these events are the beginning of a major life shift where the family has to come to terms with a loved one’s changing needs and abilities. Where will he live? Who will take care of him? Do we have the right documents in place or do we need to go to court for assistance? And who’s going to pay for everything?

To learn more, click the red button below.

Religious and Spiritual Beliefs and Health Care

Religious and spiritual beliefs can offer support and meaning to those coping with health challenges. Because these beliefs may impact medical decision-making, health care providers are generally encouraged to ask patients about their faith background. In July 2022, the University of Michigan National Poll on Healthy Aging asked a national sample of adults age 50–80 about their religious and spiritual beliefs and how those beliefs may influence their health care decisions.

Most adults age 50–80 (84%) said that religious and/or spiritual beliefs are important to them, with 71% reporting their religious beliefs are important to them (45% very important,
Adapting Activities for People With Alzheimer's Disease

Doing things we enjoy gives us pleasure and adds meaning to our lives. People with Alzheimer’s disease need to be active and do things they enjoy. However, it’s not easy for them to plan their days and do different tasks.

People with Alzheimer’s may have trouble deciding what to do each day, which could make them fearful and worried or quiet and withdrawn, or they may have trouble starting tasks. Remember, the person is not being lazy. He or she might need help organizing the day or doing an activity.

To learn more, click the red button below.
Transcript: Across the Aisle with Seth Rogen and Laura Miller Rogen

Actor Seth Rogen and filmmaker Lauren Miller Rogen spoke with the Washington Post's Leigh Ann Caldwell on December 8th to discuss for a conversation with the couple about how their personal experiences as caregivers have informed their advocacy and the prospects for bipartisan cooperation on the issue in the new Congress.

To view the transcript of the chat, click the red button below.

VIEW THE TRANSCRIPT >

New Resources in Search. Find. Help. for Older Adults and Caregivers in Public Health Emergencies
Caregivers during Emergencies

The purpose of Search. Find. Help. is to help leaders and staff of organizations serving community-dwelling older adults and their caregivers find resources they can use to support these populations during all types of public health emergencies, including disease outbreaks like COVID-19, natural disasters, and severe weather.

The site includes resources addressing social isolation, managing chronic conditions, elder abuse and neglect, caregiver support, delayed medical care, and emergency preparedness.

Search. Find. Help. has been updated with **over 60 new resources** to support older adults during other public health emergencies such as natural disasters and severe weather with a focus on disproportionately affected populations, including Tribal populations and people with disabilities.

NORC at the University of Chicago has provided an action plan to help organizations select, adapt, and implement programs to meet the needs of their communities. To view the action plan click the red button below.

The Hurdles Facing Black Families Navigating Serious Illness -- Podcast

Serious illnesses like cancer and kidney failure are painful for patients and hard on their caregivers. Services like hospice and palliative care exist to support families and ensure their loved ones live easier lives and die more comfortable deaths. But data show Black individuals are less likely to have their pain treated and less likely to use hospice and palliative care.

In this Tradeoffs podcast episode from November 10, 2022 — the latest in a series made possible by the Better Care Playbook — a researcher details ways to make this care more equitable and a caregiver shares her family’s journey navigating a serious illness.

To listen the podcast, click the red button below.
Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop

On May 16 and 17, 2022 the Roundtable on Quality Care for People with Serious Illness, the National Cancer Policy Forum and the Forum on Aging, Disability and Independence will host a collaborative public workshop that will examine opportunities to better support family caregiving for people with cancer or other serious illnesses.

The proceedings summarize presentations and discussions from the May 2022 workshop, which was hosted by the Roundtable on Quality Care for People with Serious Illness, the National Cancer Policy Forum and the Forum on Aging, Disability, and Independence. To view the archived videos and presentations, please see the project Webpage.

To view the workshop's proceedings, click the red button below.

VIEW THE PROCEEDINGS

Grandfamilies and Kinship Support Network: A National Technical Assistance Center

The Grandfamilies & Kinship Support Network is the first-ever national technical assistance center for those who serve grandfamilies and kinship families. The Network
exists, free of charge, to offer a new way for government agencies and nonprofit organizations in states, tribes, and territories to collaborate and work across jurisdictional and systemic boundaries—all to improve supports and services for grandfamilies and kinship families. Our work is rooted in cultural competence and linguistically appropriate approaches and is fully accessible to people with disabilities.

The Grandfamilies & Kinship Support Network will create lasting change for families around the country by connecting and supporting:

- Policy and program leaders at government agencies in states, tribes, and territories within aging/elder/senior services, child welfare, disability, education, housing, nutrition, Medicaid and Medicare, and Temporary Assistance for Needy Families (TANF);
- Kinship navigators; and
- Leaders of nonprofit, community-based, and faith-based organizations focused on supporting grandfamilies and kinship families.

To learn more about the Grandfamilies & Kinship Support Network, click the red button below.

**What Do We Know About Healthy Aging?**

Many factors influence healthy aging. Some of these, such as genetics, are not in our control. Others — like exercise, a healthy diet, going to the doctor regularly, and taking care of our mental health — are within our reach. Research supported by National Institute on Aging and others has identified actions you can take to help manage your health, live as independently as possible, and maintain your quality of life as you age. Read on to learn more about the research and the steps you can take to promote healthy aging.

To learn more, click the red button below.
Caregiving After Cancer Treatment Ends

Many factors influence healthy aging. Some of these, such as genetics, are not in our control. Others — like exercise, a healthy diet, going to the doctor regularly, and taking care of our mental health — are within our reach. Research supported by National Institute on Aging and others has identified actions you can take to help manage your health, live as independently as possible, and maintain your quality of life as you age. Read on to learn more about the research and the steps you can take to promote healthy aging.

To learn more, click the red button below.

Legal and Financial Planning for People with Dementia

Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease or a related dementia. Legal and medical experts encourage people recently diagnosed with a serious illness — particularly one that is expected to cause declining mental and physical health — to examine and update their financial and health care arrangements as soon as possible. Basic legal and financial documents, such as a will, a living trust, and advance directives, are available to ensure
I Am Not Alone Care Alliance

ianacare, the market leader in family caregiver benefits, is now forming the “I Am Not Alone Care Alliance” to create a full infrastructure of support across all sectors. They have galvanized key leaders and influencers from Fortune 500 companies, digital health, public sectors, and HR & benefits communities to lead the conversation and shape the future of caregiving resources. Designed for action and launched during National Family Caregivers Month, the I Am Not Alone Care Alliance will change the way public and private sectors work together to amplify the voice of millions of family caregivers and to fill the gaps - so no caregiver does this alone.

To learn more, click the red button below.
Parkinson's Disease: Causes, Symptoms, and Treatments

Parkinson’s disease is a brain disorder that causes unintended or uncontrollable movements, such as shaking, stiffness, and difficulty with balance and coordination.

Symptoms usually begin gradually and worsen over time. As the disease progresses, people may have difficulty walking and talking. They may also have mental and behavioral changes, sleep problems, depression, memory difficulties, and fatigue.

To learn more, click the red button below.

Support for Families When a Child Has Cancer

When a child has cancer, every member of the family needs support. Parents often feel shocked and overwhelmed following their child’s cancer diagnosis. Honest and calm conversations build trust as you talk with your child and his or her siblings. Taking care of yourself during this difficult time is important; it’s not selfish. As you dig deep for strength,
reach out to your child’s treatment team and to people in your family and community for support.

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

LEARN MORE
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What Is Long-Term Care?

Long-term care involves a variety of services designed to meet a person's health or personal care needs during a short or long period of time. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own.

Long-term care is provided in different places by different caregivers, depending on a person's needs. Most long-term care is provided at home by unpaid family members and friends. It can also be given in a facility such as a nursing home or in the community, for example, in an adult day care center.

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

LEARN MORE
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Veteran Caregiver Kids: America Wants to Hear Your Story

A new initiative is seeking out the voices of America's military-connected caregiving youth to further shine a light on the experiences of “hidden helpers” — children living with and serving wounded, ill or injured service members and veterans.

Children and young adults are asked to submit their stories in the way they want to tell them — through writing, drawing, film, photography or other means.

To learn more, click the red button below.

LEARN MORE
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.

*Mental Health America* (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.

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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.

LEARN MORE
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.

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.
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.
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.

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.

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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.
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.

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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.
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.

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.
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.

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.
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 health-care 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 its 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.
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 something 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.

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.
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 cancer treatment 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, caregivers have many roles. 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.

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
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 here. 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.

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.
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 [here](#). 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.

![EXPLORE THE GUIDE](button.png)

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.

![LEARN MORE](button.png)

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](button.png)
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.
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, advance care directives, costs, and availability of family and friends to help.

To learn more, click the red button below.

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.
Keep Your Mind Active

Being intellectually engaged may benefit the brain. People who engage in personally meaningful activities, such as volunteering or hobbies, say they feel happier and healthier. Learning new skills may improve your thinking ability, too. For example, one study 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. Some of the research 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.

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 written or verbal guidance. Even when you have written documents, some
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.
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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