Massachusetts Family Caregiver Support Program Quarterly Newsletter - Spring 2023

Caregiver Webinar Series

Did you miss the last *Caring for the Caregiver* webinar? Check out past webinars, hosted by the Massachusetts Executive Office of Elder Affairs (EOEA) and the MassTech Collaborative, on the EOEA YouTube channel.

Here are a few of the most recent webinars topics:

How to Talk to Your Loved One About Wishes for Care (April 2023)

We can't plan for everything. But we can talk about what is most important – in our life, and in our health care – with those who matter most. Talking with the important people in our life can bring us closer together. It also helps us create the foundation of a care plan that's right for all of us – a plan that will be available when the need arises. This April, in honor of National Healthcare Decisions Day, the *Caring for the Caregiver* webinar series was thrilled to host Kate DeBartolo from The Conversation Project to share insights with caregivers, including ice breakers, tips and tricks, and messaging ideas for how to have these conversations with the important people in your life.

Home CareServices: How Family Caregivers are Supported (February 2023)

This webinar aims to help family caregivers learn more about the benefits of home care, eligibility requirements for in-home supports, and examples of how the Home Care Program benefits older adults and their family caregivers.

FamilyCaregivers' Communication with their Loved One (December 2022)

This webinar is the second in a two-part mini-series focused on communication in families. The first webinar (see below) focuses on family caregivers' communication with family members, while this webinar focuses on family caregivers' communication with their loved one.

FamilyDynamics & Communication with Family Members (November 2022)

This webinar is the first in a two-part mini-series focused on communication in families. This first webinar focuses on family caregivers' communication with family members, while the second focuses on family caregivers' communication with their loved one.

If you have questions or comments about the webinar series, or would like to request a topic or speaker for an upcoming webinar, please contact masscaregiver@mass.gov

* * *

Information and Resources for Caregivers

How to Forgive Others After Family Caregiving Ends

Taking Care of YOU: Self-Care for Family Caregivers

Mealtime Made Easy: 6 Tips for Caregivers

Assessing the Pain of Care Recipients: Tools Available to Family Caregivers

How to Manage Finances as an Unpaid Adult Caregiver

Resources for Specific Populations of Family Caregivers

For caregivers whose loved one:

...Has Alzheimer's or Other Forms of Dementia
- Your Conversation Starter Guide: For Caregivers of People with Alzheimer's or Other Forms of Dementia
- There's No Place Like Home: Creating Safe Environments for People with Late-Stage Dementia
- 5 Ways Technology Can Make Life Easier for Caregivers of Dementia Patients

...Is a child with a serious illness
- Guide for Caregivers of a Child with Serious Illness

...Had a stroke
- Let's Talk about Being a Stroke Family Caregiver
- Caregiving for Someone After a Stroke

...Has cancer
- Support for Caregivers of Cancer Patients

...Lives far away
- Getting Started with Long-Distance Caregiving
- Eight Tips for Long-Distance Caregiving

Resource Spotlight

Five Steps for Caregivers to Gain Better Control of Their Emotions and Stress

Jamie Huysman, PsyD, LCSW, a trauma-certified caregiving expert, coined the term, "Take Your Oxygen First" in the New York Times bestseller he co-wrote. Take Your Oxygen First refers to the need to take care of yourself before you can meet the needs of others.

"Dr. Jamie" has five emotional self-regulating priorities that can help family caregivers build resilience:

1. Make time for fun and interesting care. Brainstorm a list of self-care activities that make you happy, and schedule them as part of your daily routine.
2. Be kind to yourself. You are doing your best, and that's what counts.
3. Make restorative sleep a priority. Studies have found that sleep and mental health are connected.
4. Limit your screen time. Less social media can actually mean more “real” connections and reduce feelings of depression and anxiety.
5. Learn and accept more about mental health. One of the best ways to improve your mental health is to understand it.

Personal Accounts

Kinship/Grandfamilies Thrive with Perseverance: Rosalie Tallbull (video)

Kinship/Grandfamilies Thrive with Love: Santana Lee “I understood the assignment” (video)

When My Father Got Alzheimer's, I Had to Learn to Lie to Him

“A watercolorist for most of her life, Holbrook had put her brushes down to keep an eye on her husband. Now, as he declined, she needed an outlet, some way to **ride out the emotional roller coaster**…

She wanted to express, in a way that wasn’t mournful or self-pitying, the **helplessness** she felt caring for someone with Alzheimer's.”

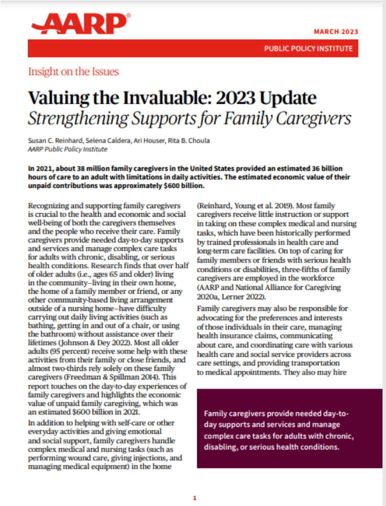
In Her Art, the Impossible World of an Alzheimer’s Caregiver
Frustration, sadness, anger, and despair. Hingham’s Sara Holbrook experienced all of that — and turned it into art.

See quote and Sara Holbrook’s photo collage “**In the Clouds**” above.

Policy & Research

President Biden Announced an Executive Order to Support Family Caregivers
President Biden issued an executive order on April 18, 2023 with over 50 directives aimed at better recognizing and supporting family caregivers. According to President Biden, “The actions we’re taking today are about dignity, security, and peace of mind for working families and caregivers all across the country.” The Executive Order builds on the nation’s first-ever National Strategy to Support Family Caregivers and highlights the need for action in support of caregivers.

Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers (see report cover)
This report pulls from multiple sources to profile who family caregivers are and the challenges they face and includes several first-person accounts of the experience. It takes a detailed look at recent developments and promising federal and state policies that support family caregivers, as well as promising practices in the public and private sectors, including the positive representation of caregivers in popular media. It concludes with specific recommendations.



AARP

MARCH 2023

PUBLIC POLICY INSTITUTE

Insight on the Issues

Valuing the Invaluable: 2023 Update
Strengthening Supports for Family Caregivers

Susan C. Reinhard, Selena Caldera, Ari Houser, Rita B. Choula
AARP Public Policy Institute

In 2021, about 38 million family caregivers in the United States provided an estimated 36 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately $600 billion.

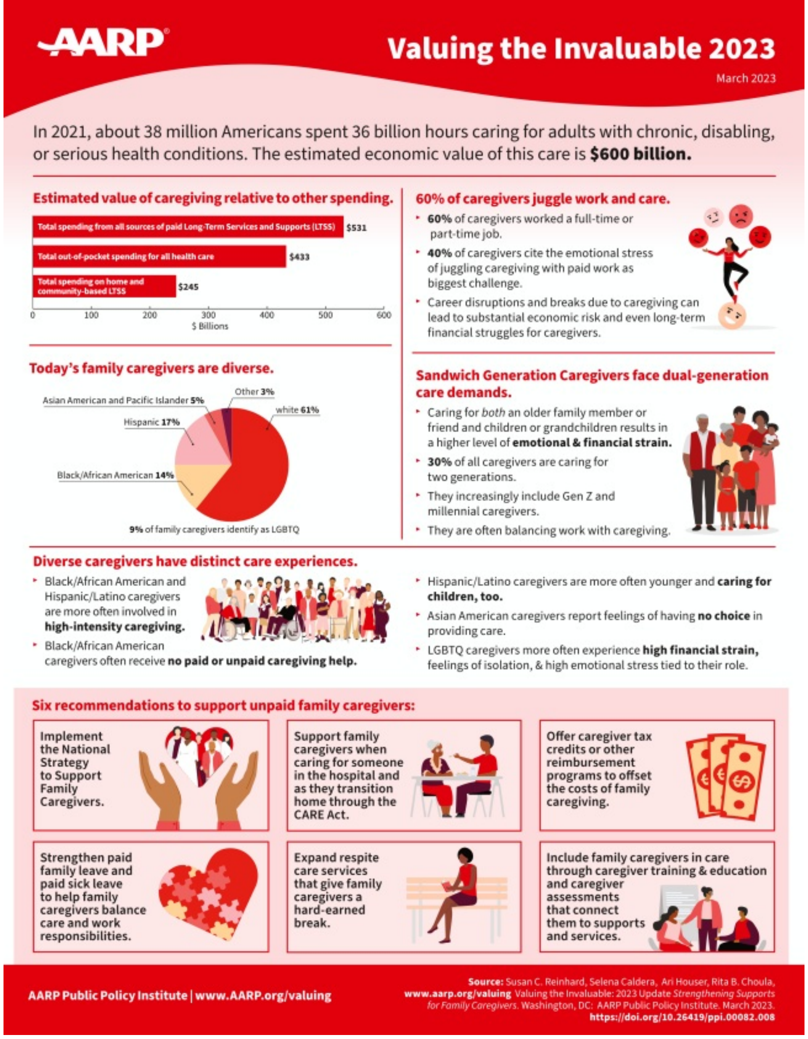
Recognizing and supporting family caregivers is crucial to the health and economic and social well-being of both the caregivers themselves and the people who receive their care. Family caregivers provide needed day-to-day supports and services and manage complex care tasks for adults with chronic, disabling, or serious health conditions. Research finds that over half of older adults (i.e., ages 65 and older) living in the community–living in their own home, the home of a family member or friend, or any other community-based living arrangement outside of a nursing home–have difficulty carrying out daily living activities (such as bathing, getting in and out of a chair, or using the bathroom) without assistance over their lifetimes (Johnson & Dey 2022). Most all older adults (95 percent) receive some help with these activities from their family or close friends, and almost two-thirds rely solely on these family caregivers (Freedman & Spillman 2014). This report touches on the day-to-day experiences of family caregivers and highlights the economic value of unpaid family caregiving, which was an estimated $600 billion in 2021.

In addition to helping with self-care or other everyday activities and giving emotional and social support, family caregivers handle complex medical and nursing tasks (such as performing wound care, giving injections, and managing medical equipment) in the home (Reinhard, Young et al. 2019). Most family caregivers receive little instruction or support in taking on these complex medical and nursing tasks, which have been historically performed by trained professionals in health care and long-term care facilities. On top of caring for family members or friends with serious health conditions or disabilities, three-fifths of family caregivers are employed in the workforce (AARP and National Alliance for Caregiving 2020a, Lerner 2022).

Family caregivers may also be responsible for advocating for the preferences and interests of those individuals in their care, managing health insurance claims, communicating about care, and coordinating care with various health care and social service providers across care settings, and providing transportation to medical appointments. They also may hire

Family caregivers provide needed day-to-day supports and services and manage complex care tasks for adults with chronic, disabling, or serious health conditions.

1



AARP

Valuing the Invaluable 2023

March 2023

In 2021, about 38 million Americans spent 36 billion hours caring for adults with chronic, disabling, or serious health conditions. The estimated economic value of this care is **$600 billion.**

Estimated value of caregiving relative to other spending.

	$ Billions
Total spending from all sources of paid Long-Term Services and Supports (LTSS)	$531
Total out-of-pocket spending for all health care	$433
Total spending on home and community-based LTSS	$245

60% of caregivers juggle work and care.

- **60%** of caregivers worked a full-time or part-time job.
- **40%** of caregivers cite the emotional stress of juggling caregiving with paid work as biggest challenge.
- Career disruptions and breaks due to caregiving can lead to substantial economic risk and even long-term financial struggles for caregivers.

Today's family caregivers are diverse.

white	**61%**
Hispanic	**17%**
Black/African American	**14%**
Asian American and Pacific Islander	**5%**
Other	**3%**

9% of family caregivers identify as LGBTQ

Sandwich Generation Caregivers face dual-generation care demands.

- Caring for *both* an older family member or friend and children or grandchildren results in a higher level of **emotional & financial strain.**
- **30%** of all caregivers are caring for two generations.
- They increasingly include Gen Z and millennial caregivers.
- They are often balancing work with caregiving.

Diverse caregivers have distinct care experiences.

- Black/African American and Hispanic/Latino caregivers are more often involved in **high-intensity caregiving.**
- Black/African American caregivers often receive **no paid or unpaid caregiving help.**
- Hispanic/Latino caregivers are more often younger and **caring for children, too.**
- Asian American caregivers report feelings of having **no choice** in providing care.
- LGBTQ caregivers more often experience **high financial strain,** feelings of isolation, & high emotional stress tied to their role.

Six recommendations to support unpaid family caregivers:

- Implement the National Strategy to Support Family Caregivers.
- Support family caregivers when caring for someone in the hospital and as they transition home through the CARE Act.
- Offer caregiver tax credits or other reimbursement programs to offset the costs of family caregiving.
- Strengthen paid family leave and paid sick leave to help family caregivers balance care and work responsibilities.
- Expand respite care services that give family caregivers a hard-earned break.
- Include family caregivers in care through caregiver training & education and caregiver assessments that connect them to supports and services.

AARP Public Policy Institute | www.AARP.org/valuing

Source: Susan C. Reinhard, Selena Caldera, Ari Houser, Rita B. Choula, **www.aarp.org/valuing** Valuing the Invaluable: 2023 Update *Strengthening Supports for Family Caregivers*. Washington, DC: AARP Public Policy Institute. March 2023. **https://doi.org/10.26419/ppi.00082.008**

Survey

Please consider responding to this 10-minute survey from the Mass Cultural Council (MCC), which aims to make our state's arts and culture organizations more accessible, inclusive, and representative of people with disabilities. Arts and culture organizations include, and are not limited to, theaters, museums, historical sites, botanic gardens, zoos, aquariums, etc. For this survey, MCC seeks feedback from people living with disabilities (physical or cognitive) and their caregivers.

Alzheimer's Association Pre-Recorded Educational Programs for Caregivers

Dementia Conversations: Driving, Doctor Visits, Legal & Financial Planning— Learn to have honest and caring conversations about common concerns when someone begins to show signs of dementia.

Effective Communication Strategies — Learn to decode the verbal and behavioral messages delivered by someone with dementia, and identify strategies to help you connect and communicate at each stage of the disease.

Managing Money — Caregivers: How much do you know about managing money? This free online program by the Alzheimer's Association will help you learn about the costs of caregiving and the benefits of early planning, and teach you how to avoid financial abuse and fraud, start a conversation about finances, assess financial and legal needs, and find support.

Understanding and Responding to Dementia-Related Behavior— Learn about some of the common triggers for behaviors associated with dementia, how to assess the person's needs, and how to intervene effectively in this educational training program for non-professional caregivers.

Living with Alzheimer's: For Caregivers — Early Stage— In the early stage of Alzheimer's disease, families face new questions as they adjust. This three-part program provides practical answers to the questions that arise in the early stage.

Upcoming Webinars and Events

Spotlight Series: Sleep & Dementia
May 29, 2:30 PM

Caring for a Patient with Dementia: Disease Progression and Care Tips
May 30, 10:00 AM

You're Not Alone: Managing Feelings of Sadness
May 30, 9:00 PM

Caregiver Coffee – Reminiscence in Caregiving
May 31, 2:00 PM

Aspects of Caregiving with Dr. BJ Miller
June 2, 1:00 PM

Grandparents Raising Grandchildren Conference
In-Person, Best Western Royal Plaza, Marlborough
June 2, 8:30 AM
colleen.pritoni@mass.gov

MA Dementia Research Center Talk with the Doc(tor)
June 2, 12:00 PM

Caring for People with Memory Loss
June 3, 9:00 AM

Money Matters for Family Caregivers
June 5, 6:00 PM

A Conversation About Dementia
June 8, 12:00 PM

Caring for Your Caregiver
June 8, 3:00 PM

Understanding and Responding to Dementia-Related Behavior
June 8, 6:00 PM

Understanding Dementia for Family and Friends
June 9, 10:00 AM

Effective Communication Strategies
June 13, 11:00 AM

Caregiving Coffee: Managing Restlessness and Sleep Issues
June 14, 2:00 PM

Caring for and Supporting LGBTQ Seniors
June 15, 12:00 PM

Dementia Conversations
June 21, 6:30 PM

Essentials of Caregiving: Learning to be a Caregiver
June 23, 2:00 PM

The Family Caregiver Support Program Fact Sheet is available on Mass.gov in the following languages:

Arabic
Chinese
English
Haitian Creole
Khmer
Portuguese
Russian
Spanish
Ukrainian

Massachusetts Family Caregiver Support Program | Mass.gov

To submit content for this e-communication, please email Molly Evans at **Molly.R.Evans@mass.gov**.