



MASSACHUSETTS FAMILY CAREGIVER SUPPORT PROGRAM

NEWSLETTER | SEPTEMBER 2020



"If we put people first in how we live our lives, how we design policies, how we design our institutions, then I believe we will create a world that is healthier, more resilient, more fulfilling..."

— Dr. Vivek Murthy

"It is — and should be — impossible to have a meaningful conversation about recovering from this pandemic without addressing an aspect of Americans' lives that is too often invisible: caregiving."

"If there were ever an excuse for inaction, there isn't one anymore."

— Melinda Gates

While there has been a steady drumbeat in recent years to address the challenges family caregivers face, the current pandemic has inspired a movement demanding change- now. Thank you to our family of caregivers and caregiver specialists for your strength and resiliency; your tireless motivation; and your selfless work towards a more just and equitable tomorrow.

MFCSP SEPTEMBER 2020
NEWSLETTER

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UPCOMING WEBINARS

American Cancer Society COVID-19 and Cancer ECHO for Cancer Caregivers
September 2, 2:00 PM

Coping with COVID...Why Do I Still Feel This Way?
September 2, 3:00 PM

Bridging the Digital Divide: On Equity in Technology and How it Might Just Change the Way We Age
September 3, 1:00 PM

COVID-19, Mental Health, and the Need for Equity
September 3-4, 10:00 AM

Debunking the Myths of Supported Decision-Making and Guardianship
September 8, 2:00 PM

COVID Caring Conversations: Tips for Families with a Loved One in Residential Care
September 11, 12:00 PM

Caregivers Count! 10th Annual Conference: Emotional Well-Being
September 12, 1:00 PM

PLUG in to End-of-life Decisions: A Safe Place to Get Your Questions Answered
September 14, 7:00 PM

Advisory Council to Support Grandparents Raising Grandchildren Meeting
September 15, 12:30 PM

Caregiving Conversations: Reflecting on Race, Older Adults, and Implications for Behavioral Health →
September 15, 1:00 PM

Burning the Candle at Both Ends: Managing Stress for Family Caregivers
September 15, 4:00 PM

Social Determinants of Mental Health for Older Adults: A New Perspective
September 23, 12:00 PM

It Takes a Dementia Village: Creating Dementia-Friendly Spaces and Programs in Every Community
September 23, 1:00 PM

Caregiver Rescue: Skills To Create Moments Of Relief and Rest
September 24, 1:00 PM

Caregivers Count! 10th Annual Conference: Technology Tools
September 26, 1:00 PM

3rd Annual Intergenerational Symposium: Strategies for Creating Engaging Intergenerational Spaces and Places and Lessons Learned—Opportunities Revealed in a Time of Pandemic
September 30, 6:30 PM

Motivating Loved Ones: How to Communicate Better and Work Together to Help Those You Care For Stay Active and Engaged
September 30, 2:00 PM



CAREGIVING CONVERSATIONS:

Reflecting on Race, Older Adults, and Implications for Behavioral Health

**Tuesday, September 15,
1:00-2:00 pm ET**

What would it look like if we acknowledged and addressed the impact of racism and disparities in providing services to older adults?

Register [HERE](#)

Please join us in exploring the implications of race and disparities in the delivery of services to older adults. Our moderated discussion with expert panelists will:

- Identify disparities and challenges inherent in existing policies and practice
- Discuss opportunities for meaningful change
- Promote strategies to increase engagement, support equity in access to services and supports, and improve outcomes



Sandra Best Bailey, MSW
Associate Director
Simmons Univ. School of Social Work



Lynda Phillips, LICSW, MS
Owner
BIO 1 Healthcare Consulting



Emmanuelle Renelique
Owner
Amazing Adult Day Health

Sponsored by the Massachusetts Association for Mental Health,
Massachusetts Department for Mental Health, and
Massachusetts Aging and Mental Health Coalition



Grandparents Day

September 13

Falls Prevention Awareness Week

September 21-25

#GoodNeighborDay

September 28

RESEARCH/POLICY

- Family Caregiving Advisory Council Refines Goals to Guide National Strategy
- Informal And Formal Home Care For Older Adults With Disabilities Increased, 2004-16
- HHS Could Enhance Support for Grandparents and Other Relative Caregivers
- Older Adults and Covid 19: Social Justice, Disparities, and Social Work Practice
- Baby Boomers as Caregivers: Results From the Behavioral Risk Factor Surveillance System in 44 States, the District of Columbia, and Puerto Rico, 2015-2017
- Dementia Caregiving Research: Expanding and Reframing the Lens of Diversity, Inclusivity, and Intersectionality
- Intergenerational Relationships, Family Caregiving Policy, and COVID-19 in the United States
- Reopening America: We shouldn't reopen the economy without paid sick and family leave
- Measuring the Impact of COVID-19 on Older Adults in Massachusetts
- State Paid Family and Medical Leave Programs Helped a Surge of Workers Affected by the COVID-19 Pandemic
- No More "One Size Fits All" Research: We Need Multicultural Data for Meaningful Patient- and Family-Engagement in America's Health and Social Care Systems

JULY 2020 CDC REPORT

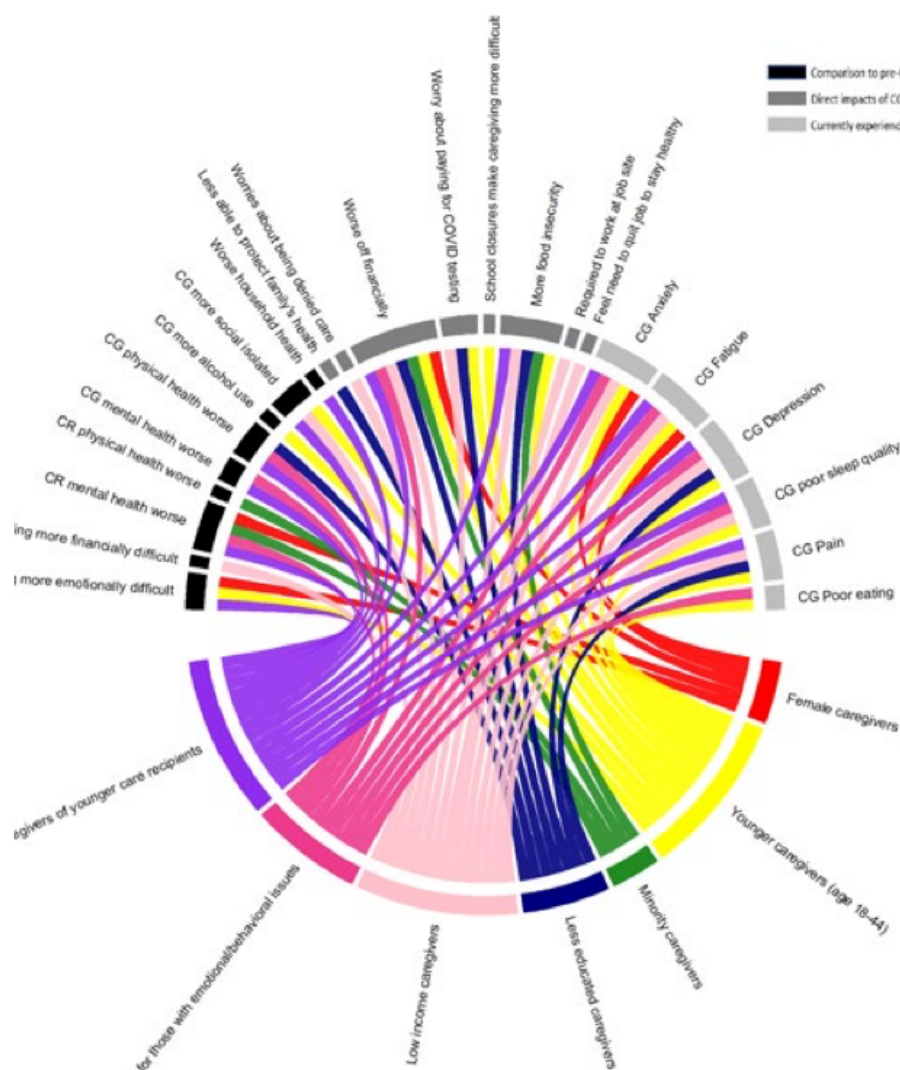
Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic

While COVID-19 is having a disproportionately hard impact on a number of sub populations, it is consistently wreaking the greatest havoc on unpaid caregivers:

- 30.7% seriously considered suicide in the past 30 days
- 32.9% started or increased substance use to cope with pandemic-related stress
- 48.4% with COVID-19-related trauma and stress related disorder (TSRD)
- 66.6% with at least one adverse mental or behavioral health symptoms
- 56.1% with anxiety or depressive disorder

COVID and the Impact on Mental Health and Caregivers: A Call-to-Action

Alexandra Drane, co-founder and CEO of Rebel Health and ARCHANGELS, joins Chris Boyer, Principal, Chris Boyer LLC, for a conversation on the newly released CDC report on Mental Health, COVID, and the Impact on Caregivers



Effects of COVID-19 on Family Caregivers: A Community Survey from the University of Pittsburgh

In the chord diagram, follow the colored bands from each type of caregiver listed in the bottom half of the figure, to see the challenges they were most at risk to experience in the upper half of the figure



WHAT HAPPENS WHEN WE LOSE OUR SOCIAL RITUALS—AND HOW TO MAKE NEW ONES

By understanding the purpose of shared rituals, we can try to preserve their intent and create shared emotion and connection.

Below is an excerpt from Yes! Solutions Journalism on [How to Make New Rituals](#)

"Sheltering in place could also inspire people to create alternative events to mark special occasions, she says, such as a Zoom dance party to celebrate a graduation, which might even end up being more memorable than what was originally planned.

Jan Stanley, who works as a celebrant—someone who designs rituals for weddings and funerals—says that it's not hard to create rituals online, if you keep certain things in mind. She suggests that you:

- Ask people to bring to their online gathering something symbolic to share, such as a candle to light, a memory or story, a picture, or a poem. Getting people to contribute in that way can help create a sense of oneness.
- Mark the moment by having someone provide an opening statement that designates the beginning of any ritual and explains the purpose of being there. That sets the tone and makes people realize that this is a special moment in time and not just another online meeting.
- Create emotional highs, perhaps using music, dancing, poetry, moments of silence, or something else with high emotional resonance to augment the experience.
- Always have a distinct ending that includes an emotional peak, because people tend to remember an event better that way will share.

Though an online ritual may lack some of the power of an in-person ritual, says Stanley, it still has value. Even doing rituals alone can be useful, she adds, if it's meaningful. Research suggests that creating rituals just for ourselves can help alleviate grief after loss and make us feel less out of control, which could help now, when the world seems so uncertain.

'If you can design a ritual to be meaningful—so that it actually touches your heart or brings someone to mind or gives you a sense of your own purpose—all the better,' she says.

Gabriel, the social psychologist, encourages people to also look beyond formalized rituals to everyday opportunities to share positive emotion and a sense of solidarity from a distance.

She points to examples from her own neighborhood, where people are putting up rainbows in their windows, drawing pictures on the sidewalk for others to see when they walk by, or leaving notes for one another on the ends of driveways. She mentions widely shared online videos showing people singing from their balconies, cheering in appreciation of health care workers, or creating drive-by birthday parades.

'People are drawn to collective rituals like these for a reason—we want to feel connected to other people and to feel a sensation of sacredness,' she says. 'These kinds of events should bring on those same sorts of feelings.'

Once the shelter-in-place orders have been lifted, though, Gabriel hopes we'll gain a renewed appreciation for shared rituals.

'Hopefully, we'll go back to them, and we'll value them even more than we do now,' she says. 'And, maybe we'll have learned some new tricks along the way, some new ways to connect to other people that we didn't have before.'"

“

THE PANDEMIC IS REMAKING WHO WE ARE. IT IS AN OPENING TO A NEW WORLD WHERE OUR CAPACITY TO LOVE EACH OTHER IS INTEGRAL TO OUR SURVIVAL
-NAFEEZ AHMED

”

RECOMMENDED READINGS

Increased Access to Mental Health Care for Older Adults: Getting Support during COVID-19

Reducing Loneliness and Social Isolation among Older Adults

Can Caregiving Cause PTSD? What experts say and what role the pandemic is playing

Loving on Empty: The Energy of Caregiving

Bereaved Families Are 'the Secondary Victims of COVID-19'

Family Advocacy for Residents During COVID

With Virtual Reality, Caregivers Can Become Patients

Caregiving Support Groups Go Virtual

Isolation, Disruption and Confusion: Coping With Dementia During a Pandemic

Five Reasons Why Now is a Good Time to Move to a Senior Living Community

Caregiving prevents workforce re-entry, study finds

How the loneliness of social isolation can affect older adults' brains

'There's Just No Voice for Us': Pandemic Creates More Difficulties for Caregivers

Compassion Fatigue: the Hidden Cost of Caregiving

Benefits of Spiritual Care for Older Adults with Dementia

Keeping Your Job While Caregiving During COVID-19

A Helping Hand for Family Caregivers: COVID-19 highlights a growing need for home care

Caring for an adult child with disabilities in retirement

What the Pandemic Can Teach Us

The Challenges of Social Isolation for the Elderly: COVID-19 has created new challenges for the elderly and their families

Recovering from Loneliness in the Age of Covid-19: A recent poll identified three out of every five Americans as being lonely

During COVID-19, a Catch-22 for Grandfamilies

The Challenges of Caring for an Adult Child With Disabilities

Alone and Confused: The Effects of Visitor Restrictions on Older Patients and Families

Blog: Caring for Caregivers During COVID-19

Assistive Technology Helps People Age in Place

How Caregiving Became More Than Just a Women's Issue

Listen, Learn, and Leverage: Why Today's Dialogue on Inequity Is Different

FINDING PURPOSE

- Let's Make This Crisis the (Grand)Mother of Invention
- How the Sandwich Generation Can Persevere During the Pandemic
- Finding Purpose and Connection During COVID-19
- How to Keep the Greater Good in Mind During the Coronavirus Outbreak
- Volunteer remotely with AARP's Create the Good initiative
- Taking A Caregiving Job To Make A Difference During Covid-19

***"Her spirits were lifted as well;
the happiness was mutual"***

FIGHTING SOCIAL ISOLATION AT A TIME OF PHYSICAL DISTANCE

Thoughtful Ice Breakers That Lead to Meaningful Conversations

We can't control how this pandemic plays out. But we can control who speaks for us if we're unable to speak for ourselves, and we can take the time to make sure they know what matters most to us. Ariadne Labs, The Conversation Project, and Cake teamed up to create **this new tool** to help families navigate discussions about end-of-life wishes in light of COVID-19

Build Bridges Across Generations

Interviewing a loved one—in person, by phone, or by video—can be a powerful way to connect individuals and generations. Check out **Legacy Project & StoryCorps** discussion guides to get started

"Stuck-at-Home" Resource Guides

SeniorPlanet helps older adults and their caregivers stay safe, informed, and entertained as they stay inside during the pandemic. Check out their **virtual fitness & wellness events, online book club** and **stuck-at-home guides** to get started

Let's Get Away, Together: "Music, Travel, and Art"

This series is comprised of interactive travel activity sessions with each week focusing on a new part of the country or cultural activity, while incorporating storytelling, music, poetry writing, and/or a simple craft. Each session will include a follow-up message filled with tips, activities, and recipes for families to continue to enjoy after the virtual trip. The focus of each group is to explore a new world, experience a variety of engaging opportunities, and enjoy a sense of camaraderie and community

Let's Get Away Together is intended to be an enjoyable activity for family caregivers and the person they care for. Those receiving care who are able to participate in the discussion and activities are encouraged to attend with their family caregiver

9/8—Art Inspired by Nature, Let's talk about Self Care

9/15—Let's Go to Catalina!

9/22—Must-See Paintings!

9/29—Let's Take a Road Trip; West Coast edition!

A Road Map to Caregiving



Aging & Memory Loss

Road Map Series

I. Dementia Diagnosis

II. Research Participation

III. Caregiving

When someone you care about is dealing with Alzheimer's disease (AD) or a related dementia: information on building a care team, accessing resources and getting the information and help you need to provide support and maintain health and well-being for both the individual who is newly diagnosed and their caregiver.

Caregivers: Who are they?

Primary caregivers are often a family member or close friend who are sometimes unpaid and untrained to manage many of the issues they face when someone they care about is diagnosed with Alzheimer's disease or a related dementia. It is important for caregivers to know they do not have to go it alone. Caregiving is mentally and physically taxing, so having access to the tools and support they may need while supporting someone through the journey of living with dementia is critical to maintaining health and well-being. This often requires the help of your doctor and other healthcare providers.

Why do caregivers need support?

Research shows that caregivers are at increased risk of facing loneliness, depression, and other medical issues. Caregivers are often on duty 24 hours a day and must get the help they need to support themselves and the person they are caring for. Several tools and resources are needed to support you on your journey. Building a support network to support someone living with dementia is crucial for successful caregiving. At first you may feel like you can handle things on your own but allowing others to support you will prevent primary caregiver burnout, depression, and health problems.

The following pages contain the information and resources to get you started on the caregiving journey. There are several different types of resources. Always begin by talking with your doctor and letting him or her know if you are feeling overwhelmed and need additional information and support. Most hospitals and health care centers have a social worker on their team. Social workers can support you on your journey and help you along the way.



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CAREGIVERS' TOOLKITS

- A Road Map to Caregiving: Aging & Memory Loss Road Map Series
- Caregiver Toolkit: Resources to Make Caregiving Easier
- Are you worried about your elderly parents? 8 tips to help seniors stay mentally acute in isolation
- Keeping Family Together During COVID-19: A Checklist
- Five-Minute Coronavirus Stress Resets

