MASSACHUSETTS FAMILY CAREGIVER SUPPORT PROGRAM

NEWSLETTER | NOVEMBER 2020

NATIONAL FAMILY CAREGIVER MONTH

In support of the more than one million Massachusetts residents who provide frequent or daily care to their family members, the Baker-Polito Administration has proclaimed November 2020 as Family Caregiver Month in the Commonwealth.

In the midst of so much recent loss and devastation, we come together to celebrate the incredible dedication of family caregivers.

Thank you for going above and beyond, today and every day. Thank you for bringing peace to those around you during this difficult time. Thank you for your resilience.

Thank you for all you do.
The theme for 2020’s National Family Caregivers Month is “Caregiving in Crisis.” During National Family Caregivers Month 2020, Caregiver Action Network (CAN) will be addressing the new realities family caregivers face with their loved ones during these uncertain times.

To coincide with the NFC Month theme, CAN published five caregiver essays that illustrate the challenges they identified of “Caregiving in Crisis.”

- Video appointments are great, but they come with their own challenges.
- It was hard enough to cover dad’s added costs and now I’m on unemployment.
- I want to keep grandma at home and out of the nursing home.
- It’s just so hard not to be with mom and she’s worse because of it.
- With COVID, how much risk is too much?
“Being a caregiver in this pandemic is all about trust. The families are worried. We’re listening to the media about people dying left and right in nursing homes, assisted living, and in home. That can affect your mental health.”

“Mystic Valley has helped us out tremendously... They have been fabulous, whether it is the support group where you talk to people going through the same situation or troubleshooting direct problems that are specific to our age and issue. Our journey is a bit different due to our age and finances, the fact that we have children in their 20’s and also taking care of our aging parents all while I work.”

“I thought I had it all together, but with the distance learning, I got lost in the shuffle.... And I thought it was just me until I talked with the other grandfamilies, and I found out that it was difficult for them also. It took me about two to three weeks to even get on the distance learning... I was lost, trying to with the social media and the virtual, the Zoom and things that I wasn’t familiar with.”

“My worst fear for Mom is that if she gets sick my dad and I can’t be with her. Or, if she declines so rapidly from her Alzheimer’s that we won’t have a chance to say goodbye in person. I want to be with her if these things happen. It aches not being able to hug and kiss my sweet mom.”

“We do get 24-hour skilled nursing care [for her son James]. However, with the pandemic, we haven’t always had skilled nurses that were cleared to come into the home. You don’t have any escape. You’re constantly in that caregiver role. There is no break. There’s no rest.”

“I am the caregiver for my husband, who is a disabled veteran. He served in Iraq in 2003. I feel like we kind of got into a groove with the caregiving routine over the last couple of years. But the pandemic has definitely put a wrench in all of that, with having the kids home.”

“I think traditionally people tend to think of their own health as being theirs and when you’re in a situation like we’re in you realize that your health is a big issue not just for you and not just for your spouse, but for your grandchild as well. And so then when COVID-19 comes along, now given our age and looking at the statistics of who is likely to be infected and suffer severe consequences from the infection, that raises the stakes of that game far, far higher and of course the stress that goes along with that.”

“Even though I might not have chosen this, he’s made me so much of a better person, brought me joys that I never thought I could have, and sadness that I didn’t expect either, but has also taught me a lot about life.”

This program is funded in whole or in part by contracts with the Massachusetts Executive Office of Elder Affairs and funding from the Administration for Community Living.
PERSONAL ACCOUNTS OF CAREGIVERS

- Her Parents Survived A Bombing And An Internment Camp. Now She’s Their Caregiver
- Watching My Mom Care For My Grandma Shaped The Person I Am Today
- The Passwords He Carried: I Had To Get My Father’s Affairs In Order. You Do Too
- Alz Blog: “The Red Zone” By Miriam Green
- ‘I Just Want To Hold Her And Kiss While She Can Still Appreciate My Presence’: One Man’s Fight To Visit His Wife
- My Mother Has Dementia. Here’s What I’ve Learned From Caring For Her For 8 Years

"Communities of color and immigrants experience higher levels of loneliness associated with social isolation because it is generally part of their culture to have very close-knit relationships with extended family members as they provide a sense of safety, security, and comfort."

The Effects of COVID-19 related Social Isolation on the Mental Health of Racialized Communities

COVID RESOURCES FOR COMMUNITIES OF COLOR

- Strength & Resilience: African American Family Caregivers Discussion
- The Effects Of Covid-19 Related Social Isolation On The Mental Health Of Racialized Communities
- Public Service Announcements For Aapi Families Facing Covid-19 Discrimination
- Aa And Nhpi In-Language Resources For Coronavirus
- Racial equity and health disparities in the age of COVID-19: What new strategies are needed?
- Double Jeopardy: COVID-19 and Behavioral Health Disparities for Black & Latino Communities in the U.S.
- Hidden Truth: 2.3 Million Black Men Are Family Caregivers

HOW TO COPE DURING THE HOLIDAYS

If you cannot be with family or friends this year

Send Kind, Meaningful Gifts Or Cards, And Open Virtually

Volunteer

Honor Your Grief

Take Care Of Your Health From The Inside Out

Lindsay Tiger
8 Ways To Cope If You Can’t See Family And Friends This Holiday Season
October 20, 2020
Caregiver Resources During COVID: You Can Feel Safe With Us
November 5, 1:00 PM

Understanding the Different Types of Dementia and the Best Approaches to Each
November 5, 12:00 PM

Conquering Caregiver Overload
November 6, 1:00 PM

Virtual Alzheimer’s Caregiver & Wellness Conference
November 7, 11:00 AM

Empowering the Dementia Caregiver
November 10, 10:00 AM

Why Supporting Family Caregivers Matters Now: Emerging Supports for Family Caregivers Providing Complex Care
November 10, 12:00 PM

Pain and Dementia: Approaches that Work - Cultural Competence & Health Disparities
November 10, 1:00 PM

#SaludTues: Let’s Celebrate Our Caregivers!
November 10, 1:00 PM

November Symposium: Let’s Talk about Dementia And Culture
November 10, 1:00 PM

Behaviors: The Good, the Bad, and How to Support Creative Interventions
November 12, 12:00 PM

Medicaid Supports for Family Caregivers
November 12, 1:00 PM

Fall into Wellness Annual Men’s Health Forum: Discuss Health Topics with Medical Professionals & Your Peers
November 12, 1:00 PM

Caregiving in a Pandemic: Accessing Services & Supports
November 12, 2:00 PM

HFC Caregiver Tips Workshop Series: Creative Activities + Movement to Engage Loved Ones
November 12, 7:00 PM

COVID-19: Tips for Alzheimer’s Caregivers
November 13, 11:00 AM

Avoiding Caregiving Burnout During COVID-19
November 13, 2:00 PM

The Impact of COVID-19 on Individuals and Families Living with Alzheimer’s
November 16, 11:00 AM

Caregiving and the Holidays: Stress Reducing Tips & Tools
November 16, 11:00 AM

Virtual Caregiver Workshop: Caregiver Burnout Prevention
November 16, 4:00 PM

Coping with the Holidays
November 17, 11:00 AM

Staying Connected: Promoting Social Connectivity During COVID-19
November 17, 12:00 PM
#SupportingCaregivers

To celebrate the one-year anniversary of the founding of the Massachusetts Caregiver Coalition, the webinar will showcase Massachusetts employers discussing how supporting caregivers comes to life in the workplace. We will reflect on how COVID-19 has changed caregiving and continue to build towards a future where all employers recognize, honor, and support the caregivers in their ranks.


## UPCOMING EVENTS & WEBINARS

**Understanding and Responding to Dementia-Related Behavior**  
November 17, 3:30 PM

**RAISE Family Caregiving Advisory Council Full Advisory Council Meeting**  
November 18, 12:30 PM

**Flattening the Caregiver Crisis Curve: A Torchlight Conversation to mark Family Caregiver Month**  
November 18, 1:00 PM

**Well-Being Tips: Stress Management for Family Caregivers**  
November 18, 2:00 PM

**Navigating Uncertainty: Caregiving in a Time of Change**  
November 18, 3:00 PM

**Conquering Caregiver Overload**  
November 18, 3:00 PM

**Effective Communication Strategies**  
November 19, 12:00 PM

**Maintaining Services and Supports for People Living with Dementia and their Caregivers During COVID-19**  
November 19, 2:00 PM

**Making the Connection: Introducing a Toolkit to Support Telephone Reassurance Programs**  
November 19, 3:30 PM

**Grief, Loss and Mourning in the Time of COVID**  
November 19, 4:00 PM

**Navigating Your Caregiver Journey: Tips, Resources and Self-Care**  
November 19, 7:00 PM

November 20, 12:00 PM

**Hope for the Holidays – Coping with Grief during the Holiday Season (multiple dates in November)**  
November 24, 5:00 PM

**Staying Resilient in Times of Prolonged Stress: What’s In Your Toolbox to Stay Healthy?**  
December 1, 11:00 AM

**Social Isolation among Older Persons: Hidden in Plain View**  
December 3, 2:00 PM

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“The one and only blessing of COVID-19 is that it has made, to many, what was invisible visible, and that’s the beginning of a powerful activism.”

Bob Beitcher  
Motion Picture Television Fund
RESOURCES FOR RESILIENCE

ALZHEIMER’S ASSOCIATION MA/NH PROGRAMS IN SPANISH

Como reducir el estres durante el dia (Dealing with Stress Around the Holidays)
November 9, 10:00 AM

Información básica sobre el Alzheimer (The Basics of Alzheimer’s)
November 18, 6:00 PM

Plan de emergencia (Emergency Planning)
November 23, 10:00 AM

BLUE CROSS BLUE SHIELD OF MASSACHUSETTS WELLNESS WEBINARS

Nutrition Do’s and Don’ts During Uncertain Times
November 5, 2:00 PM
Presenters: William Rowbottom & Tricia Silverman

Nutrition and Sleep: Fascinating Connections
November 18, 10:00 AM
Presenters: Lisa Famham & Tricia Silverman

Taming Your Mind with Mindfulness Techniques
December 8, 2:00 PM
Presenters: Jenna Feitelberg & Janet Fontana

TECHNOLOGY AND OLDER ADULTS 3-PART SEMINAR SERIES

Join Dr. Karen Fortuna for a seminar series on addressing practical issues in accessing technology designed specifically for older adults, engaging older adults with technologies, teaching older adults how to use technologies, and developing aging services technology programs.

November 9, 11 AM - 12 PM
November 16, 11 AM - 12 PM
November 23, 11 AM - 12 PM

PODCASTS ABOUT CAREGIVING

“When I’m 64”

Happy Healthy Caregiver

Crisis Conversations: Family Caregiving

Working Daughter

Tight Knit

The Shape of Care
THE WILL

UNPRECEDEDENT CHALLENGES

- Can Caregiving Cause PTSD? What Experts Say And What Role The Pandemic Is Playing
- The Pandemic Has Shown What Happens When We Don’t Support Families
- For Family Caregivers, COVID-19 Is A Mental Health Crisis In The Making
- Alone But Resilient: What We’re Learning About Social Isolation Among Older Adults Amidst The Pandemic
- It Shouldn’t Take Medical Training To Help A Loved One Get Great Care
- Family, Interrupted: A New World Of Worry
- Caregivers Of Elderly Loved Ones Face Heavy Emotional, Physical, Financial Toll
- For Caregivers, A Difficult Job Becomes Nearly Impossible During The Pandemic
- The Chaotic Circle Of Caregiving: Parenting Up And Down The Generational Ladder Has Become Almost ‘Laughably Impossible’ During The Pandemic
- Fighting Inequity In The Face Of COVID-19

ACHIEVING BALANCE

- Over 70% Working Caregivers Experienced High Levels Of Stress
- New Survey Shows Work-Life Balance Particularly Hard On Women During Pandemic
- Protecting Your Finances During The Coronavirus Pandemic

THE WAY

GETTING BY

- 9 Strategies To Help A Parent Who Refuses Care
- Caring For A Loved One At Home: Elder Q&A With Joan Hatem-Roy
- Helping Hands Need A Break, Too: How To Lend Support Without Burning Out
- Caring For A Senior Loved One: How To Encourage Family Participation
- The New Sound Of Music Therapy In Long-Term Care
- COVID-19 Meets Flu Season: How Seniors And Caregivers Can Prepare
- COVID-19: 5 Tips To Face Your Anxiety
- When Caregiving Is Part Of Retirement: Pro Tips
- Top 11 Caregiver Duties To Know
- Alzheimer’s: Tips To Make Holidays More Enjoyable

BUILDING BRIDGES

- How To Help Elderly People Stay Connected Throughout The Pandemic
- Ways To Make Video Calls To Seniors With Alzheimer’s Or Dementia In Nursing Homes
- Digital Technology For The Family Caregiver
- How To Build Resilience From The Stress Of The Coronavirus
- An Entire Village In France Built For People With Alzheimer’s
- Changing How We Provide Care: Lessons Learned From The Pandemic
- What The U.S. Can Learn About Caregiving From The World
**Eat healthy, well-balanced meals**
**Get plenty of sleep**
**Take deep breaths or meditate.** Try this 5-minute stress relief guided meditation or this playlist of on-demand yoga classes that are under 10-minutes.
**Take breaks from watching, reading, or listening to news stories that may increase anxiety**
**Call MassSupport, the 24/7 anonymous, statewide hotline for counseling and support: 888-215-4920**

**NUTRITION TIPS FOR CAREGIVERS**

- **Alzheimer’s Association:** Nutrition Tips For Helping Those Living With Dementia
- **Family Caregiver Alliance:** Feeding And Nutrition for Individuals with Dementia
- **Caring For Your Nutrition When Caregiving**
- **Feeding Your Loved One: Tips For Caregivers By ACL’s National Nutritionist Judy Simon**
- **Caring For YOUR Nutrition By ACL’s National Nutritionist Judy Simon**
- **Abbott Nutrition Health Institute:** Maximizing The Caregivers Role (infographic on left)
Caregivers in Crisis: Caregiving In The Time Of COVID-19
The Rosalynn Carter Institute for Caregiving (RCI) undertook a study of caregiving in the time of COVID-19 to understand the direct experience of caregivers, particularly changes in and causes of stress, since the beginning of the COVID-19 pandemic. Caregivers expressed a need for more support than they are getting, including respite and daycare; social interaction; peer support and self-care; financial assistance; and clinical and in-home care services.

Recalibrating For Caregivers: Recognizing The Public Health Challenge
From Crisis to Opportunity: The Rosalynn Carter Institute identifies public health approaches to better serve caregiver health, and well being in its new report. Recalibrating for Caregivers analyzes shifting demographics, economic impact, and caregiver physical and mental health data, and calls for better understanding of how caregiving status affects health. The report makes a case for breaking down silos across health care, government, and business to create an infrastructure that better supports caregivers.

Something’s Gotta Give: COVID-19 Could Rapidly Expand Family-Leave Policies; It Could Also Deal A Serious Blow To Women In The Workforce
Caregiving during the pandemic has heightened the pressure facing workers, especially women, as they navigate changing workplace policies and increased demands at home, new research reveals. The report suggests that addressing the gender pay gap and requiring family leave policies to mandate paying employees while they care for a sick loved one would help ease the burden.

The Impact of Caregiving on Mental and Physical Health
Blue Cross Blue Shield Association’s (BCBSA) latest study in the Health of America Report series examines the health impact associated with caregiving. BCBSA also partnered with ARCHANGELS on a recent survey of caregivers:

ARCHANGELS SURVEY*
61% OF AMERICANS are worrying about, taking care of, or looking out for a friend, neighbor, or family member due to COVID-19.
55% OF CURRENT CAREGIVERS would not have identified as caregivers before the COVID-19 pandemic.

Growing Older in America: Aging and Family Caregiving during COVID-19
New reporting from the Associated Press-NORC Center for Public Affairs Research (AP-NORC) shows that more than one-third of U.S. family caregivers have seen their responsibilities increase due to COVID-19. Yet, 2020 has not led to any heightened awareness when it comes to preparations for growing older or providing support to others.

To adapt to COVID-19, many caregiving for older loved ones are taking advantage of new service options

Growing Older in America: Aging and Family Caregiving during COVID-19
Among those who were already providing care before the pandemic, 36% said their caregiving responsibilities increased due to the pandemic. Added responsibilities are more acutely felt by caregivers have lost jobs or income during COVID-19; 42% of those under financial strain said their caregiving workload increased, compared with 25% of those who did not report financial hardship.

Five Things You Should Know From The AP-NORC Center’s Long-Term Care Poll Among American Adults:
- Compared to 2018, more say they have done little or no planning for their own care needs (46% vs. 37%) and believe it is unlikely that a loved one will need care (43% vs. 34%).
- 17% are currently providing ongoing living assistance to an aging family member or friend, and rates are similar among those age 18-39 and those age 40 and older.
- For 36% of people who started proving care before the outbreak, their responsibilities have increased as a result of COVID-19.
- More now think health insurance companies (59% vs. 50% in 2018) and Medicare (56% vs. 45%) should have a large responsibility in paying for the costs of ongoing living assistance.
- 75% of caregivers have used telehealth to provide care during the outbreak.

36% OF ALL CAREGIVERS SAY THEIR WORKLOAD HAS INCREASED DUE TO COVID-19

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<tr>
<th>Service</th>
<th>Age 18-39</th>
<th>Age 40+</th>
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<tr>
<td>Meal Delivery</td>
<td>58%</td>
<td>45%</td>
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<td>Telehealth</td>
<td>49%</td>
<td>50%</td>
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<tr>
<td>Video Chat Check-Ins</td>
<td>47%</td>
<td>33%</td>
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<td>Senior Hours At Stores</td>
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Alzheimer’s and Dementia Caregiving
Susan provides care for her elderly father who has Alzheimer’s disease. She moved to his home in order to provide 24/7 care. He awakens frequently during the night and requires assistance at these times. She hasn’t accepted any help in the home or been interested in Adult Day Health due to COVID-19 and does almost all the caregiving herself. Her siblings are paying her for the care she provides but have not been assisting with direct care. Susan stated she has been coping well despite everything.

Balancing Eldercare and Childcare
Sarah is caring for her mother, who has dementia and has moved in with Sarah and Sarah’s family. Before COVID her mother spent five days a week at a supportive day program, which she loved. When the day program closed, and Sarah’s son’s school closed, she had to quit her job to take care of both mother and son. Just as she was getting to the point of burn-out the day program reopened and her son went back to school, though only two days a week. However, Sarah’s mother was soon asked to leave the day program because she refused to keep her mask on, and got belligerent with staff members when they tried to convince her to wear it. Sarah is now looking for an assisted living facility with a memory unit that her family can afford.

Self-Care
Cassandra’s regular art classes were cancelled in March at the start of the pandemic. When she told her Family Caregiver Program Specialist and the rest of her caregiver support group about a month ago that she was feeling lonely and missed painting, they encouraged her to form a new group and resume her painting passion. Cassandra went on to paint – and sell online – two paintings!

Grandparents Raising Grandchildren
John started with the Family Caregiver Program in 2018 when caring for his granddaughter, who was six years old at that time. According to John, his daughter suffers from PTSD as a result of her military service and is unable to care for her daughter properly. John and his daughter currently have co-guardianship. His daughter often brings him to court regarding custody issues and this takes an emotional toll on him. Having his granddaughter home learning remotely/hybrid has been a challenge but he is making it work. He had to arrange for a computer, learn how to log on for virtual educational classes, learn to use the schools platform for consults with specialists and establish a new email account dedicated to school communications.

Please note that these stories are anonymized and representative of caregivers in the Massachusetts Family Caregiver Support Program.