

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.



Special Edition Newsletter for
Family Caregiver Month

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NATIONAL FAMILY CAREGIVERS MONTH

CAREGIVING IN CRISIS

During National Family Caregivers Month, we address the new realities family caregivers face with their loved ones during these uncertain times.



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?

RECOGNIZE **ASSIST** **INCLUDE** **SUPPORT** **ENGAGE**

National Family Caregivers Month

Administration for Community Living

IN THEIR OWN WORDS

“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

Coping with Loss

- 9 Celebration Of Life Ideas To Honor Your Loved One
- Grief: Taking Care Of Yourself After A Loss, And Helping Someone Else After A Loss
- Grief And COVID-19: Saying Goodbye In The Age Of Physical Distancing
- Coping With Loss – One Step At A Time
- When A Loved One Dies From COVID-19
- I Wrote About Losing My Wife To Younger-Onset Alzheimer's. This Is What Helped Me Feel Less Alone

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

UPCOMING EVENTS & WEBINARS

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



Virtual Symposium: Let's Talk About Dementia and Culture Dementia affects every community, but not in the same way.

Join JF&CS for a conversation about disparities in the risk of developing dementia, and in access to dementia diagnosis, research and care, and to explore cultural values and ways of understanding dementia.

When: Tuesday, November 10, 2020
1:00 - 4:30 p.m.

Where: Online, via Zoom video conferencing
Cost: Free of charge.

RSVP: Use the link above in this post

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

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

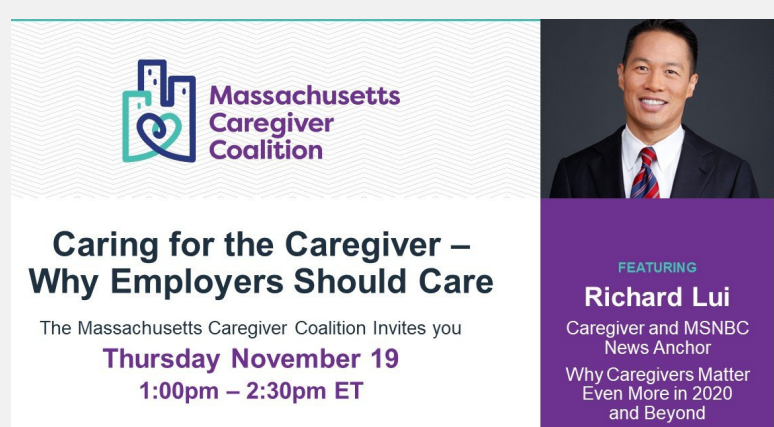
Maintaining Services and Supports for People Living with Dementia and their Caregivers During COVID-19
November 19, 2:00 PM

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

There Must Be a Better Way Than This!
November 19, 4:00 PM

“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



The graphic features the Massachusetts Caregiver Coalition logo on the left, which includes a stylized house icon with a heart inside. On the right is a portrait of Richard Lui, a man in a suit and tie. Below the portrait, the text reads: 'FEATURING Richard Lui Caregiver and MSNBC News Anchor Why Caregivers Matter Even More in 2020 and Beyond'. The main title of the webinar is 'Caring for the Caregiver – Why Employers Should Care', followed by 'The Massachusetts Caregiver Coalition Invites you' and the date and time: 'Thursday November 19 1:00pm – 2:30pm ET'.

#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.

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

20th Annual "Caregivers Are Learning More (C.A.L.M) Conference: Celebrating the Caregiver in You
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

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 Farnham & 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"

Crisis

Conversations:
Family Caregiving

Happy Healthy
Caregiver

Tight Knit

Working
Daughter

The Shape of
Care

THE WILL

UNPRECEDENTED 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

- In Some Families Buckling Under The Caregiving Burden, The Lower Wage Earner Is Leaving The Work Force. Usually That's The Wife
- 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

BE KIND TO YOURSELF

Caring for a loved one can be difficult enough during non-COVID times. Winter holidays in the midst of the pandemic add yet another challenge. Here are a few self-care practices and mental health resources to prioritize self-care:

- 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

**Anonymous,
confidential &
free help to all
Massachusetts
residents,
organizations
& communities**



CALL TODAY:
888-215-4920

NUTRITION AND AGING: MAXIMIZING THE CAREGIVER'S ROLE

PEOPLE ARE LIVING LONGER

By 2050, the number of older adults (60+) globally is expected to reach 2 billion, up from 900 million in 2015.¹

Aging is different for everyone. It's a complex process that introduces physical, emotional, cognitive, and economic changes² that can make it harder for older adults to access the nutrients they need, placing them at an increased risk for malnutrition.

EFFECT OF THE AGING PROCESS ON NUTRITION STATUS

1. MENTAL HEALTH
Loss of memory, confusion, dementia

2. ECONOMIC HEALTH
Poverty/limited income, food insecurity, difficulty finding transportation

3. EMOTIONAL HEALTH
Social isolation, loneliness, depression

4. PHYSICAL HEALTH

- Altered body composition: loss of muscle, increase in body fat
- Sensory changes: taste, smell, and perception of thirst
- Poor dentition: difficulty chewing, inability to eat certain foods
- Chronic (long-term) health conditions: cancer, diabetes, heart disease

UP TO 50% OF OLDER ADULTS ARE AT RISK FOR MALNUTRITION³

MALNUTRITION

Malnutrition—which can refer to both under- and overnutrition—is an imbalance in a person's energy and/or nutrient intake.⁴ It can cause loss of muscle mass, making it harder to maintain ongoing health and independence.⁵

The primary focus of this resource is undernutrition.

MALNUTRITION IN OLDER ADULTS CAN:

- Lead to more health complications, falls, and hospital readmissions^{6,7}
- Increase healthcare costs⁸
- Decrease quality of life⁹

WHAT SHOULD CAREGIVERS LOOK FOR IN OLDER ADULTS?

WEIGHT

Have they recently lost weight? Do their clothes appear to be fitting more loosely?

EATING HABITS

Have their eating habits significantly changed? Do they seem less interested in the foods they once enjoyed?

HYDRATION

Has their fluid intake decreased significantly?

OTHER FACTORS CAREGIVERS SHOULD CONSIDER:

ACCESS TO FOOD

- Is there enough food in the home?

INDEPENDENCE

- Can they leave the home to get the food they need?
- Can they prepare meals?
- Are they able to feed themselves?

BEHAVIOR CHANGES

- Are they showing signs of weakness?
- Do they display signs of confusion or a decline in mental ability?

SOCIAL CHANGES

- Do they have limited social contact with family and friends?

FINANCIAL CHANGES

- Have they mentioned a change in their financial status or difficulty affording the food they need?

anhi.org

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)

RESEARCH/POLICY

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 SURVEY⁵

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.

2020 ARCHANGELS National Caregiver Survey

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 providing 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%

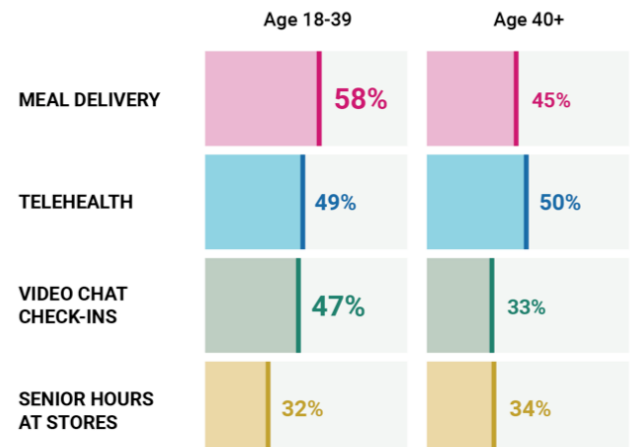
OF ALL CAREGIVERS SAY THEIR WORKLOAD HAS INCREASED DUE TO COVID-19

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.

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



The AP-NORC Center conducted this study with funding from The SCAN Foundation. The poll includes 1,893 interviews with a nationally representative sample of Americans age 18 and older, including 565 caregivers, from the AmeriSpeak® Panel. The overall margin of sampling error is +/- 3.0 percentage points at the 95 percent confidence level, including the design effect. For more information, visit www.longtermcarepoll.org.

STORIES OF FAMILY CAREGIVERS DURING THE PANDEMIC

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 time. 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 caregiver 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.