



# MASSACHUSETTS FAMILY CAREGIVER SUPPORT PROGRAM

NEWSLETTER | SUMMER 2022



I have come to believe that  
**caring for myself**  
is not self indulgent.

Caring for myself is an  
**act of survival.**

- Audrey Lorde

MFCSP SUMMER 2022  
NEWSLETTER

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# UPCOMING EVENTS

## The Grief Journey of the Dementia Caregiver

August 31, 1:00 PM

This program offers clinicians a breakdown of the types and stages of grief that affect caregivers of persons living with dementia. The program will discuss how to identify the area of stress that is most burdensome to each particular caregiver and ways to lessen that burden in order to help that caregiver continue to provide optimal care.

## Integrating Technology into Caregiving

August 31, 7:00 PM

Join a Zoom webinar where participants learn how to integrate technology into caregiving for a person living with dementia. Guest speakers include Jennifer Watt, Occupational Therapist with the Behavioural Response Team in Geriatric Mental Health at LHSC and technology expert Ron Beleno, Consultant, Coach and Mentor from RB33. Together, Jenny and Ron will showcase a broad range of tools available to help you with caregiving and address everyday challenges that you might be facing, or potentially could face in the future. They will share information on what these tools can be used for taking into consideration the person living with dementia's right to privacy, their cost, where to get them, and how to set them up.

## Communication in Dementia

September 7, 11:00 AM

A Person With Dementia is suffering from a terminal brain disease. Understanding how memory works, knowing the type of dementia your resident has, along with the stage of the disease, allows caregivers to target conversations to the memories that continue to function. Using this skill allows for interactions with old memory and can lead families and professional caregivers to new insights into their loved one's younger life.

## Navigating a Dementia Diagnosis and Care Needs

September 7, 1:00 PM

Knowing the warning signs of Alzheimer's disease is important for early detection and diagnosis. Family members often are the first to notice the signs, but may struggle on how to approach their loved one about scheduling an appointment with their doctor. Once they do broach the subject, they may be met with resistance or denial. If a diagnosis is received, the individual and their family may be at a loss for what do next and what to expect for their loved one's care needs. Join this webinar during World Alzheimer's Month to learn more about what to do next after a dementia diagnosis, what changes to expect and how to best care for someone living with dementia. Participants in this webinar will be able to:

- Review the 10 warning signs of Alzheimer's disease and the importance of diagnosis
- Discuss what to expect after a diagnosis and what changes are likely to occur
- Learn communication strategies and care tips to best support the individual
- Discover resources for professionals and families for diagnosis, care and support

## Common Family Reactions to Mental Illness

September 8, 1:00 PM

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.

## Caregiving & Dementia

September 14, 2:00 PM

Learn about the impact of Alzheimer's disease. The difference between Alzheimer's and dementia; stages and risk factors; current research and treatments available for some symptoms. In addition, learn about approaches to communication and challenging behaviors, and how to create a plan in case you become ill and cannot care for your loved one. For more information email [mrcrc@csuchico.edu](mailto:mrcrc@csuchico.edu) or call (530) 898-5925.

## **Alzheimer's Association Time-Limited Specialized Support Groups:**

- Support group for female caregivers | Second Monday of every month | Monday, September 12 | 7 - 8 PM | [Click here to register](#)
- Support group for caregivers who are adult children | Third Wednesday of each month | Wednesday, September 21 | 6:30 - 7:30 PM | [Click here to register](#)
- Chinese-Mandarin Caregiver Support Group: Virtual | Wednesday, September 21 | 7 - 8 PM | [Click here to register](#)
- Support group for LGBTQ caregivers (Time-Limited: Wednesdays until 11/16) | Every Wednesday | September 28 - November 16 | 3:30 PM - 4:30 PM | [Click here to register](#)

# CAREGIVING IN THE MEDIA

## [As Pandemic Continues, Unpaid Caregivers Face Worsening Mental Health Issues](#)

A growing number of Americans have found themselves in unpaid caregiving roles since the onset of the COVID-19 pandemic, helping care for family members, neighbors and friends.

## [Investing in Caregiving: An Equitable Way to Reduce Inflation](#)

Better paid leave and child care policies can help the economy while easing the burden on women and families.

## [For Unpaid Family Caregivers in the Workforce, The Burden Grows](#)

For the tens of millions of people in the workforce who also care for ailing or aging loved ones, the strain of juggling professional and personal responsibilities can take a heavy toll.

## [Caregiving for Children and Elderly Parents Can Strain Women Professionals](#)

Caregiving can be extremely challenging for professional women as many must juggle their careers with motherhood and with their elderly parents/relatives. While home health care aides can help, a majority of women take on the caregiving responsibility themselves.

## [This Is Us? How TV Does and Doesn't Get Men's Caregiving](#)

Depicting the remarkable caregiving capacities of men in America is the next big challenge for Hollywood.

## [What New Family Caregivers Really Need to Know](#)

Regular exercise, respite breaks and connecting with others will help you in this challenging role.

## [Jobs Aplenty, but a Shortage of Care Keeps Many Women From Benefiting](#)

A dearth of child care and elder care choices is causing many women to reorganize their working lives and prompting some to forgo jobs altogether, hurting the economy at a moment when companies are desperate to hire, and forcing trade-offs that could impair careers.

## [The Emotions of Caregiving Captured on Camera](#)

The winners of the National Council on Aging (NCOA) third annual photo contest created some incredible depictions of caregiving, aging, and love. Read about the winning entries and enjoy the full gallery of entries submitted to this year's contest.



## PERSONAL ACCOUNTS

### [Op-Ed: At 29, I Wasn't Prepared to be a Caregiver. Life Had Other Plans](#)

"Caregiving means being trusted with the culmination of someone else's life. It's a gift to be allowed to support someone who is approaching the end of their life, but it also takes an emotional toll. At 29, I became the caregiver to both my mother and grandmother."

### [The Underground Economy of Unpaid Care](#)

"More than 40 million people provide unpaid care for adults. My mother was one of them."

# RESEARCH OPPORTUNITIES

## **Are You Caring for a Loved One With Dementia**

Researchers at Weill Cornell Medicine are conducting a research study examining well-being and resource use in dementia caregivers. The aim of this study is to identify and examine the needs of caregivers and the types of resources and support services that would be most beneficial to promote well-being in caregivers.

If you are eligible and agree to participate, you will be asked to complete an online survey lasting 20-30 minutes. Then, you will be given the option to participate in a follow-up phone interview with a member of the research staff. You will be asked to answer some questions about your demographic characteristics, care responsibilities, challenges experienced, and ways you have coped with those challenges. Then, you'll be asked to answer some questions about your use of community resources, barriers to accessing and using resources, and suggestions for resources that you would be interested in using in the future based on your own personal needs.

You will receive a stipend of \$25 for your completed surveys. For those who choose to participate in the open-ended interview, you will be compensated with another \$40. If you have any questions about this survey, please feel free to email [fbf4001@med.cornell.edu](mailto:fbf4001@med.cornell.edu) or call (646)481-2858.

## **Participants Needed for Study on Caregiving for Family Member with Memory Problems**

Are you helping a family member with memory problems? The Virginia Tech Center for Gerontology is seeking grandchildren, siblings, nieces/nephews, and step family members (any relationship) living in Virginia to participate in a research study about caring for a relative with dementia living in the community (not in an assisted living or nursing home). This study involves one initial phone interview (approx. 70 minutes) and a brief phone interview for 8 days in a row (15-20 minutes each evening).

You will be asked questions about your experiences providing care, family involvement and use of paid services, and challenges you face caring for your relative.

Compensation is \$110 for full participation (VT IRB# 20-742). Interested? Visit the study website [careex.isce.vt.edu](http://careex.isce.vt.edu), call: 540-231-9250 or email at [careex@vt.edu](mailto:careex@vt.edu).

## **Caregiver Perspectives on Alzheimer's Disease and Related Dementias Clinical Trials**

A University of Illinois Urbana-Champaign research team is conducting a study to learn more about engaging family caregivers of racial/ethnic minority participants in clinical trials for Alzheimer's Disease and related dementias (ADRD).

Researchers would like to learn more about your experiences with helping your relative navigate participation in clinical trials for ADRD. They hope to learn about ways that they can better support family caregivers so they can better support their relative through these trials.

To participate in this study, the participant must be:

- Age 18 or older
- Speak and understand English
- A caregiver for someone with ADRD who has either a) received information about a clinical trial, b) been invited to participate in a clinical trial, or c) has participated in a clinical trial
- Identify as part of a racial or ethnic minority community

Participation includes a 25-30 minute virtual interview. Participant will receive a \$25 gift card upon completing the interview. Please contact Dr. Minakshi Raj if you are interested in participating: [mrj@illinois.edu](mailto:mrj@illinois.edu)

## **Caregiving While Black Course**

Caregiving While Black is a six week culturally appropriate caregiving training and education course. The overall goal of this project is to address the cultural reality of "Caregiving while Black" during a public health crisis. The project aims to develop and prototype-test a highly accessible program designed to enhance the mastery of Black American caregivers to provide care to family members or friends living with a dementia illness in a time of crisis.

A \$40 gift card will be provided for participation in each baseline and post-intervention interview and each semi-structured interview. If you'd like more information, click [here](#).

# How-To Guides and Resources for Caregivers

## [Home Safety Checklist for Alzheimer's Disease](#)

Use this room-by-room checklist provided by the National Institute on Aging to alert you to potential hazards and to record any changes you need to make to help keep a person with Alzheimer's disease safe. You can buy products or gadgets necessary for home safety at stores carrying hardware, electronics, medical supplies, and children's items.

## [Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide](#)

Get Alzheimer's caregiving information and advice in this comprehensive, easy-to-read guide produced by the National Institute on Aging. Learn caregiving tips, safety information, common medical problems, and how to care for yourself.

## [Make Yourself a Priority, Too: Tips for Caregivers](#)

Caregiving can be rewarding, but difficult. Learn how you can put yourself back on the priority list.

## [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. As a long-distance caregiver, you can provide important respite to the primary caregiver and support to the aging family member.

## [Video on Medications in Older Adults](#)

Learn more about how the aging process can affect how the medication is absorbed, used in the body, and exits the body. What alternative medications may need to be discussed with a health care provider.

## [10 Tips for Responding to Dementia Anger](#)

Video released by Dementia Careblazers with 10 tips for dealing with anger in dementia.

## [Latino Grandfamilies: Helping Children Thrive Through Connection to Culture and Family](#)

New tool elevates cultural strengths and helps organizations better support families.

## [In Caregiving, These Mindfulness Practices Could Help](#)

Coping with depression, anxiety, or insomnia? Research is finding that certain mindfulness practices can help make caregiving a little more manageable.

## [Whether You're a Caregiver or Know Someone Who Is, These 12 Books and Movies Will Hit Home](#)

Whether you've been thrust into the role of caregiver or you've eagerly taken it on, you have assumed a great responsibility. You probably know that better than anyone. That's why finding books and movies that reflect your experience or provide some guidance or maybe even just make you laugh can be such a boon.

## [How to Talk to Aging Parents About Health & Wealth](#)

Why experts recommend not waiting to talk to aging parents about their financial well-being.

# Research and Reports

NAC Releases New Report!

[Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity.](#)

The National Alliance for Caregiving (NAC) released a new report, [Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity.](#) Building on the priority area of clinical trials recruitment and retention identified in NAC's 2019 report [Paving the Path for Family-Centered Design: A National Report on Family Caregiver Roles in Medical Product Development.](#) this report synthesizes outputs from a series of three roundtables. In collaboration with Health Leads, NAC mobilized its network of researchers, policymakers, innovators, patients, families and caregivers to discuss and develop strategies for improving how researchers engage caregivers from populations most impacted by structural inequities in order to better understand how to increase representation of diverse patients in clinical trials.

Included in this report:

- Summary of caregiver expert convening including their key insights on caregivers' role in clinical trials and barriers to patient and caregiver participation;
- Summary of clinical trial roundtable including current strategies that improve caregiver engagement and support caregiver roles related to trials;
- Direct quotations from caregiver experts about their experiences with clinical trial participation;
- Outputs of a co-design session with both caregiver experts and clinical trial experts;
- Individual-level, community-level and systems-level focus areas for acting on these co-developed recommendations.

## Caregiver Blogs

**The Caregiver's Voice** - Written by caregiving expert Brenda Avadian, this blog brings humor and inspiration to caregiving topics.

**The Unprepared Caregiver** - Written by former caregiver Dr. Azchary White, this honest and informative blog discusses the challenges of caregiving and ways to cope.



MARCH 2022 REPORT

REIMAGINING CLINICAL TRIAL  
RECRUITMENT THROUGH A  
FAMILY-CENTERED LENS:

CAREGIVER RECOMMENDATIONS  
FOR ENHANCING CLINICAL TRIAL  
PARTICIPATION DIVERSITY



NAC's report underlines that engaging caregivers more effectively in the clinical trials process to promote better trial enrollment diversity requires investment and collaboration from not only industry partners and sponsors, but also from federal regulatory agencies, policymakers, healthcare leaders, community care providers and patients and caregivers themselves. Recognizing the value – the contributions, the expertise, the health impact – of what caregivers do, as partners in innovation, is a key part of creating a more equitable, person and family-centered health care system.