

# THIS WEEK IN CAREGIVING



March 23, 2022



## CAREGIVING IN THE NEWS

### EEOC Releases Information about Employment Discrimination Against Caregivers

WASHINGTON – The U.S. Equal Employment Opportunity Commission (EEOC) today released a technical assistance document, [“The COVID-19 Pandemic and Caregiver Discrimination Under Federal Employment Discrimination Law,”](#) and an update to its COVID-19 [“What You Should Know”](#) explaining discrimination against employees and job seekers with family caregiving responsibilities.

Based on existing EEOC policy guidance, these documents outline how discrimination against applicants or employees with caregiving responsibilities can violate federal equal employment laws when based on a protected characteristic such as sex (including pregnancy, sexual orientation, or gender identity), race, color, religion, national origin, age (40 or older), disability or genetic information. For example, an employer’s assumptions or stereotypes about caregivers may result in illegal discrimination when those assumptions lead the employer to make employment decisions based on a protected characteristic, even if the employer’s decisions are well-intentioned.

During the pandemic, employees who are caregivers have adjusted to quarantine requirements or abrupt closures or schedule changes at schools, care facilities, childcare centers or businesses.

*From: U.S. Equal Employment Opportunity Commission | March 14, 2022*

[READ MORE](#)



### Now Is the Time to Act for Youth Caregivers

I am 34 years old and have been a caregiver for 23 of those years. My mother became disabled when I was 11, a result of a relatively routine spinal surgery performed incorrectly. My older brother dropped out of college to care for me and our mother, which included

### Women Are Far Less Financially Prepared for Retirement than Men: TransAmerica Study

There are a number of obstacles that women must overcome when saving money for retirement — starting with the gender wage gap, according to Stacy J.

paying all of our household bills. I primarily assisted my mother with mobility aid, wound and intimate care and medication administration. We did not have any home health assistance, such as nurses, physical therapists or social workers.

My childhood was marked by social isolation, anxiety over my mother's health and our family finances and internalized pressure to succeed. As I grew into young adulthood and my mother's health somewhat stabilized, my caring role shifted to one slightly more anticipatory in nature: I knew that one day she would grow old and become my full responsibility, so I threw myself into education and work, hoping to carve out a middle-class existence that would support her, myself and future children of my own.

*From: American Society on Aging | Published: March 15, 2022*

[READ MORE](#)



Miller, a Tampa, Fla.-based certified financial planner (CFP). Women typically earn less money than men, which results in lower retirement savings.

Miller said that because "women are often the caretakers in the family," they may have to leave the workforce to care for children and aging parents. Missing periods of work can result in lower earnings over time and "fewer opportunities for pay raises and promotions."

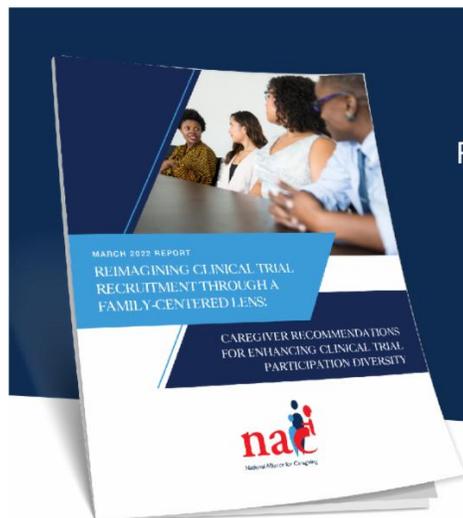
Most woman caregivers have had to make work adjustments, such as missing days of work (36%), working an alternative schedule (28%), reducing their hours (27%) and even quitting their jobs (10%), TransAmerica reports.

*From: Fox Business | Published: March 21, 2022*

[READ MORE](#)



## NAC NEWS AND UPDATES



**JUST RELEASED!**

Reimagining Clinical Trial Recruitment Through A Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity

[DOWNLOAD NOW](#)

### **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 is proud to present *Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity*, a new report developed with sponsorship

from Travele Therapeutics. 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.

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.

To read the report and access our findings, click on the red button below.

LEARN MORE



## World Carers Conversation Returns May 19, 2022 as a Global, Virtual Event

As the uncertainty around the future of the global COVID-19 pandemic continues, support for carers remains critical. NAC is convening global leaders, experts, influencers, researchers, policymakers, innovators, and other stakeholders in caregiving to share their unique research, case studies, programs, interventions, and perspectives on the future of caregiving as part of this event.

This free event will be made available to the public via Zoom and Facebook Live. The 2020 World Carers Conversation enjoyed participation of caregiving experts and stakeholders from six continents (Africa, Asia, Europe, Oceania, North America, South America) and fifteen countries (Australia, Canada, China, France, Ghana, India, Ireland,

Israel, Mexico, New Zealand, South Korea, Taiwan, United Kingdom, United States) with more than 4,000 attendees.

Continue to watch this page as links to register for the event and more information will be coming soon.

LEARN MORE



## The Circle of Care Guidebook Series

The National Alliance for Caregiving's *Circle of Care* library is a series of guidebooks dedicated to providing resources, support and information to caregivers caring for someone in a specific disease space. Part of an ongoing effort of NAC, these first three guidebooks were developed with the assistance of both patient-advocacy and consumer-facing partners:

- **Circle of Care: A Guidebook for Mental Health Caregivers**
- **Circle of Care: A Guidebook for Caregivers of Children and Adolescents Managing Crohn's Disease**
- **The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Diseases**

NAC is proud to lend their expertise on caregiving through these guidebooks. To access the guidebooks for yourself and to share them with other caregivers in your life, please visit the link below.

VIEW THE GUIDEBOOKS



An advertisement for a report titled 'Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers'. The report cover is shown on the left, featuring a photo of a diverse group of people. The text on the cover includes 'NOVEMBER 2021 NATIONAL REPORT', 'CAREGIVING IN A DIVERSE AMERICA', and 'BEGINNING TO UNDERSTAND THE SYSTEMIC CHALLENGES FACING FAMILY CAREGIVERS'. Logos for NAC (National Alliance for Caregiving), Minority Quality Forum, and Diverse Elders Coalition are at the bottom. A red button says 'DOWNLOAD NOW'. The text 'JUST RELEASED!' is at the top right. At the bottom, it says 'MADE POSSIBLE THROUGH SPONSORSHIP BY AMGEN'.

JUST RELEASED!

Caregiving in a Diverse America:  
Beginning to Understand  
the Systemic Challenges  
Facing Family Caregivers

DOWNLOAD NOW



MADE POSSIBLE THROUGH SPONSORSHIP BY



## **NAC Releases New Report: Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Diverse Family Caregivers in the U.S.**

The National Alliance for Caregiving is proud to present *Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Family Caregivers in the U.S.*, a new report conducted with sponsorship by Amgen, Inc., with support from the Diverse Elders Coalition and in partnership with the National Minority Quality Forum. Based on a secondary analysis of the survey results found in *Caregiving in the U.S. 2020*, the data presented includes multiple logistic regression analyses by Dartmouth College researchers. The report highlights significant disparities in support, caregiving intensity, health, and financial impacts among African American, Hispanic and Asian American and Pacific Islander caregivers, LGBTQ caregivers, as well as caregivers across different income brackets and geographical areas. While conducting the research for this report, it became clear that more inclusive methods of data collection are needed to inform research on the needs and possible supports and services that can be provided to diverse family caregivers.

The findings in this report highlight:

- African American, Hispanic, Asian American/Pacific Islander, LGBTQ, rural and socioeconomically diverse caregivers;
- Disparities in living situations, financial status, caregiving activities, self-reported health, and information and services used;
- Personal stories of diverse family caregivers that provide human context to the data;
- Next steps in ensuring data collection and research is inclusive of and equitable to all family caregivers;
- Future policies and improvements to supports, services and the health care system that can better the caregiver experience for diverse populations.

**LEARN MORE ABOUT THE NAC REPORT**



### **Addressing the Needs of Diverse Family Caregivers for Older Adults**

This 20-page report is the product of a series of activities conducted by the Diverse Elders Coalition (DEC) and its members' organizations, and in partnership with the National Alliance for Caregiving, to better understand and highlight the lived experiences of diverse family caregivers for older adults. It highlights key findings from 300+ diverse caregivers for older adults from the DEC's constituent communities, including racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ+) people as they provide care through the pandemic. The goal of the full length report is to offer research and recommendations to help ensure services and supports for caregivers intentionally address health disparities and systemic barriers that diverse family caregivers for older adults face.

**READ THE REPORT**



**The National Alliance for Caregiving Releases a White Paper Analyzing Existing Incentives for**

# Caregiver Services

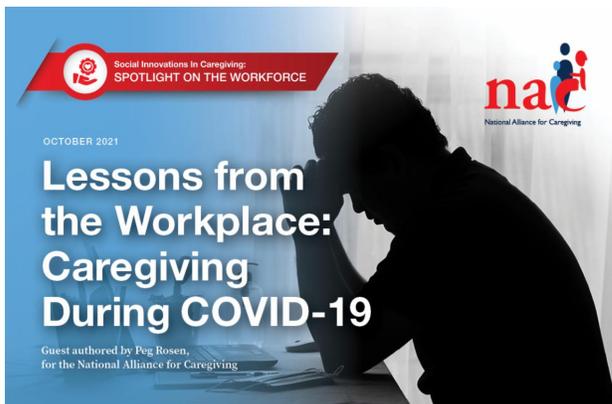
Caregivers are not well integrated into U.S. healthcare systems. Across care settings, caregivers lack formal and consistent roles on the care receiver's care team and can struggle to manage their care recipient's needs with their own. Only 29 percent of caregivers report being asked by a healthcare professional about their caregiving needs; this rate drops to 13 percent when the question referred to what the caregiver needed to be able to care for themselves ([2020 Report of Caregiving in the U.S.; AARP and National Alliance for Caregiving](#)).



Caring For The Caregiver:  
**Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team**

[DOWNLOAD](#)

[LEARN MORE](#)



## Lessons from the Workplace: Caregiving During COVID-19

**New clarification** from the U.S. Equal Opportunity Employment Commission confirms that caregiver stereotypes can result in violation of Federal laws. The EEOC Chair, Charlotte A. Burrows, encouraged employers to understand their responsibilities and underscored the collective interest in protecting caregivers from workplace discrimination as workplaces shift to a post-pandemic world and caregiving continues, “The work that caregivers do – whether as employees or as unpaid workers in the family– is in all of our interests. By ensuring that caregivers know their rights and employers understand their responsibilities, the EEOC will help ensure that America’s recovery from the pandemic is an equitable one”.

**There are 23 million working caregivers in this country.**

One in six working Americans provides unpaid care to a family member or friend with a chronic, serious, or disabling health condition. Cancer researcher Shivapriya Ramaswamy counts herself among the privileged minority in this significant, but historically marginalized, group.

Employed by a Fortune 500 pharmaceutical in the Boston Area, Ramaswamy has a steady salary and access to copious caregiver-friendly benefits, among them paid family medical leave, backup elder care, assistance referral services, and flexible work arrangements.

Yet, during the four years that Ramaswamy lived with and cared for both her aging parents, she made little use of what was on offer. “It took

time I didn’t have to go over what was available... and going to HR for help felt too public and impersonal,” she says. Though she desperately wanted a more flexible schedule, she never considered asking. “I had colleagues who worked some days from home.

“

I’d find myself staring at my computer screen, unable to think at work, partially because I was exhausted and worried because I was so worried about what was going on at home.

They were seen as less committed,” she says. “I couldn’t afford that stigma.”

So Ramaswamy—like many of the 23 million working caregivers in this country—stretched herself until she nearly snapped. “I’d find myself staring at my computer screen, unable to think at work, partially because I was exhausted and partly because I was so worried about what was going on at home,” she says. “I know that I brought some of this on myself. But the truth is I didn’t feel comfortable discussing my caregiving issues at work and never thought of my employer as a solution to my problems.”

Ramaswamy is, indeed, among the most privileged working caregivers in this country. Still, her story illustrates many of the issues that have generally stood between caregivers and the

In November’s [article](#) of NAC’s Spotlight series, Social Innovations in Caregiving, the National Alliance for Caregiving detailed the hardships the COVID-19 crisis magnified for millions of working caregivers and explored the mismatch between what family caregivers need to meet the demands of working while caregiving and what benefits and supports employers offer. “The pandemic has exposed the reality that working Americans must too often choose between caring for loved ones and holding onto their jobs,” said Grace Whiting, former President, and CEO of NAC.

Offering potential solutions on how employers can address this mismatch, NAC advances recommendations for workplace policies and practices that help caregivers thrive at work and home. These recommendations include flextime, compressed workweeks, and public policy strategies to help reinforce workplace solutions such as redefined paid leave criteria.



## EVENTS & OPPORTUNITIES

### The Society to Improve Diagnosis: Age-Friendly Care Fellowship and Age-Friendly DxQI Seed Grant

**Seed Grant Program deadline: March 25, 2022**

The Society to Improve Diagnosis (SIDM) and The John A. Hartford Foundation (JAHF) are committed to improving health care and ensuring better health outcomes for patients. By recognizing our shared vision and motivation to address diagnostic disparities affecting older adults specifically, they are expanding the [DxQI Seed Grant Program](#) to include an Age-Friendly Care Seed Grant that focuses on improving diagnostic excellence in the older adult population.

This work is vital because diagnostic error in older adults is common and errors frequently arise from contributing factors that are unique to this population, including polypharmacy, cognitive issues such as dementia, mobility limitations, and chronic illnesses.

SIDM's DxQI Seed Grant Program supports the development and implementation of projects designed to improve diagnosis and eliminate harm from diagnostic error in vulnerable communities. More specifically:

- The Seed Grant Program engages healthcare organizations to identify, develop, and test interventions aimed at improving diagnostic quality and reducing harm from diagnostic error. The Seed Grant offers an award of \$50,000 and the application is scheduled to close on **March 25**.

To learn more about this opportunity, click the red button below.

**LEARN MORE**



### Common Respiratory Diseases in Older Adults

**March 29, 2022 | 1:00 PM - 2:00 PM EST | Online**

This webinar is intended for social workers, nurses, care staff and family members caring for the older adult population who may be at risk for or who have common respiratory diseases. The webinar will discuss common diseases and how they affect older adults, tips to mitigate risks, and resources.

Participants in this webinar will be able to:

- State common respiratory diseases of older adults.
- Define how these diseases can affect older adults.
- Explain management of common respiratory diseases in older adults.
- State simple tips to mitigate risks of common respiratory diseases in older adults.
- Identify common respiratory disease resources.

To learn more about the webinar, click [here](#). To register, click the red button below.

## Solicitation of Nominations to Serve on the Advisory Council To Support Grandparents Raising Grandchildren

**Deadline: April 11, 2022**

The Principal Deputy Administrator of the Administration for Community Living (ACL) seeks nominations for individuals to serve on the Advisory Council to Support Grandparents Raising Grandchildren. The council identifies, promotes, coordinates, and disseminates to the public information, resources, and the best practices available to help grandparents and other older relatives both meet the needs of the children in their care; and maintain their own physical and mental health and emotional well-being. The Advisory Council is specifically directed to consider the needs of those affected by the opioid crisis, as well as the needs of members of Native American Tribes.

Nominations must be submitted electronically by 11:59 p.m., Eastern on April 11, 2022 to be considered for appointment.

Method of Submission: Nominations, including all requested information (see Nomination Process below) and attachments, must be submitted electronically to: [SGRG.mail@acl.hhs.gov](mailto:SGRG.mail@acl.hhs.gov).

To learn more about this call for nominations, click [here](#).

## Solicitation for Nominations To Serve on the Family Caregiving Advisory Council

**Deadline: April 11, 2022**

The Principal Deputy Administrator of the Administration for Community Living (ACL) seeks nominations for individuals to serve on the Family Caregiving Advisory Council. The council studies and prepares findings, conclusions, and makes recommendations to the Administrator of ACL/Assistant Secretary for Aging on matters pertaining to: (a) Evidence-based or promising practices and innovative models for the provision of care by family caregivers or support for family caregivers; and (b) Improving coordination across federal government programs. The Advisory Council advises and provides recommendations to the Administrator on recognizing and supporting family caregivers.

Nominations must be submitted electronically by 11:59 p.m., Eastern on April 11, 2022 to be considered for appointment.

Method of Submission: Nominations, including all requested information (see Nomination Process below) and attachments, must be submitted electronically to: [RAISE.mail@acl.hhs.gov](mailto:RAISE.mail@acl.hhs.gov).

To learn more about this call for nominations, click [here](#).

## Call for Applications for the 2022-2023 Class of Health and Aging Policy Fellows

Are you committed to improving health and aging? Are you interested in learning about policymaking to increase your impact?

If so, we invite you to apply to join the next class of Health and Aging Policy Fellows!

As a Health and Aging Policy Fellow, you have the opportunity to join a dynamic community of 166 Fellows who are committed to improving health and quality of life for older Americans.

The one-year Fellowship runs from October 1 – September 30 and has full-time and part-time tracks. It is conducted as a hybrid program of mentoring, networking, learning and practicum experiences. Health and Aging Policy Fellows work across diverse fields of aging. They develop lifelong partnerships and networks. Individually and collectively they are improving the lives of older adults around the country.

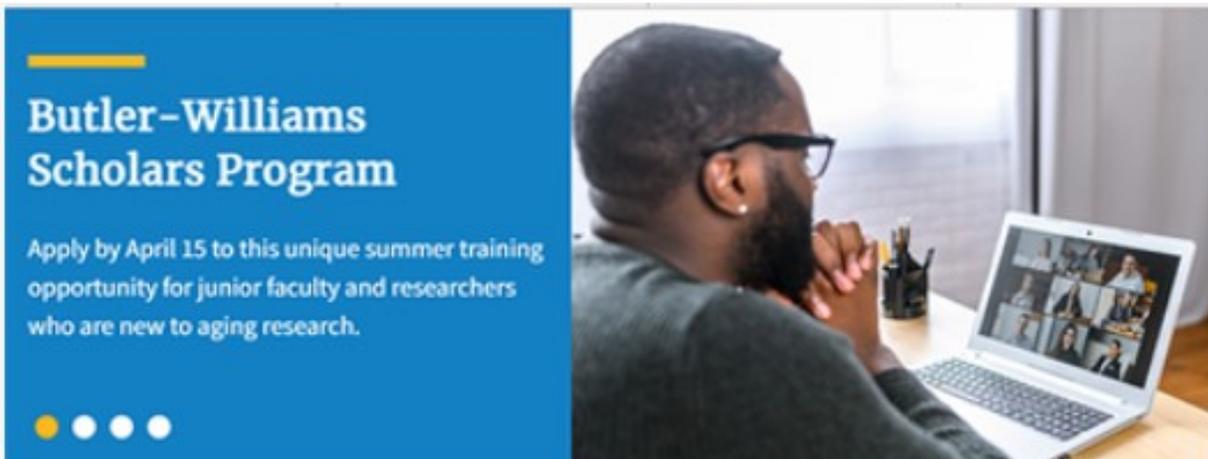
The Health and Aging Policy Fellows Program aims to create a cadre of leaders who will serve as change agents in health and aging policy to ultimately improve the health care of older adults. The year-long fellowship offers a rich and unique training and enrichment program that is focused on current policy issues, communication skills development, and professional networking opportunities to provide Fellows with the experience and skills necessary to help affect policy.

**Submission deadline: April 15, 2022**

Fellowship begins October 2022

To learn more about the fellowship, click [here](#). To apply, click the red button below.

**CLICK HERE TO APPLY FOR THE FELLOWSHIP**



**Butler-Williams  
Scholars Program**

Apply by April 15 to this unique summer training opportunity for junior faculty and researchers who are new to aging research.

## **Call for Applications: The Butler-Williams Scholars Program 2022**

The National Institute on Aging's (NIA) Butler-Williams Scholars Program has a call for applications for their 2022 cohort.

The program provides distinctive opportunities for researchers and faculty who are new to the field of aging to gain more knowledge about this field. It includes lectures, seminars, and small group discussions in research design relative to aging, including issues relevant to aging of ethnic and racial minorities. Lectures will cover topics in research on aging, including: the biology of aging; genetics and Alzheimer's disease; and health, behavior, and aging.

Researchers with an interest in health disparities research are encouraged to apply.

**Applications are due April 15.**

To learn more about the Butler-Williams Scholars Program, click [here](#).

To apply, click the red button below.

[CLICK HERE TO APPLY FOR THE PROGRAM](#)



# VISION HEALTH

## ADVOCACY COALITION

### Thyroid Eye Disease Patient & Caregiver Event

**April 16, 2022 | 8:30 AM - 10:30 AM EST | Rosemont, Illinois**

Living with or caring for somebody with thyroid eye disease? Join us for a free discussion on living with and managing the disease.

#### About this event

##### Location:

Sheraton Suites Chicago O'Hare  
6501 Mannheim Road  
The Chicago Room  
Rosemont, IL 60018

##### Schedule:

Saturday, April 16

- 8:30am - Complimentary Breakfast & Registration
- 9:00am - Program

##### Important COVID-19 Information:

To promote the health and safety of this indoor event and the community as a whole, all attendees will be asked to provide proof of either COVID vaccination or negative COVID test results (taken within 48 hours of event) at check in.

Parking is free and will be validated after the event.

##### Contact Information:

For any questions, please contact Lauren Carter-Early at [lcarterearly@allianceforpatientaccess.org](mailto:lcarterearly@allianceforpatientaccess.org) or (202) 951-7076.

To register, click the red button below.

[REGISTER FOR THE EVENT](#)





# SAVE THE DATE!

## The Public Health Opportunities and Challenges of Dementia Caregiving

June 14th-15th, 2022

You are invited to the in-person BOLD Public Health Opportunities and Challenges of Dementia Caregiving Conference on June 14 & 15! Join the BOLD Public Health Center of Excellence in Dementia Caregiving in person @McNamara Alumni Center (MN), and hear from experts what states and communities are doing to elevate dementia caregiving as a public health issue.

To learn more or register for the conference, click the red button below.

REGISTER



### PATIENT AND CAREGIVER STUDIES

#### Study of Caregivers Caring for Parents Who Mistreated Them

The University of Wisconsin is seeking to interview adult children who are caring for a parent who caused them harm in childhood. The leads of this study hope to understand these caregivers' experiences, motivations and interactions with the healthcare system. The goal of the study is to inform the creation of more robust support and resources for these caregivers and assist healthcare professionals to recognize, assess, and intervene more effectively when working with individuals and families with this history.

To learn more about the study, click the red button below. To view the Facebook group for this study, click [here](#). To participate, click the red button below.

LEARN MORE ABOUT THE STUDY



SURVEY RESEARCH CENTER  
AGING & BIOPSYCHOSOCIAL INNOVATIONS  
UNIVERSITY OF MICHIGAN

## INVITATION TO TAKE PART IN THE



## Stress and Well-Being in the Lives of Caregivers Study

The University of Michigan's SWELCare study focuses on the daily experiences, well-being, and cardiovascular health of individuals living with a family member or friend who is experiencing cognitive decline. The study team is looking for caregivers and persons with cognitive decline over the age of 18 to participate. No formal diagnosis of dementia is required.

### WHO CAN TAKE PART IN THE STUDY?

Individuals who are Black or White, living with and helping a family member or friend who has Alzheimer's or related dementia and are residents of the state of Michigan.

### WILL I BE PAID FOR PARTICIPATING IN THE STUDY?

YES! The family member/friend and the person living with dementia will receive a combined amount of up to \$400 for taking part in the study.

To learn more about the study, click [here](#). To participate, click the red button below.

**PARTICIPATE IN THE STUDY**



## Survey from Lupus and Allied Diseases Association on Health Technology Assessments

Lupus and Allied Diseases Association, Inc. (LADA) is inviting U.S. based patient advocacy organizations to participate in a brief survey regarding Health Economic Assessments (HEAs), Health Technology Assessments (HTAs) and Value Assessments (e.g. ICER Drug Reviews).

The results will help us to better gauge the current level of knowledge and experience that organizations have with these assessments and to inform the degree of educational resources needed to better prepare groups to participate.

**Please have only one individual take the survey on behalf of your organization and once you have completed it please share the survey with your patient advocacy networks based in the United States only.**

This project is being developed and managed entirely by LADA and once the survey is closed we will share the findings.

**TAKE THE SURVEY**



**LGBTQ+ Research Connections**

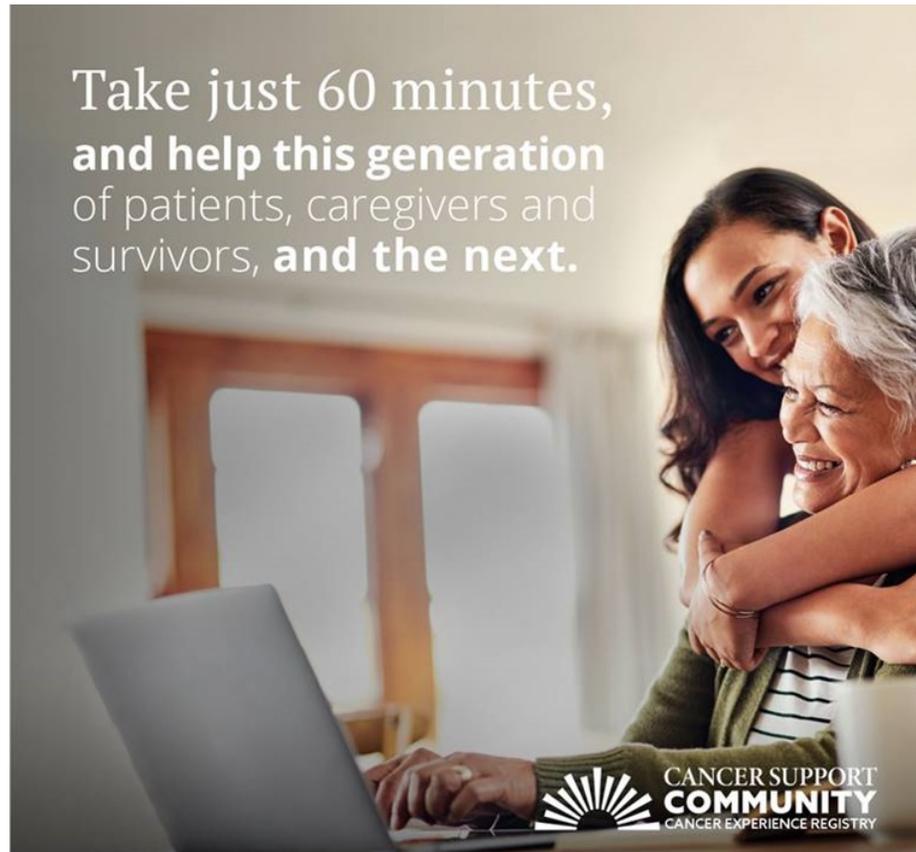
## LGBTQ+ Research Connections

LGBTQ+ Research Connections is a new offering through the National Resource Center

on LGBT Aging. Each year the NRC receives numerous requests to help identify older LGBTQ+ people to participate in academic research studies. LGBTQ+ inclusive research is important to expand the knowledge base related to aging as an LGBTQ+ person. Through LGBTQ+ Aging Research Connections, academic researchers are invited to submit an application for review and approval for listing on the website. LGBTQ+ community members will then be able to learn about research opportunities they may wish to participate in.

Research opportunities are updated on a monthly basis.

[Browse Current Research Opportunities >](#)



## Cancer Support Community Invites You to Share Your Experience

The Cancer Support Community (CSC) believes in addressing the emotional, physical, practical, and financial needs of those impacted by cancer. The Cancer Experience Registry (CER) survey captures these experiences to ensure support services better reflect patient and caregiver needs, enhance cancer care, and influence healthcare policies. The survey is open to breast cancer and all other cancer patients, survivors, and caregivers over the age of 18.

To learn more about the CER, click [here](#). To take the survey, click the red button below.

[TAKE THE SURVEY](#)

>



## **Yale Families Coping Together With Alzheimer's Disease Study**

If you are at least 18 years old, and you have a parent at least 55 years old and has early stage dementia, you and your parent may be eligible to participate in a free and confidential study to understand your experience coping with dementia together. Participation involves one 2-hour interview session and a one 2-hour interactive session with you and your parent completing tasks together now and one year later. Interview and interaction sessions can be completed over the phone, by mail, or on the computer.

**Compensation of up to \$600 for completing all sessions .**

To learn more or to see if you are eligible to participate, please contact Kathleen Williams at (203)641-5373 or email her at [kathleen.williams@yale.edu](mailto:kathleen.williams@yale.edu).

## **Alzheimer's Disease and Related Diseases (ADRD) Partner/Spousal Caregiver Study**

This study by Rush University's College of Nursing will explore how partner/spousal caregivers manage/deal with the challenges of caring for persons with Alzheimer's disease and related dementias (ADRD). Additionally, the study will explore the feasibility and acceptability of recruiting, interviewing, and consenting partner/spousal caregivers using technology.

To participate in this study, you are must:

- be at least 65 years old
- self-identify as a partner/spousal caregiver
- have a partner/spouse who has been diagnosed with Alzheimer's disease by a healthcare professional
- have a partner/spouse is at least 65 years old
- have a partner/spouse resides in the same household

If you volunteer to be in this study, your participation will consist of an online interview using Zoom. Your participation would involve one interview session, which will take approximately 60 minutes of your time.

- Participants will receive a \$25.00 Target gift card upon completion of the interview. Participation is completely voluntary, information collected is protected, and participants may terminate at any time.

For more information or to volunteer participation please contact:

Shandra Burton, MSN, RN, PhD Student  
Rush University, College of Nursing  
(463)701-1565  
shandra\_burton@rush.edu

## Black Male Dementia Caregiver Burden Study

GW School of Medicine and Health Sciences is actively recruiting Black men aged 30-85 who are either caregivers or non-caregivers of loved ones diagnosed with dementia. Participants will engage in a series of questionnaires, surveys, and a focus group, and can receive up to \$125 in compensation. Click the link below for additional information.

LEARN MORE



## Intuition Study

Biogen has officially opened enrollment for the virtual Intuition Study in the United States. Using everyday devices, this first-of-its-kind study aims to measure changes in thinking and memory in adults, as well as identify longer-term changes in brain health. For more information about who is eligible and how to enroll, click the link below.

LEARN MORE



---

**IN CASE YOU MISSED IT...**

## What is Caregiver Discrimination?



A conversation with EEOC Legal Counsel Carol Miaskoff discussing employment discrimination against family caregivers, the EEOC's role in addressing it, and what to do if you think you've experienced discrimination.

---



## Black and Aging in America

Black and Aging in America®, a new report by the National Caucus and Center on Black Aging (NCBA), presents summaries, statistics, and perspective on the status of Older African Americans. By examining social, economic, health and other indicators, in comparison to other racial and ethnic groups, this report illustrates progress as well as the many challenges that remain.

Some organizations, academic studies, and government agencies consulted for this report define seniors as over age 55. However, unless otherwise noted, this report reflects information on the 65-and-older cohort. Black and Aging in America® condenses this broad spectrum of information into one simplified presentation—a readily accessible portrait of the status of Older African Americans.

To read the report, click on the red button below.

[READ THE REPORT](#)





## Answers On Aging Podcast

Answers on Aging is a monthly podcast inviting listeners to take a deep dive into the work of USAging and our members on hot topics, current events, their work in the field and more. Stream the [first episode](#) now to hear from USAging CEO Sandy Markwood who shares with us her thoughts about the road ahead for USAging members and the entire Aging Network.

To learn more about the podcast, click the red button below.

[LEARN MORE](#)



## The Hospital-at-home Presents Novel Liabilities for Physicians, Hospitals, Caregivers, and Patients

Healthcare is increasingly provided in a patient's home, with potential cost savings and clinical improvements. But the hospital-at-home also raises unique liability issues not only for physicians and hospitals but also for caregivers and patients.

A new article in the journal *Nature* discusses these issues as they pertain to medical professionals as well as unpaid caregivers. To read the article, click the red button below.

[READ THE ARTICLE](#)





## Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile

Family caregivers are experiencing higher levels of isolation and stress due to COVID-19, which has complicated access to respite care and in-home paid caregiving.

Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile describes an ongoing project to enhance counseling, training, and other services offered by California's 11 nonprofit Caregiver Resource Centers (CRCs).

Published by the Family Caregiving Institute at UC Davis in Sacramento, CA, the report highlights the CRCs' deployment of an interactive online system to assess and meet caregivers' needs during the pandemic. The report also proposes using data collected in that system to support evaluation of the CRC service model.

Notably, compared with other caregiver populations, CRC clients are more likely to:

- Provide complex medical/nursing care at home
- Live with a care recipient
- Care for people who have dementia and cannot be left alone

[READ THE REPORT](#)



## Supporting Family Caregivers of Older Adults with a History of Trauma: Implementation Recommendations for the National Family Caregiving Strategy

The Administration on Community Living has played a crucial role in ongoing efforts to develop a national family caregiving strategy.

In support of those efforts, agencies representing diverse populations and experts from various disciplines have drafted recommendations on person-centered, trauma-informed care for family caregivers of elders with a history of trauma.

The recommendations are aimed at:

- Increasing the use of family caregiver support services
- Promoting better outcomes for both caregivers and care recipients

[READ THE RECOMMENDATIONS](#)



## Improving Primary Care for People With Disabilities

The National Association of Councils on Developmental Disabilities (NACDD), with support of UnitedHealthcare Community & State (UHCCS), partnered with the UHCCS National Federally Qualified Health Center (FQHC) Advisory Board and the National Advisory Board (Boards) to more fully understand the challenges individuals with disabilities face when accessing primary care and to identify ways the health care system can be strengthened to deliver comprehensive, person-centered care that best meets their needs. NACDD coordinated community surveys of individuals with disabilities, caregivers, state Developmental Disability (DD) Council leaders, and health care professionals from across the nation in August 2021 to collect feedback and anecdotal evidence on primary care access. These surveys were promoted through the Boards, within the NACDD network of consumers and advocates, and to health care provider partners. The brief provides an overview of those findings with insights from members of the Boards.

[READ THE BRIEF](#)



**Yoga 4 Caregivers**

Yoga4Caregivers offers a safe, private, non-judgmental online community focused on educating and empowering Caregivers (family/chosen family/professional) to explore the embodied self-care practices of yoga, meditation and mindful movement. These tools are proven to calm the nervous system, increase the mind-body connection and improve physical health, mental health and well-being.

We call this community a Caregiver Kula. Kula is a Sanskrit term that means, an intentional community of the heart. This community is supported by volunteer Yoga Teachers, Yoga Therapists and Wellness Educators.

All Caregivers including family, chosen family and medical/social service professional caregivers are welcome here. All have a shared experience of anxiety/stress, burnout and compassion fatigue.

To follow Yoga4Caregivers on Twitter, click [here](#). To join on Facebook, click the red button below.

[Join Yoga4Caregivers on Facebook](#)



## Video Series: Tips for Managing Alzheimer's and Dementia Symptoms

Research shows that individuals – including those living with **dementia** – want to stay at home. That goal may become difficult for someone with Alzheimer's disease or another form of dementia. This video series provides tips from Dr. Lakelyn Hogan, Home Instead gerontologist and caregiver advocate, to help you be the best care partner so your loved one may enjoy living at home safely.

To access the video series, click on the link below.

[VIDEO SERIES](#)



## Top 17 Resources for Family Caregivers

**A list of caregiver favorites**

from Family Caregiver Alliance



## Top 17 Resources for Family Caregivers

If you're a family caregiver, you may have questions about your care recipient's health condition, care planning or how to navigate daily care activities. This one-sheet of top resources produced by the Family Caregiver Alliance provides a wealth of answers and guidance to these questions and more. This list contains the most popular resources as rated by the family caregivers we've served for more than 40 years. We hope they help

you too!

To access the list of resources, click the red button below.

LEARN MORE



## A Guide to Finding an LGBTQ+ Inclusive Long-Term Care Community

Welcoming policies, practices, and culture are all factors that should be considered when trying to find an inclusive and welcoming long-term care facility for LGBTQ+ elders. Learn how to properly screen facilities for these and other factors in a resource created by the **Human Rights Campaign Foundation** and **SAGE**.

VIEW THE GUIDE



## Community-Based Respite Care: Training Caregivers and Family to Provide in-home Care for Indigenous Older Adults Living with Dementia

The International Association for Indigenous Aging has announced the availability of a new Indigenous respite care toolkit that will help build capacity for the provision of community-based respite care. The goal of the toolkit is to build capacity for community-based respite care by creating an opportunity for education, training, and increasing awareness in Indigenous communities.

VIEW THE TOOLKIT



FOLLOW US TO STAY CURRENT ON CAREGIVING!

