A few years back, Sheila’s mom, Marlene, crashed her car in Sheila’s driveway. Sheila and her three brothers made the difficult decision to take away their mom’s car. “She didn’t like that situation, but I told her, this is for everyone’s safety,” says Sheila. Sheila then noticed that her mom was struggling to do basic things like keep track of time, make decisions about what to buy at the grocery store and to shower properly. Not long afterwards, Marlene was diagnosed with dementia, and Sheila, who is now 60, was spending seven days a week at her mother’s house, cooking and cleaning and helping to bathe her.

All of Marlene’s children live within an hour of her Michigan home, yet Sheila, who lives the closest and is the only daughter, ended up in charge of most of the work. When Sheila, who requested that her last name not be used, told her brothers that their mom wasn’t showering, for example, her younger brother said that he and his wife had noticed she smelled the last time they visited — but “they didn’t ask if I needed any help, or assist mom,” Sheila says. “They just went about their lives.”

Collaboration between siblings is vital when caring for an aging parent — and that can present a challenge for even the most solid of sibling relationships. It’s a challenge that more and more people are facing: In the United States, the number of caregivers of family or others aged 50 and over increased by 7.6 million from 2015 to 2020 to reach a staggering 41.8 million, according to a report by the nonprofit National Alliance for Caregiving and the AARP. This means that today, around 17 percent of Americans are caring for an aging individual.

The Covid-19 pandemic has only exacerbated the situation; elderly people, especially those with preexisting medical conditions, are more vulnerable than their younger peers to Covid-related complications. This has piled on stress for caregivers like Sheila, who spent the entirety of lockdown in 2020 taking care of her quarantined mother while the rest of Sheila’s life was put on hold.

*From: Knowable Magazine | January 28, 2022*
The Department of Veterans Affairs (VA) has announced plans to expand three of its home- and community-based caregiving services to its 171 medical centers by the end of 2026.

“These evidence-based programs allow veterans to age in place, avoid or delay nursing home placement and choose the care environment that aligns most with their care needs, preferences and goals,” said Scotte Hartronft, a physician and the executive director of the VA’s Office of Geriatrics and Extended Care. “Veterans using these programs have experienced fewer hospitalizations and emergency department visits, reduced hospital and nursing home days, and fewer nursing home readmissions and inpatient complications.”

Which three services are expanding?

Services are expanding to areas with the highest unmet needs and will include the addition of 58 medical foster homes, 70 veteran-directed care programs and 75 home-based primary care teams within these programs:

- **Home-Based Primary Care:** This program is for service members who need in-home support for ongoing diseases and illnesses that affect their daily lives. A VA physician oversees a team that provides health care services to veterans in their own homes. It is designed for veterans facing isolation and veterans whose caregivers need extra help.

- **Medical Foster Home:** A trained caregiver provides services to a few people in a private home. Some, but not all, residents are veterans. The VA inspects and approves all Medical Foster Homes, which serve as alternatives to nursing homes.

- **Veteran-Directed Care:** Veterans of any age may be eligible to receive personal care services for help with daily living activities such as bathing, dressing and preparing meals. Veterans are given a budget for services that are managed by service members themselves or their representatives.

Caregivers for loved ones with dementia experience their duties in ways that are unique to the individuals they’re caring for.

Some wrestle with the behavioral issues of the people in their care, while others must balance caregiving and work or struggle to navigate the Medicaid system, line up day care, or track down a reliable in-home professional.

“There is no one way to care for a loved one who has dementia,” says Amy Goyer, caregiver and author of “Juggling Life, Work and Caregiving.”

Goyer feels that every caregiver’s perspective could be useful to someone else going through the same thing. She recently hosted a webinar that opened a window on the lives of three Pennsylvania caregivers – one for a father, one for a husband, and one for a partner’s mother.

The three women had a couple things in common, including the stress of shouldering the burden and the strain on their finances of paying for the all-day care that family members required, especially in the later stages of dementia.

But the similarities ended there. To understand the variety and depth of each person’s experience, there is no substitute for hearing directly from them in this webinar, which was sponsored by AARP, the Alzheimer's Association, and the Pennsylvania Association of Area Agencies on Aging.

Here are snippets of their stories:

Robin Madison’s husband had Lewy body dementia, and Madison had four jobs: wife, mother, breadwinner, and caregiver. Her husband was 18 years older, and she was fully aware that she might one day have to take care of him. On the good days, he could be entertained by playing music on his tablet or watching television for hours. But he was often ill-tempered and difficult to manage.

Madison described her seven years of caregiving as a “battle” – a battle to get a diagnosis, to work at home while her husband roamed the house, and to secure consistent end-of-life caregivers for her husband, who died last year.

From: AARP | Published: January 25, 2022

From: Center for Retirement Research | Published: February 1, 2022
The National Alliance for Caregiving Seeks New President and Chief Executive Officer

The National Alliance for Caregiving is seeking an energetic and passionate leader to carry out innovative research, engage in advocacy, and drive policy changes to improve the lives of family caregivers. The ideal candidate is an experienced leader and effective communicator with significant experience working with in public policy, public health, health or social service systems, prevention, aging, or other related sectors of relevance to family caregivers. Applications will be accepted on a rolling basis from January 26 to February 16, 2022. Please see the attached job description for more details.

JOB DESCRIPTION

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.
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, 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.

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.

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).

Lessons from the Workplace: Caregiving During COVID-19

In the first article of its new Spotlight series, Social Innovations in Caregiving, the National Alliance for Caregiving details the hardships the COVID-19 crisis magnified for millions of working caregivers and explores 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,” says
Grace Whiting, President, and CEO of NAC.

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

NAC's Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

The National Alliance for Caregiving recently produced The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses, resource designed in partnership with Global Genes and with support by Mallinckrodt Pharmaceuticals to provide caregivers with the support, services and specialized information they need to care for a child with a rare and/or serious illness. This guidebook offers an extensive list of resources to help a caregiver in any situation throughout the entirety of their journey as a rare disease caregiver, compiled by those in the rare disease space and caregivers themselves. This list is supplemented by the specialized information needed in order to care for a child with a rare and/or serious illness. If you or someone you know cares for a child living with a rare and/or serious illness, make sure to check out the guidebook at the link below.
You’ll learn about:

- The process of getting an accurate diagnosis for a rare and/or serious illness;
- Genetic testing, clinical trials and support groups that can help;
- Information on treatment and care coordination with specialized teams;
- Understanding the cost of care and treatment;
- Advocating for your child, their care and in their disease space;
- Empowering your child to manage their rare and/or serious illness through all aspects of their life, including when they become an adult; and
- Caring for yourself and your family.

There is also an appendix with a comprehensive list of online resources, supports and services for caregivers, the child living with the rare and/or serious illness, and his or her family that are referenced throughout the guidebook.

Click on the button below to access the Guidebook.

[VIEW THE GUIDEBOOK]

EVENTS & OPPORTUNITIES

Our Journey: Lived Experiences of Multicultural Family Caregivers
February 9, 2022 | 12:00 PM - 1:00 PM ET | Online

Join us on Wednesday, February 9th, from 12:00 p.m. to 1:00p.m. for this caregiver webinar. Lily Liu, former AARP historian/archivist, will share her lived experience as a family caregiver for her mother who has Parkinson's Disease and dementia. Her perspective will give caregivers, health care professionals and community partners a greater understanding of the unique issues that multicultural, immigrant family caregivers face. Lily's journey from "The Dragging Daughter" to "The Dragon Daughter" highlights the importance of family caregivers seeking out information and resources to be empowered as they provide care.

[REGISTER]
ARCH National Respite Network and Resource Center Conference: Call for Abstracts

The ARCH (Access to Respite Care and Help) National Respite Network and Resource Center has announced a call for session abstracts to be presented at the National Lifespan Respite Conference.

The National Lifespan Respite Conference will take place on September 14-15, 2022 in Madison, WI. The conference will offer valuable, up-to-date information for families, professionals and other stakeholders related to respite supports for caregivers. Conference keynote speakers and breakout sessions will offer a multitude of opportunities to Reimagine Respite for Lifespan Respite Care Programs and the broader respite network that supports caregivers.

ARCH is looking for presentation proposals that focus on respite care, but cross over multiple disciplines, reflecting the wide range of options required and utilized by caregivers across the lifespan. Proposals may center around the following tracks:

- Innovative Service Delivery throughout the Lifespan
- Advances in Research and Evaluation
- Strengthening the Respite Provider Workforce
- Advocacy and Networking for Sustainability
- Family Caregiver Perspectives
- Lifespan Respite Track

Abstracts must be submitted by March 1.

To learn more and apply, click the red button below.

LEARN MORE

Dole Caregiver Fellows

Dole Caregiver Fellows are the heart and soul of the Elizabeth Dole Foundation. They are active military and veteran caregivers from across the nation who are carefully selected each year to represent the Foundation in a formal capacity.
Through the Dole Caregiver Fellowship, caregivers receive support, training, and a platform to address the issues impacting the community. They also share their stories directly with national leaders and decision makers within the business, entertainment, faith, and nonprofit sectors to transform the culture of care in our country.

Applications are due March 1. To learn more about the fellowship and apply, visit the link below.

The Joy of Using LEGO Serious Play in Caregiving  
**March 4, 2022 | 12:00 PM - 1:00 PM ET | Online**

March 4th, from noon to 1:00p.m. LEGO Serious Play (LSP) is a methodology that was developed to help organizations communicate, listen and work more effectively together through the building and sharing of LEGO brick models. In this session, Loretta Woodward Veney, family caregiver and trained LSP facilitator, will teach participants what LSP is, and how it can be used with care partners, care receivers and in Memory Café sessions to spark past memories, make new memories and bring joy and hope to the caregiving experience.

The Pope Scholarship

The John and Betty Pope Caregivers Scholarship is designed to support students engaged in informal caregiving roles, while helping them learn about the importance of caregiving and ultimately reach their higher education goals. The scholarship encourages recipients to explore career opportunities within the care economy, as well as bring strengths and skills developed through their personal caregiving experiences to other fields. The scholarship is open to full-time Georgia Southwestern State University students who are providing care for a loved one or pursuing a career related to caregiving. Students are awarded funding to cover in-state tuition, with additional funding allotted to on-campus housing and books as needed.

Caregiving can overshadow students' academics and other personal responsibilities. The Pope Scholarship alleviates some of the financial burdens for students while facilitating meetings, projects, and community engagement to better their understanding of caregiving.

Scholarship applications are due March 15. To learn more about the scholarship and its requirements, visit the link below.
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

PATIENT AND CAREGIVER STUDIES

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...
Research opportunities are updated on a monthly basis.

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.
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.

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 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.
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...

Master Plan for Aging One Year Anniversary Summit

With its Five Bold Goals and 23 Strategies, the California Master Plan for Aging has inspired unprecedented levels of coordinated action across the state’s growing network of aging and disability providers, policy makers, advocates, and experts. On January 21, 2022, several MPA stakeholders and partners came together for a public virtual event to celebrate what we have been able to accomplish together in this first year and share what’s planned for the year ahead. ASL and Closed Captioning were provided.

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.
My Social Security Account

A free and secure my Social Security account provides personalized tools for everyone, whether you receive benefits or not. You can use your account to request a replacement Social Security card, check the status of an application, estimate future benefits, or manage the benefits you already receive. All from anywhere!

Sign up here

Start the New Year Building Your Caregiving Community

If connecting with fellow caregivers is one of your New Year’s goals, sign up today to get support from the VA’s Building Better Caregivers® (BBC) six-week online workshop. Meet other caregivers who share similar challenges and learn new ways to reduce stress, improve communication with your care partner and discover self-care techniques to reach your goals.

Explore the online workshop

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...
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 >

Project Issue Brief: Vaccination Equity in the COVID-19 Era

The COVID-19 Vaccine Education and Equity Project's issue brief examines the impacts and lessons learned from the pandemic, summarizing data on current disparities in COVID-19 vaccination rates, the decline in most routine vaccinations that has occurred during the pandemic, and providing context about longstanding health disparities that existed before the pandemic but continue today.

To read the report in English, click the red button below. To read it in Spanish, click here.

READ THE REPORT >

Welcome to The Arc’s Virtual Program Library

The Arc's virtual program library is a free hub of on-demand activities that can be done from home by people with disabilities, their families, and service providers.

The library is expanding all the time and has activities in a wide variety of areas, such as arts, life skills, health and wellness, virtual clubs, and more.

Browse listings to find activities like:

- Participating in dance, yoga, and other movement activities
- Learning about internet safety
- Virtually touring places like Disney World and museums
- Making your own Jeopardy templates
- Finding self-advocacy support

GET STARTED >

Planning for the Future Is Possible. The Arc is Here to Help.

Thinking about the future after a caregiver is no longer able to provide support to a loved one with disabilities is difficult. To make it less daunting, The Arc’s Center for Future Planning has a wide range of tools and resources to support you through the process. Whether you’re looking for information about financial planning, housing, supported
decision-making, or more, we’ll help you get started and stay organized!

Our newest resources include an informative video series on ways to save money and protect public benefits. The videos are also available in Spanish. Not sure where to start? Email futureplanning@thearc.org if you have any questions.

GET STARTED

New Resources from Caring Men Global

Caring Men Global Inc. has published two new resources for male caregivers. In conjunction with the development of CMG’s website, a new page has been added to help men adjust to their new caregiving roles. This feature provides caregivers with a guideline to help them know where to begin.

Because the importance of having caregivers maintain their physical and mental health as they take care of their loved ones is often lost -- and as a consequence, frequently results in caregiver burnout -- GMG has also created a new guide tailored to helping male caregivers avoid burnout and find ways to meet their needs.

To learn more about Caring Men Global Inc. and how to access their new guide, click the on the red button below.

Learn more about Caring Men Global Inc.

NASHP RAISE Act State Policy Roadmap for Family Caregivers: Part 4 - Financial and Workplace Security for Family Caregivers


The purpose of the roadmap is to support states that are interested in developing and expanding supports for family caregivers of older adults by offering practical resources on identifying and implementing innovative and emerging policy strategies. The Financial and Workplace Security for Family Caregivers section is highlights how states are supporting employed family caregivers and promoting financial security among caregivers.

Congress enacted the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act in 2018, which created an Advisory Council to develop the country’s first national Family Caregiver Strategy. NASHP created this roadmap with guidance from policymakers and leaders from across state government, using the RAISE Act goals and recommendations as a framework.
One Caregiver Resource Center

This new site aims to serve as a platform to support caregivers and adults with intellectual and developmental disabilities (IDD) who may be at risk of, or are living with Alzheimer’s disease or related Dementia (ADRD). As an aging service provider who works closely with caregivers of all ages, demographics, and capacities, we are excited to provide a centralized tool that will provide direct access to webinars across the county, trainings, updated research, and resources.

Diverse Family Caregivers Toolkit

Download the Diverse Elders Coalition's Resources for Providers: Meeting the Needs of Diverse Family Caregivers Toolkit. This toolkit offers topline information on what providers need to know, and key pieces from our comprehensive training curriculum, Caring For Those Who Care: Meeting the Needs of Diverse Family Caregivers. Whether you've already attended one or more of our trainings, or this is your first time looking into what's available to help you support diverse family caregivers, we think you'll find these resources to be invaluable in building a more welcoming, supportive practice.

FOLLOW US TO STAY CURRENT ON CAREGIVING!