The National Alliance for Caregiving joins with the entire caregiving advocacy community in mourning the passing of our founder, Gail Gibson Hunt, who died peacefully at her home on January 13th.

Her vision and passion shaped caregiving, here in the U.S. and abroad. Gail founded the National Alliance for Caregiving in 1996 as a way to address and meet the needs of caregivers in an aging America. Under her leadership, a group of national organizations worked together to create a new association that could address the public policy needs of families and quantify the impact of one of the largest unpaid workforces in our society. Gail brought the organization from its humble beginnings to the position of national powerhouse and global expert. Beginning with the 1997 ground-breaking research study, Caregiving in the U.S., conducted in partnership with AARP, Gail made sure NAC played a pivotal role in shaping public policy for family caregivers and those in their care. During her tenure as president and CEO, she expanded NAC’s work beyond aging-related eldercare issues to include new research on the economic impact of caregiving, the business case for supporting family responsibilities in the workplace, children as caregivers, and new disease-specific work in multiple sclerosis, diabetes, mental health, rare disease, cancer, and Alzheimer’s disease.
her ailing grandparents. Then her mom had a stroke at 63, and her dad developed Alzheimer’s. Later, her sister was diagnosed with Cushing’s disease.

Over the years, Goyer crisscrossed the country to care for her loved ones. At some points, they lived with her. Other times, she monitored them from afar. Now AARP’s national family and caregiving expert, Goyer, 61, says the most notable change in caregiving in her experience has been technology — particularly the smart tech that many seniors rely on to stay safe in their homes.

“New technologies are coming up all the time, and people are always sending me things to look at,” says Goyer, who oversees the organization’s Family Caregivers Discussion Group on Facebook, which has more than 8,000 members.

According to a 2020 report from AARP and the National Alliance for Caregiving, approximately 48 million Americans are caring for someone over the age of 18. About half of all caregivers used at least one piece of technology or software to assist with their responsibilities.

Goyer recommends getting a medical alert system as a basic starting point for caregivers of the elderly. You may remember the phrase “I’ve fallen, and I can’t get up!” from a commercial that premiered in the late 1980s. That system, LifeCall, is still one of the most popular ways to keep seniors safe in their homes. Here’s how it works: People who need monitoring will have a pendant or wristband affixed to them. If they have an accident, such as a fall in the bathroom, they can push the alert button to call for help.

There have been advances in this arena, such as radar fall detectors that can be placed throughout the home to monitor motion. If a person falls, the proper authorities will be notified without the person having to push a button.

When the coronavirus pandemic went into full force in early 2020, health care workers were lauded for being the frontline warriors against the highly contagious and deadly virus.

Nurses, doctors, EMTs, and other hospital staff were in the thick of the most concentrated centers of infection, prompting social media campaigns and PR efforts to show gratitude toward medical staff.

But health care workers are more than those who work at hospitals and doctors’ offices. In many cases, those providing the most immediate care are family members and in-home caregivers who are not only trying to keep themselves healthy, but they’re also working tirelessly to keep family members safe.

“Many times the care we have here in California the majority of care is done by us: family members and elder caregivers. We are an essential part of the health care system,” said Dr. Donna Benton, research associate professor of gerontology at USC and director of the USC Family Caregiver Support Center and Los Angeles Caregiver Resource Center.

Benton, along with other community advocates, spoke at a press conference on Thursday, Jan. 13 about the massive community of caregivers in California, a vast majority of whom are women, immigrants, and/or people of color.

According to Benton, there are 4.5 million family caregivers in California, meaning that there are millions of caregivers in the state who have been struggling accessing personal protective equipment (PPE) and other essential needs and services to better care for their patients during the pandemic.

From: Washington Post | Published: January 20, 2022

From: Asian Journal | Published: January 19, 2022
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).

LEARN MORE

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.

There are 23 million working caregivers in this country.

"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."

They were never so less committed,” she says, “I could tell that something was wrong.”

Employed by a Fortune 500 pharmaceutical company, Whiting found herself juggling a demanding job with her caregiving responsibilities. "I was constantly exhausted and didn’t have enough time to do anything outside of work," she says. "I realized that I needed to find a way to work from home, but I didn’t know how to make it happen."

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.

READ HERE

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.

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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](button)

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**EVENTS & OPPORTUNITIES**

**Selflessness in Practice: A Conversation on Caregiving with MSNBC’s Richard Lui & AARP’s Jean Accius**

**January 27, 2022 | 4:00-5:00 PM ET | Online**

Whether for a child, parent, loved one, or self, the difficulties of these times have revealed so much about an often thankless job — caregiving.

Exploring MSNBC’s Rich Lui’s “anti-self” help book, *Enough About Me*, and in conversation with caregiving expert Dr. Jean Accius of AARP, we will discuss practices on how to be selfless in a world that asks so much of us.

Come to learn from and engage with these brilliant thought leaders. We hope to see you there!

![REGISTER](button)

**Health Affairs Briefing: Caring for Those with Complex Needs**

**January 28, 2022 | 1:00-2:30 PM ET | Online**

For the past year, Health Affairs has published a series of articles on Health Affairs Forefront (formerly Health Affairs Blog) on the topic of caring for people with complex health and social needs, a field that has gained prominence over the last 10 years. The goal of the series has been to: elevate the science, policy and best practices relating to this high-need population; inform our readership about that progress; and provide a
platform for leading voices to raise important questions about what comes next. The result has been a diverse and impressive collection of work examining the many pathways to improved care and responsive policymaking. These efforts have been defined by their flexibility, innovation, and a willingness to reach across multiple medical specialties, hospitals, home health agencies, as well as social service providers and behavioral health interventions.

You are invited to join Health Affairs Editor-in-Chief Alan Weil on Friday, January 28, 2022, for a virtual forum on the topic, spotlighting key elements from the collection and elevating voices of patients, caregivers and advocates who know firsthand the practical and policy challenges of caring for this growing element of America’s health care population.

To register for the event, click [here](#). To learn more, click below.

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**Join NIH UNITE's Listening Sessions**

The **UNITE initiative** was established to identify and address structural racism within the National Institutes of Health (NIH)-supported community and the greater scientific community.

NIH’s initiative aims to establish an equitable and civil culture within the biomedical research enterprise and reduce barriers to racial and ethnic equity in the biomedical research workforce.

**WHAT:** The listening sessions are part of UNITE’s efforts to listen and learn. Key stakeholders at all levels of the biomedical research community who work and serve in diverse settings and hold various roles, and who partner and collaborate with research teams have important experiences and insights to share.

The insights that you share will provide valuable information on the full range of issues and challenges facing diverse talent within the scientific and administrative workforce and will help develop priorities and an action plan.

Please find the schedule of listening sessions below and register for a session that best aligns with your affiliation.

**Wednesday, January 26, 2022 — 6:00 p.m. – 7:30 p.m. ET — Students and Trainees**
[register for this session](#)

**Thursday, January 27, 2022 — 3:00 p.m. – 4:30 p.m. ET — Research Staff**
[register for this session](#)

**Tuesday, February 1, 2022 — 1:00 p.m. – 2:30 p.m. ET — Colleges and Universities**
[register for this session](#)

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**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.

**LEARN MORE >**

**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.

**LEARN MORE >**

**PATIENT AND CAREGIVER STUDIES**

Take just 60 minutes, and help this generation of patients, caregivers and survivors, and the next.
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.

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...

Working While Caregiving: Conversations with Caregivers
This conversation includes: Jessica Strong, Co-Director of Applied Research at Blue Star Families; Geri Lynn Maples, Caregiver, Dole Fellow and Dayton & Southwestern Ohio Chapter Director at Blue Star Families; and Conwell Smith, Chief External Affairs Officer at the Rosalynn Carter Institute for Caregivers. The conversation focuses our attention on educating, equipping, and creating awareness surrounding the challenges that caregivers experience in the workplace. We will discuss tips and tricks for navigating these challenges and share resources available to both caregivers and employers.

My Social Security 2021 - Third Party Social Media Toolkit

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!

VIEW THE TOOLKIT >
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 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

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**

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**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**

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**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.
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

A centralized platform to support caregivers and adults to support caregivers and adults with intellectual and developmental disabilities who may be at risk of, or are living with, Alzheimer’s disease or related dementia.

WE ARE HERE TO SUPPORT YOU!

onecaregiverresourcecenter.org

Find resources on....
- Healthy Aging
- What is Dementia?
- Dementia in Adults with an Intellectual and Developmental Disability
- Effective Communication about Dementia
- Advanced Planning and End of Life Decisions
- Self-Care and Respite for Caregivers
- Research and Clinical Trials
- Upcoming Educational Opportunities

......and more!

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.
Livanta #MyRole Social Media Toolkit

To help improve public awareness of family caregivers and increase family caregivers’ self-identification, Livanta has created #MyRoleCounts, a social media toolkit for partners and stakeholders. The social media toolkit consists of a variety of recommended graphic files, social media posts, and hashtags. Content is written using simple, plain language. Graphics are vibrant, use eye-catching colors, and cultural diversity to engage followers. Items from the toolkit can easily be downloaded below from Livanta’s website or cross-posted on social media.

Click the link below to download and share the kit today!

DOWNLOAD HERE

Dental Help for Adults With Disabilities

Special care dentistry (SCD) is a branch of dentistry that facilitates care for impaired patients with physical, intellectual, sensory, mental, emotional, medical, or social disabilities.

Special care dentistry is taught as a postgraduate course that equips dentists to offer dental services to patients with special care needs.

International organizations like the Special Care Dentistry Association (SCDA) are made up of oral dental professionals dedicated to promoting the oral health of persons with special needs.

Those qualified for special-care dentistry are people who need free comprehensive dental treatment. This includes:
- The elderly
- Disabled people
- Mentally and medically compromised persons
The Family Caregiver Alliance (FCA) is publishing a series of blogs and one-page infographics as part of a series about specific dementia caregiving programs that are found in Best Practice Caregiving.

Best Practice Caregiving (bpc.caregiver.org) is a free online database that helps health care and social service organizations identify, compare and adopt best-fit programs for their clientele and community.

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!

facebook  twitter  linkedin