

THIS WEEK IN CAREGIVING



January 5, 2022



CAREGIVING IN THE NEWS

Unpaid Family Caregivers Lose \$522B in Wages Every Year

Caregiving for a close relative or friend is financially, physically and emotionally taxing. RAND Corp. research shows family caregivers lose a staggering \$522 billion in wages every year while caring for a close relative or friend. But it is not just the loss of income that puts a financial strain on the 53 million people in the United States who provide care to someone close to them.

Ten million caregivers aged 50 and older will lose a total of \$3 trillion in wages, pensions, retirement funds and other benefits due to their caregiving duties, according to the National Alliance for Caregiving. These figures are more staggering when you consider that nearly two-thirds of family caregivers are employed, meaning they are juggling caregiving responsibilities with their job.

The cost of caring for a loved one is high. Family caregivers spend, on average, one-quarter of their annual income on caregiving expenses, according to AARP. Three-quarters of these family caregivers spend more than \$7,000 annually on out-of-pocket expenses, and this increases to as high as \$11,000 for caregivers of someone with dementia.

The financial toll is made worse by the emotional and physical strain. According to the Family Caregiver Alliance, caregivers report poorer health and endure chronic stress.

While many family caregivers are supported by direct-care providers, those individuals are often under-trained and work grueling hours for low pay and limited benefits. One-in-eight direct-care workers live in poverty, and three-quarters earn less than the average living wage, according to research published in *Health Affairs*.

The lost wages, the physical and emotional stress, the lack of support, the inadequate training and few viable alternatives create a large and growing problem that we must address, especially given the aging population. Policymakers must face this reality now with creative solutions that meet the full extent of the challenge.

From: Route Fifty | December 21, 2021

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[The Stress of Caregiving](#)

[9 Items That Make Home](#)

Caregiving Easier

It is commonly understood that caregiving can be overwhelmingly stressful. It is perfectly normal to feel a range of emotions in response to this. It's an experience that can produce sadness, anger, confusion, guilt, and anxiety about having those feelings.

It can feel shameful to admit this, and yet normalizing these feelings is important so people can feel less alone and more able to communicate what they are going through to gain support. Here are some key tips for caregivers:

1. Therapy helps.

Consider seeing a therapist to discuss what this is bringing up for you. It is normal to feel burdened and to feel fear, anger, resentment, and anxiety. And it is also normal to then worry about your own life and your own fate.

Given how complicated family life can be, it is also perfectly normal for people to navigate complex family dynamics as they are expected to provide caregiving for a parent, spouse, etc. Perhaps, you love the other person, yet don't like how he or she treated you growing up or over the years. You likely want to be in a position where you're not feeling guilt or resentment, where you can show care in a pure way yet while also honoring your own needs and your own right to be respected.

2. Gather the troops.

Consider joining a support group for caregivers; some are now offered virtually as well. You might ask your own physician or your loved one's medical team for suggestions, or contact your local hospital, caregiving alliance, or in the case of dementia and Alzheimer's, the Alzheimer's Association.

3. Self-care is crucial.

As you go about finding the best agencies and resources to help care for your loved one, be sure to explore ways to take good care of yourself—through healthy eating, vigorous exercise, rest, social activities, talking with a therapist, meditating, writing, yoga, etc.

From: Psychology Today | Published: December 29, 2021

Caregiving is hard, but don't let your home make it harder.

Bathrooms, dim lighting and even furniture pose risks when taking care of a loved one. But new tools and techniques can improve the safety of a home, making caregiving a bit easier. And it doesn't need to be complicated in order to be helpful.

“Household items and a home environment, once innocuous, need to be reconsidered through a new lens,” says Monica Moreno, senior director of care and support at the Chicago-based Alzheimer's Association, which offers a home safety checklist to help caregivers keep those living with dementia safe and independent as long as possible. AARP's free Homefit Guide features smart ways to make a home comfortable and a great fit for people of all ages.

Here are nine tools designed to help caregivers ease the burden of daily challenges.

1. Sit-to-stand toilet

Research shows that a quarter of falls take place in the bathroom, so assistive toilet seats with adjustable handlebars and seat heights — for safe and stable toilet transfers — are helpful when dealing with weakness and instability issues.

“It's common for individuals to easily sit down to go to the bathroom, but then they can't get off the toilet,” says registered nurse Eboni I. Green, cofounder and CEO of Caregiver Support Services, based in Omaha, Nebraska. “Or if they have the ability to get off, they might grab on to an unsecure towel rack and can easily fall.”

2. Adjustable beds

“These may be costly, but they're a real investment in helping to adjust comfort levels with the push of a button,” says Green. These beds can help create an upright position for eating and are a good tool for preventing bedsores. They also allow for quicker repositioning, and safer and faster transfers in and out of bed. “These beds are revolutionary,” Green says.

From: AARP | Published: December 21, 2021

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EVENTS & OPPORTUNITIES

The National Rehabilitation Research and Training Center on Family Support
at the University of Pittsburgh presents:

Building Bridges: Advancing Family Caregiving Research Across the Lifespan

Second Biennial Conference on Caregiving Research

March 3-4, 2022

Building Bridges: Advancing Family Caregiving Research Across the Lifespan

The National Center on Family Support (NCFS) is excited to host their second **biennial conference** on caregiving research in Pittsburgh, Pennsylvania.

This conference will bring together a multidisciplinary group of national leaders in caregiving research, policy, and practice across the lifespan. Sessions will showcase innovations in research and build bridges across disciplines and conditions to address the urgent community, clinical and policy needs of family caregivers.

Registration Information

Register before January 6, 2022 to take advantage of our early bird rates!

General Registration: \$250

Post-Doctoral and Clinical Trainees: \$100

Students: \$25

REGISTER NOW!

The National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh and the University of Pittsburgh School of Nursing are collaborating to provide nursing continuing professional development (NCPD) contact hours for the educational activity entitled: Building Bridges: Advancing Family Caregiving Research Across the Lifespan – Second Biennial Conference on Caregiving Research. Nurses completing the entire activity and evaluation tool may be awarded a maximum of 10.75 contact hours of NCPD. The University of Pittsburgh School of Nursing is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission Accreditation.

REGISTER FOR THE CONFERENCE

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.

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COVID-19 Study

The University of Tennessee College of Nursing is seeking adults who are currently providing care (at least 8 hours a week) to an older adult with a chronic condition.

Are you a caregiver for an older adult with a chronic condition? Please consider taking part in this important research study to understand caregiving during #COVID-19. The University of Tennessee College of Nursing is seeking adults who are currently providing care (at least 8 hours a week) to an older adult with a chronic condition for a research study. The purpose of the study is to understand the experiences of caregivers during COVID-19. The study involves responding to an online survey questionnaire with questions related to caregiving and one interview to talk about their experiences using online caregiving resources. The one-time interview takes approximately 30–45 minutes to complete. Participants will receive a \$25 Amazon gift card for completing the interview and a separate \$10 Amazon gift card for completing the survey.

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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.

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IN CASE YOU MISSED IT...

MSNBC Caregiving Segment with NAC President & CEO C. Grace Whiting


MSNBC speaks to National Alliance for Caregiving President and CEO C. Grace Whiting on the needs of family caregivers and in what ways the Build Back Better bill will support these needs if it is passed. Grace highlights respite infrastructure, Paid Family Medical

Leave, and current ways in which caregivers can connect with other caregivers to find support, information, and those going through similar experiences in order to feel less isolated.

Click below to view the video.



RESEARCH & RESOURCES



NOVEMBER 2021 NATIONAL REPORT
CAREGIVING IN A DIVERSE AMERICA:
BEGINNING TO UNDERSTAND
THE SYSTEMIC CHALLENGES
FACING FAMILY CAREGIVERS

nac
National Alliance for Caregiving

Minority Quality Forum

DIVERSE ELDER'S COALITION

JUST RELEASED!

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

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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



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.

The Arc's Virtual Program Library for People With Disabilities Is Now Live!



Looking for online activities that someone with disabilities in your life can use to keep busy as the weather cools down?

We're excited to share our new Virtual Program Library, a free hub full of on-demand activities that can be done from home by people with disabilities, their families, and service providers.

Topics include arts, community and life skills, health and wellness, virtual clubs, and more.

Visit the hub to check out the resources we have so far and share it with your networks so it can continue to grow into a robust resource for people with disabilities and their supporters!

BROWSE THE LIBRARY

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

The National Academy for State Health Policy (NASHP) has released section 4 of a new RAISE Act State Policy Roadmap for Family Caregivers, "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 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.

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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

Click here!

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.

[VIEW WEBSITE](#)

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](#)

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Is What Matters to You Today the Same as Two Years Ago?

Millions of people will travel to see friends and family in person over the upcoming holiday season, many for the first time in nearly two years. Our world and society have changed dramatically over the course of the COVID-19 pandemic and the upheaval has led many to reevaluate their own hopes and expectations for the future.

Now is a good time to talk about what matters to you with those who care about you, especially related to your health and care needs as you age. It's also an opportunity to have conversations with people whose care you may be responsible for.

Whether you are a clinician or other professional working with older adults, or you are considering what matters in your own personal life, here are resources to help begin or facilitate these sometimes difficult conversations.

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Do you provide
transportation?
Do you prepare
meals?

YOU MAY BE A CAREGIVER!

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 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



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 pharma giant 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 partly 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."

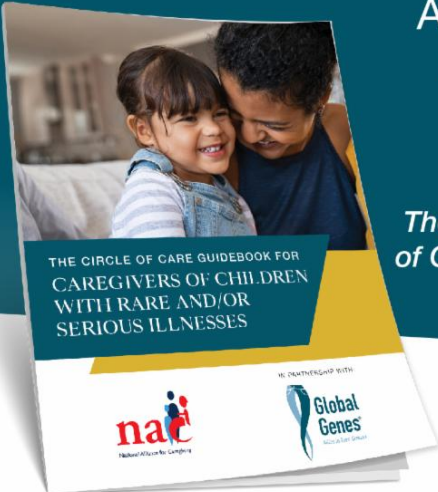
Ramaswamy is, indeed, among the most privileged working caregivers in this country. Still, her story illustrates many of the issues that have generally stood between caregivers and the

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.






READ
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Are you or someone you know caring for a child with a rare and/or serious illness?

Download our guidebook
The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

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    MADE POSSIBLE WITH SUPPORT BY: 

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
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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

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Best Practice Caregiving: Infographic Series on Dementia Caregiving Program

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.

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What's Public Health Got To Do With... Family Caregiving?

Trust for America's Health (TFAH) has published a blog, "What's Public Health Got To Do With... Family Caregiving?," to launch its new monthly blog series on Age-Friendly Public Health Systems. This series is designed to stir up conversation, generate interest, and challenge healthy aging stakeholders to engage more deeply in age-friendly public health issues.

Author of this month's blog on "What's Public Health Got To Do With... Family Caregiving?," Megan Wolfe, TFAH's Senior Policy Development Manager, outlines five potential roles for public health departments to support caregivers, organized according to TFAH's AFPHS 5Cs Framework. The roles include collecting and disseminating data, coordinating existing supports and services, connecting and convening multiple sectors, communicating, and complementing existing supports.

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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.

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Dementia Care Providers Database

Best Practice Caregiving is a free online database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers.

In the Best Practice database you will find detailed information about:

- focus of each program
- (e.g., reducing stress, understanding dementia, planning care, skill-building, health & wellness, etc.)
- program implementation
- research findings
- direct utilization experiences of delivery sites
- program developer information.

Click the button below to access the database.

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Home Is Where the Care Is

What if you were one of the 2 million adults who are homebound in the United States? Wouldn't you want care to come to you? With the nation's older adult population increasing, home-based primary care is quickly becoming the future of health care for patients who are medically complex. New resources share needed information about delivering primary care in the home:

- The **Better Care Playbook's Home-Based Primary Care Collection** provides research, resources and tools for delivering care at home. The collection includes blogs from Rush@Home detailing its care model elements and implementation insights, and the Department of Veterans Affairs highlighting its successful program.
- A **Home Centered Care Institute (HCCI) House Calls 101 course** offers a simulated educational experience to help you get started with home-based primary care.

Click [here](#) to the online course. Click the button below to browse the collection.

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The John A. Hartford Foundation's Dissemination Center

Funded and disseminated by **The John A. Hartford Foundation**, The American Association of Retired Persons (AARP) has released a new series of how-to videos and accompanying resource guides that walk family caregivers through what to expect before, during, and after a planned or emergency hospital stay.

The videos and resource guides, many of which are available in both English and Spanish, are free of charge and were developed by Home Alone Alliance members—the

The “How-To” videos and resource guides for family caregivers are on specific medical/nursing tasks – including preparing special diets, managing incontinence, wound care, mobility, and managing medications.

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Navigating the Pandemic: A Survey of U.S. Employers

Employers play a vital societal role by providing employment, work experience, employee benefits, and the ability for workers to save and invest for a secure retirement. This report examines the pandemic's impact on employers across the company, their response, and timely opportunities. A strong employee benefits package, including retirement benefits, health insurance, workplace wellness programs, and caregiver support, can create a win-win situation for employers and their employees. Especially now, as our nation is emerging from the pandemic, employers need support from policymakers to continue paving the way for their recovery and to make it as easy as possible to enhance their business practices and expand their benefits offerings.

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