

THIS WEEK IN CAREGIVING



December 1, 2021



CAREGIVING IN THE NEWS

From: National Alliance for Caregiving | Published: December 1, 2021

NAC and Global Genes Publish New Guidebook for Caregivers of Children with Rare Illnesses

Living with and caring for a child with a rare or serious illness has unique challenges and unique rewards. Oftentimes, the mainstream advice for caregivers doesn't apply.

Caregivers face a long road to getting an accurate diagnosis, navigating options for treatments, advocating for support services, and finding a way to pay for out-of-pocket expenses. Additional obstacles arise when doctors, teachers, childcare centers, and other community members don't understand the illness or how to accommodate the child's needs. It all can feel like too much to bear alone.

That's why all of us at Know Rare were so encouraged to learn that the National Alliance for Caregiving (NAC), in partnership with Global Genes, has released a new handbook specifically for Caregivers of Children with Rare and/or Serious Illnesses.

"The Circle of Care Guidebook is intended to help Caregivers navigate through the varied experiences and challenges of rare and serious medical conditions, guided by the insights, achievements, and learnings of other caregivers and experts," NAC says.

From: Know Rare | Published November 23, 2021

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Caregiving and Bereavement: Does the LGBTQ+ Community Need Stronger Support?

Acting as primary caregiver for a dying parent is a heavy burden for anyone.

Can Caregiving Help Your Career? Yes! Leverage These 5 Skills To Get Ahead

If you're like most people, you've spent a lot more of your time giving care over the

Martin, who preferred not to use his last name, assumed that role for his mother after outliving his own cancer prognosis by 20 years. Yet Martin remains remarkably upbeat while candidly discussing his experiences giving and receiving care.

From the start, Martin felt the responsibility of caring for his terminally ill mother fell to him because he was single. “There seems to be a lot of families that treat their LGBT children differently than their [heterosexual,] married children,” said Martin, a gay man “of a certain age.” It was assumed he had fewer responsibilities. “They’re from the heterosexual-normative lifestyle, and they’re used to the thought, that my family is different, my family doesn’t really exist.”

Being gay was “undiscussed,” Martin said. And because he didn’t have a partner at the same time that his mother was sick, Martin was left to pick up the slack.

“That included making meals, visiting her every day, spending hours helping her to get dressed, undress, go to the bathroom — doing the things caregivers do,” Martin said. When she entered assisted living during her final months, Martin visited her every day, keeping her company and “making sure her life was easier,” he said.

From: Pride Source | Published: November 18, 2021

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last couple years—to children, to elder relatives, to friends or neighbors. For some, caregiving has meant stepping back from career growth—but it doesn’t have to.

In addition to the challenges of caregiving, it also results in the development of key skills which are highly transferable to your job. But recognizing the skills and articulating them for employers is critical to getting ahead.

The number of people providing care has risen significantly over the last couple years, and a study by Case Western Reserve University reports that according to the National Alliance for Caregiving (NAC) and the American Association for Retired Persons (AARP), there are about 66 million family caregivers in the US and about half of these work outside the home. In addition, more than half of caregivers are women. The “caregiving economy”—the value of the work performed by unpaid caregivers—is valued at \$450 million annually, according to the NAC and the AARP.

Caregiving is time consuming and according to a study by Fidelity, a person caring for children spends an average of 61 hours per week, and a person caring for adults spends about 28 hours per week, on average. In addition, women report spending about twice as much time as men providing care.

From: Forbes | Published: November 21, 2021

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EVENTS & OPPORTUNITIES

Webinar: Congressional Briefing on Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults

Date: December 8, 2021 at 1:00 PM (EST)

Join the Diverse Elders Coalition and its members, in partnership with the National Alliance for Caregiving, as they discuss findings from their recently released report, Family Caregiving for Older Adults from Diverse Communities. The report highlights impacts of

the COVID-19 pandemic on family caregivers; related implications for older adults from diverse communities; and ways to strengthen recommendations from the recently released RAISE Family Caregivers Act Initial Report to Congress to better address the unmet needs of racially and ethnically diverse family caregivers.

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**Understanding Aging
and Dementia in
Adults with
Intellectual
Disabilities (IDD)**



THURSDAY, DECEMBER 9TH
1 PM – 2:30 PM (PST) 4 PM – 5:30 PM (EST)
VIA ZOOM

Trainers: Kathleen Bishop, Ph.D. and Kathryn Pears, MPPM

Webinar:

**Understanding Aging
and Dementia in Adults
with IDD**

**Date: December 9, 2021 at 4:00 -
5:30 PM (EST)**

At the end of this webinar, hosted
by the National Task Group in

Intellectual Disabilities and Dementia Practices, attendees will be able to:

- Understand the Impact of Aging on Adults with Intellectual Disabilities
- Provide an Overview of the Risk of Dementia in Aging Adults with Intellectual Disabilities
- Explain How the Challenges Unique to Intellectual Disabilities Impacts Service and Support Needs
- Understand What Dementia Is...And Isn't
- Increase Your Knowledge of Potentially Treatable Medical Conditions that Mimic Dementia
- Cite Established Guidelines for Diagnosing Dementia in Adults with Intellectual Disabilities

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AHHQI has an open RFP: 2022 Home Health Grant Request for Proposals

The Deadline is December 23, 2021

The Alliance for Home Health Quality and Innovation (AHHQI) seeks to sponsor a research project to help advance home health care and may seek to improve care delivery at home through quality and innovation. Funding will be awarded up to a total of \$75,000 maximum (including indirect costs). Multiple projects may be funded if they do not exceed the total funding allocated for all projects of \$75,000. Proposals are due by close of business on Thursday, December 23, 2021.

**APPLY
HERE**

PATIENT AND CAREGIVER STUDIES

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



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 New 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?

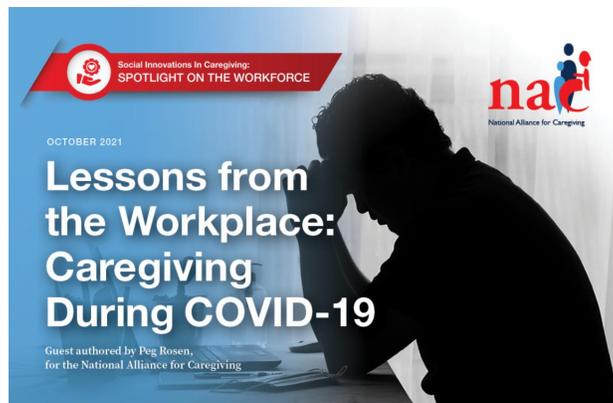
YOU MAY BE A CAREGIVER!

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 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."

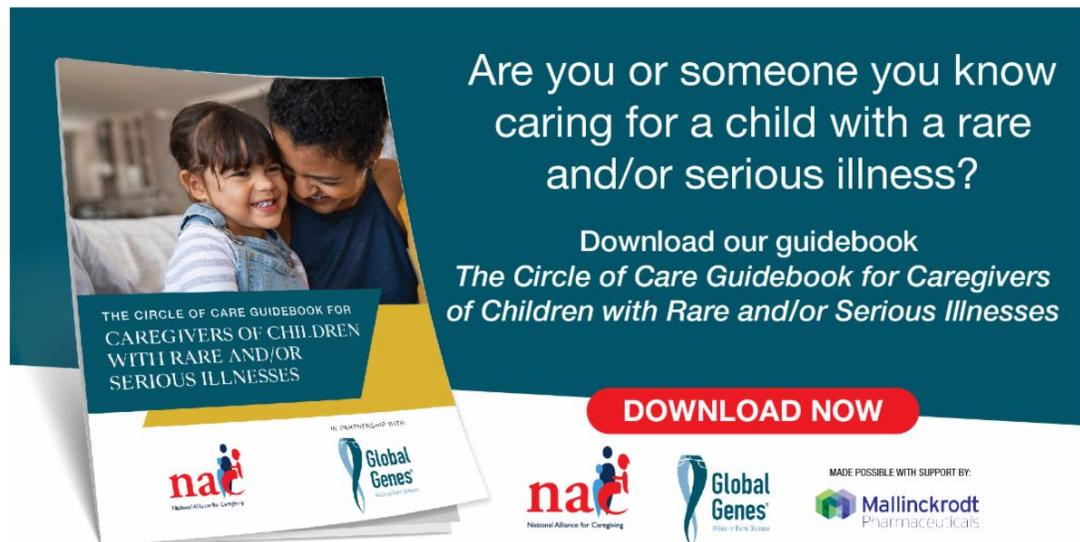
Ramaswamy is, indeed, among the most privileged working caregivers in this country. Still, her story illustrates many of the issues that have generally stood between caregivers and the

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.

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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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IN PARTNERSHIP WITH

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
>

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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Plain Language Resource for Crime Victims With Disabilities

A new fact sheet, created by The Arc's National Center on Criminal Justice and Disability, is designed for people with disabilities to understand their rights if they are victimized. The document outlines different types of abuse, what people with disabilities -- or the caregivers who help them -- can do if they become a crime victim, and where to go for help. **Download it now** and share it in your 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 [here](#) to learn more about the database or click the button below to access it.

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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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Report: The United States Should Recognize and Support Caregiving Youth

In the United States, more than 5.4 million children and adolescents under age 18 provide care for family members who are aging or have chronic illness, disability, or other health conditions that require assistance.

In this policy study published in the Society for Research in Child Development's *Social Policy Report*, the authors describe youth's care for the family and highlight the increasing prevalence, global challenges, and uneven successes of measurement and categorization. They briefly summarize research on how caregiving affects youth's academic, social, and emotional well-being. Next, they present novel, emerging evidence from the public school-based 2019 Youth Risk Behavior Survey for the State of Florida, which suggests that as many as 24 percent of middle school students and 16 percent of high school students provide at least some care to the family on a regular basis. Drawing on this evidence, the authors' discuss targeted social programs which have been shown to promote the well-being of caregiving youth outside of the United States, as well as a 13-year-old school-based intervention in The School District of Palm Beach County, Florida.

The report concludes with specific recommendations for a path toward recognizing and supporting caregiving youth via policy and practice in the United States. Its aim is to increase the awareness and feasibility of identifying and supporting caregiving youth and their families via government-organized data collection and targeted social policies.

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2021 Global State of Caring Report

The International Alliance of Carer Organization's 2021 Global State of Care report

provides an in-depth profile of the issues, approaches, policies, and innovations that are needed to support carers. It profiles the carer policies and practices in 18 countries. This interacting tool features carer initiatives addressing six universal carer priorities:

- Recognition: Legislation and awareness campaigns
- Financial support: Income support, pensions, and benefits
- Work and education: Carer-friendly workplaces and educational initiatives
- Health and well-being: Health and social supports
- Information and knowledge: Resources and education
- Evidence-informed practices: Innovative policies and practices

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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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