

# THIS WEEK IN CAREGIVING



January 19, 2022



## CAREGIVING IN THE NEWS

### **A Can-do Attitude Is a Good 1st Step for New Caregivers**

New caregivers can easily become overwhelmed by their responsibilities. But all of us who are caregivers were also overwhelmed at the start of our own caregiving journeys. Daunting is an overused term, but it is the most descriptive word for caregiving newbies. It is daunting to learn the ropes, especially when caring for someone with dementia or its most common form, Alzheimer's disease. If this describes your state of being, I am here to let you know that you can do it!

It can be difficult for new caregivers to imagine how they will get through it, if they're looking at the big picture. How can you possibly provide adequate care, knowing as little as you know right now? The answer is simple: You'll learn, and don't try to absorb the big picture.

No one can predict what will fall in their direction — not the good, the bad, or the ugly. Attempting to look ahead with untrained eyes will only overwhelm new caregivers. In the beginning, we don't even know what we don't know.

#### **Start here**

If you know someone who is where you were, get them to join a caregiver support group. A full-time caregiver won't have much time to attend meetings, but there will be resources and support information available there, along with knowledgeable, empathetic listeners who can offer helpful advice.

The best way to look for a local support group is to search on Google or to contact a local chapter of the Alzheimer's Association. Or seek out helpful books written by caregivers like Carol B. Amos, who authored "H.O.P.E. for the Alzheimer's Journey: Help, Organization, Preparation, and Education for the Road Ahead."

*From: Alzheimer's News Today | January 17, 2022*

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**Black-Owned Hospice  
Seeks to Bring Greater  
Ease in Dying to Black  
Families**

**What to Know at the  
Beginning of Your  
Caregiving Journey**

IN THE WINTER OF 2016, we were walking in a long, deviating oval around Trout Lake, on the east side of Vancouver, and Kenny said, “I think there’s something wrong with Omma.” He sped up.

“Wrong how?” I hurried to keep pace.

We’d been together for four years at that point. He chewed his lip and squinted down at our dog padding between us. It was a gorgeous day, and there were dogs everywhere, chasing, yawping.

“Did she say something?” I asked.

“No. But you know how she’s been calling. A lot.”

I did know. Sometimes we woke to a dozen missed calls from Kenny’s 68-year-old mom. The week before, they’d made lunch plans, confirmed the location twice, and she still wound up waiting at the wrong restaurant. This lost quality of hers had been coming on so slowly, though, that it seemed halfway natural. Then again, my take didn’t count for much because, to me, Kenny’s mom was always a little obscured by a language barrier—her English was rudimentary and my Korean non-existent.

“Well, what are we talking about?” I asked Kenny as we turned off the path, onto the lakeshore. “Do you mean something mental? Like you think she’s got dementia?”

*From: KHN | Published: January 10, 2022*

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The turn of the calendar year is my time for reflection. I look back on what’s happened in the past 12 months and form dreams for the year ahead. This December my look back has extended much further. I realized it’s been more than a decade since I became a caregiver for my mother, and my life changed forever. I can hardly remember when my days didn’t revolve around caregiving — whether I was tending to a loved one through illness or injury, raising a child or operating a business that serves other caregivers. As I take stock of all these experiences, here’s what I wish I had known when I became a family caregiver and a few of the lessons, big and small, I learned along the way.

### **You may become a caregiver at any age**

Caregiving is not a life event we know will happen in a certain time frame, like wisdom teeth coming in or giving birth. We expect that we may take care of our elders or aging parents, probably when we are in our middle age and have established our careers or had children. But it doesn’t always happen that way. Sometimes an out-of-nowhere diagnosis or injury can upend the lives of a whole family in the span of a day. I’m not sure why our culture doesn’t embrace this truth and prepare for it. It would be so much easier to settle into the experience of caregiving resulting from a diagnosis or injury if we were comfortable in the knowledge that we may be a caregiver at 20, 50 or even 90. If you have friends or family you love, then someday — any given day — you may be called to care for them, regardless of whether you had other plans.

*From: AARP | Published: December 28, 2021*

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## EVENTS & OPPORTUNITIES

### **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.

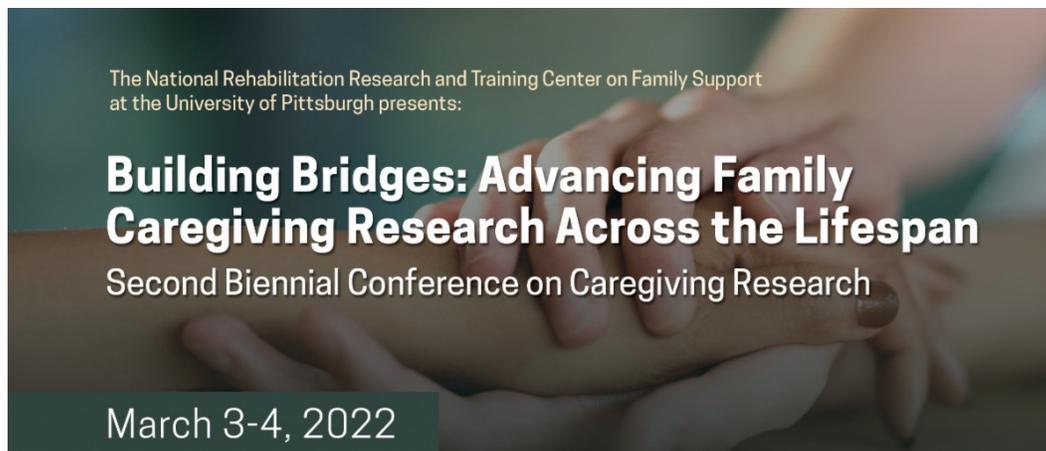
The insights that you share will provide valuable information on the full range of issues and challenges facing diverse talent within the scientific and administrative workforce and will help develop priorities and an action plan.

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 [here](#)]

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

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



## 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**



## **PATIENT AND CAREGIVER STUDIES**



### **Cancer Support Community invites you to share your experience**

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

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

**TAKE THE SURVEY**





Does your  
parent  
have any  
memory  
loss?

## **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 are must:

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

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

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

For more information or to volunteer participation please contact:

**Shandra Burton, MSN, RN, PhD Student**

## 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



## 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.

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



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

## Daughterhood, The Podcast: A Conversation with C. Grace Whiting

The podcast spoke with C Grace Whiting, while she was serving as the president and

CEO of the National Alliance for Caregiving. They spoke right after the infrastructure bill had been passed but the provisions that addressed caregiving and other social services had been removed. They had such an extensive conversation covering many issues and emotions that caregivers deal with including where caregivers can find support, the range of emotions and trauma we experience in our journey and even how Wonder Woman fits into caregiving.

Click the red button below to listen to the podcast.

[LISTEN TO THE PODCAST](#)



## RESEARCH & RESOURCES



**JUST RELEASED!**

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

[DOWNLOAD NOW](#)



MADE POSSIBLE THROUGH SPONSORSHIP BY  
**AMGEN**

### **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**



## **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**



## **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**

## 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.

**LEARN MORE**



### 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](http://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](#)

[LEARN MORE](#)



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

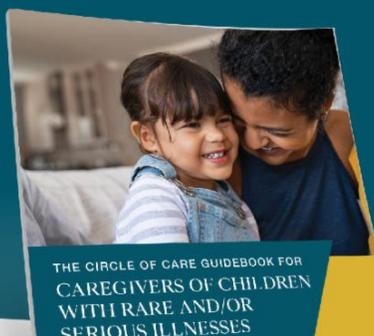
## Lessons from the Workplace: Caregiving During COVID-19

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.

**READ HERE**





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*

DOWNLOAD NOW





# 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

[SEE MORE](#)  
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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](http://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.

SEE MORE



## 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.

SEE MORE



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