

How Palliative Care Supports Caregivers in Policy and Practice

Scott Bane, JD, MPA

Jonathan Cottor, MBA, MPH

Stacie Sinclair, MPP

Salom Teshale, PhD

Center to
Advance
Palliative Care™

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Speakers



Scott Bane, JD, MPA
Senior Program Officer
The John A. Hartford Foundation



Salom Teshale, PhD
Senior Policy Associate
National Academy for State
Health Policy



Jonathan Cottor, MBA, MPH
Chief Executive Officer, Founder
National Center for Pediatric
Palliative Care Homes



Stacie Sinclair, MPP, CSW
Associate Director, Policy
Center to Advance Palliative Care

Objectives

- Describe the most pressing needs of caregivers for people living with serious illness
- Describe the relationship between palliative care and improved caregiver experience
- Identify opportunities to support caregiver policy initiatives

Audience Question

How do you support caregivers in your daily practice?

(Share in the chat!)



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CAPC/NASHP: The Intersection of Palliative Care and Caregiver Support



July 31, 2024

Scott Bane, JD, MPA

Senior Program Officer

The John A. Hartford Foundation



The
John A. Hartford
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A private philanthropy
based in New York City,
established by family
owners of the A&P
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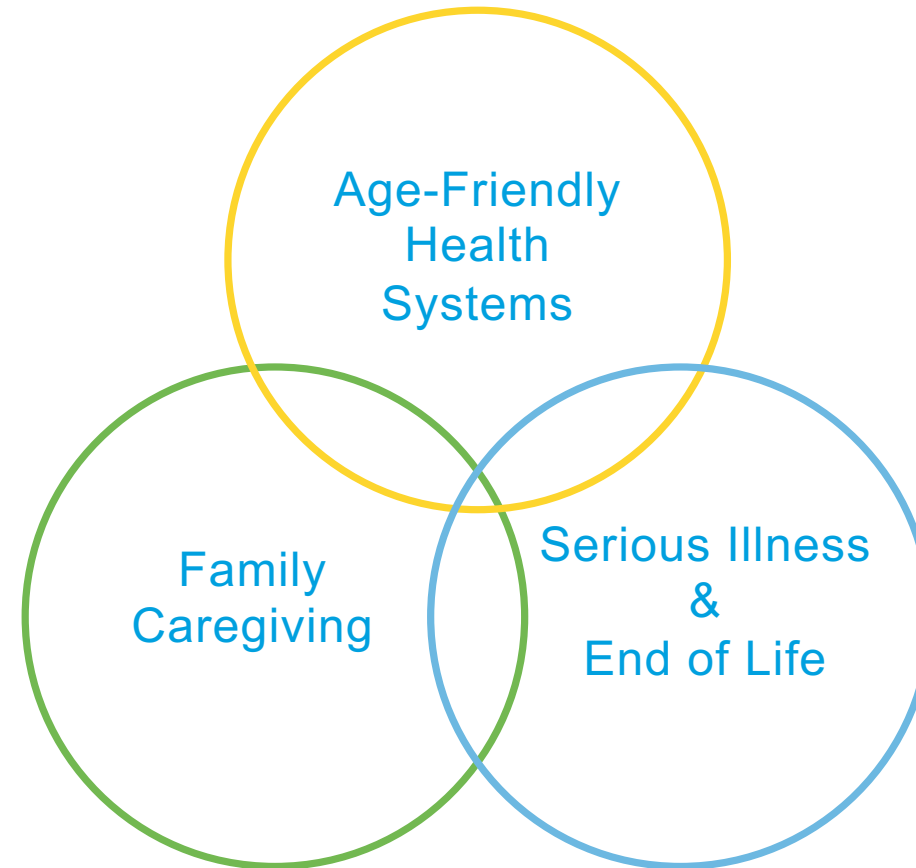
Mission & Priorities



The
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Foundation

DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

PRIORITY AREAS



DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

JAHF Serious Illness Grantmaking



The
John A. Hartford
Foundation

Promotes care that preserves dignity and honors the wishes of older adults and their families by:

- Increasing access to palliative care
- Developing approaches for preparing the health care workforce
- Fostering communication and community-based solutions while informing public policy



JAHF Family Caregiving Grantmaking



The
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Our grantmaking:

- Improves ability to support caregivers
- Raises awareness to drive change
- Creates large-scale change in partnership with national efforts





What is palliative care?

An interdisciplinary team-based specialty that:

- Provides an added layer of support for relief of pain, symptoms, and stresses of serious illness
- Focuses on patient and family quality of life alongside curative or life-prolonging treatment:
 - ✓ Curable illness
 - ✓ Chronic illness
 - ✓ Progressive/terminal illness





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Thank You!

Scott.Bane@johnahartford.org

WWW.JOHNHARTFORD.ORG

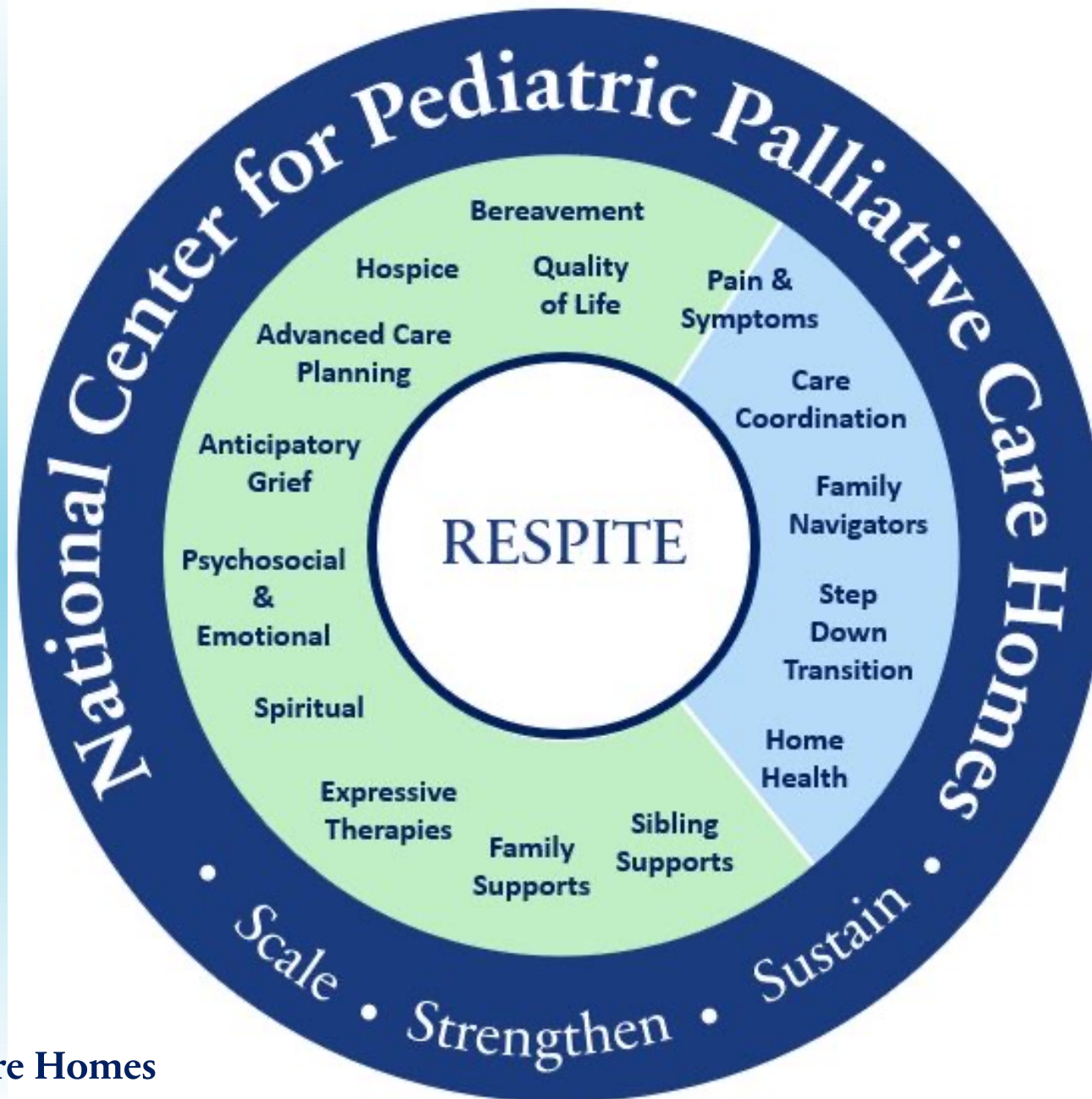
DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

Family Caregiver Perspective

Jonathan Cottor, MBA, MPH

**National Center for
Pediatric Palliative Care Homes**

ncppch.org



National Center for
Pediatric Palliative Care Homes



January 23, 2002
Ryan and Big Brother Ethan
9 mos.



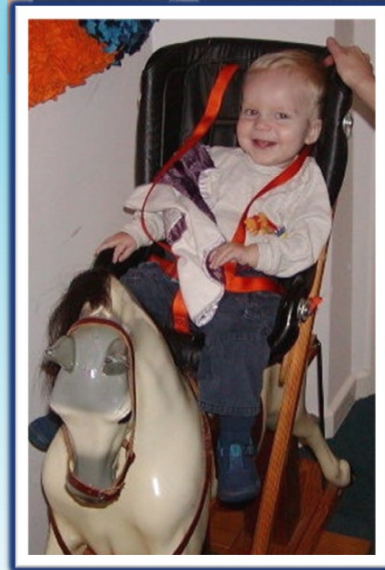
Ryan at 17 years





1982



National Center for
Pediatric Palliative Care Homes





+54  **= 266?** 

National Center for
Pediatric Palliative Care Homes





Lisa

to hello ▾

Thu, Aug 17, 2023, 12:38 PM



Hi! I'm really interested on information and how to be more involved in my own communities in order to found a pediatric hospice.

I would love to talk to someone to gain more knowledge, and direction, and possibly mentorship.

My name is Lisa I currently live in Tampa, FL and have a disabled daughter with a rare disease.



CHRA Website <jcottor@ncppch.org>

to hello ▾

Thu, Aug 24, 2023, 2:45 PM



My name is joline and I have over 20 years of experience working with pediatric patients with life threatening illnesses and Med fragile children. I have always wanted to open a pediatric respite home as there is a HUGE need in our islands. Any and all information you can help me with would be greatly appreciated!

Mahalo



Valorie

This is only a dream for so many of us. We've never been able to get respite. We've only had a day away from our child 4 times in almost 20 years...bless those who so this needed work. 🙏

1w Care Reply Hide



Why So Few Homes?

Unclear Licensing

- The system is designed for adults
- No clear licensing for children's programs

Lack of Funding

- Existing houses run mostly on philanthropy donations
- No appropriate Medicaid reimbursement



A Children's Respite Home is an extension of a family's own support and home.



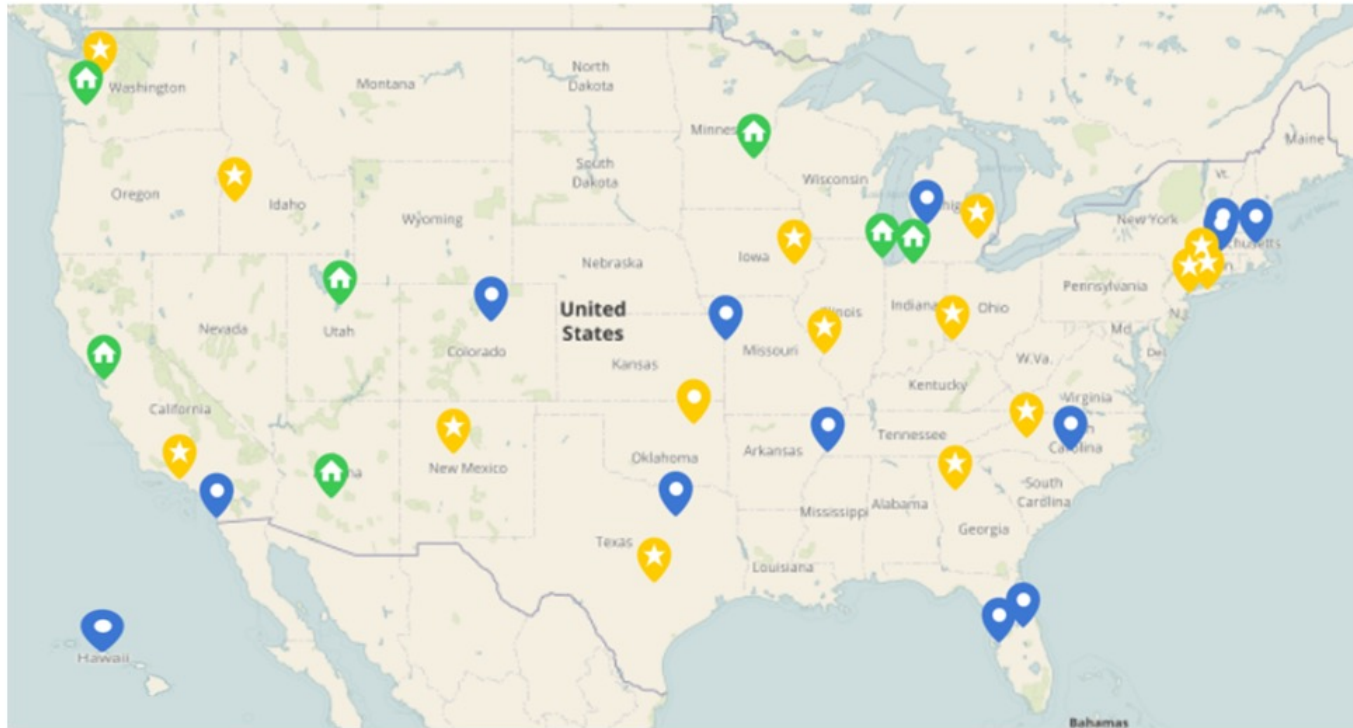
Existing Homes



Emerging Homes



Conversations Beginning



7 Existing

+ 17 Emerging

**+13
Beginning**

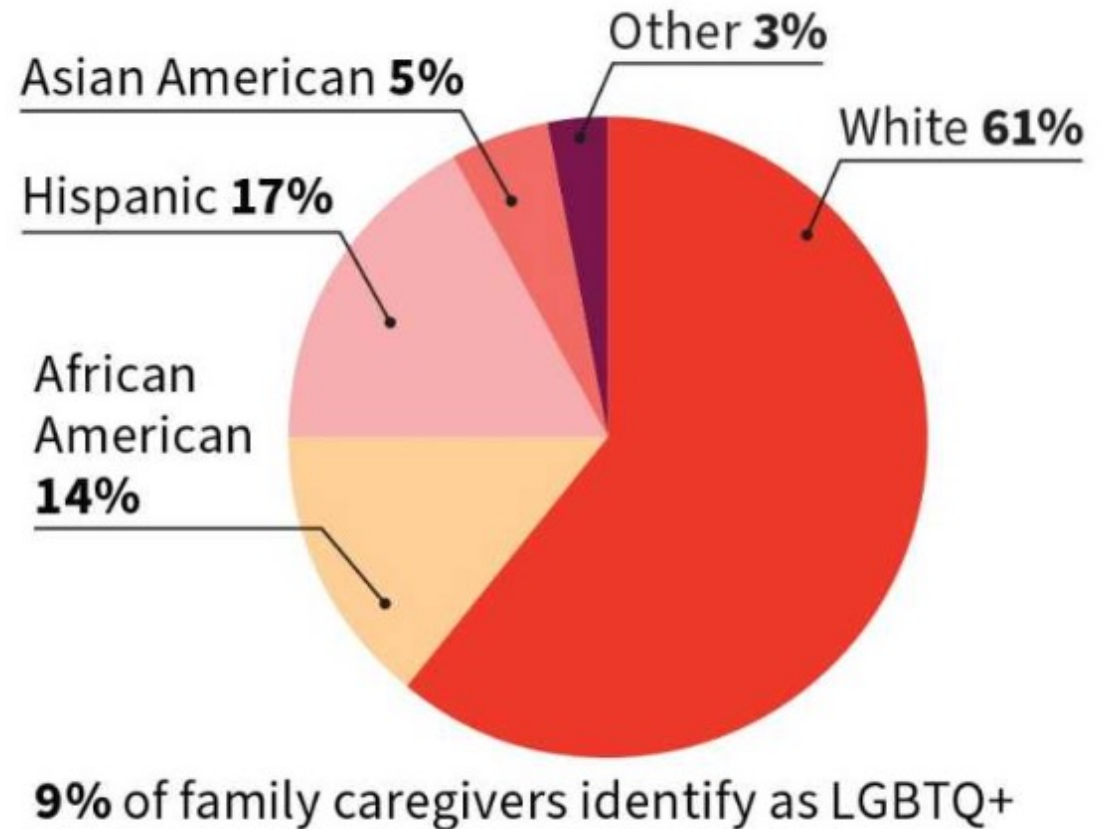
**= 37
25 States**

The Intersection between Palliative Care and Caregiving

Stacie Sinclair, MPP

Caregiver Profile

- Approx. 48 million family caregivers in U.S.; avg. 18 hours of care per week
- Tremendous diversity, with implications for care experiences and support needs



Caregiving Responsibilities and Impact

- Lifting
- Bathing
- Delivering Meals
- Transportation
- Handling Difficult Behaviors
- Managing Medications
- Navigating Family Dynamics
- Etc.

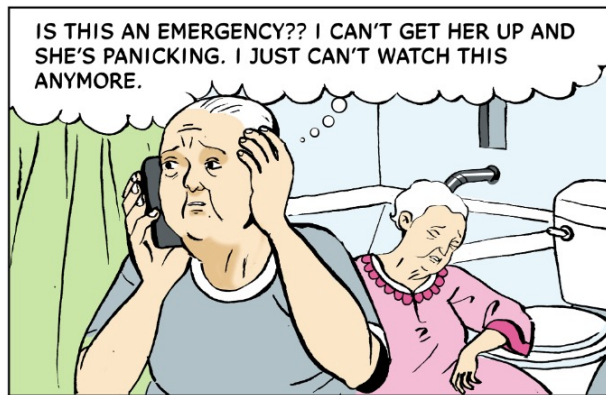
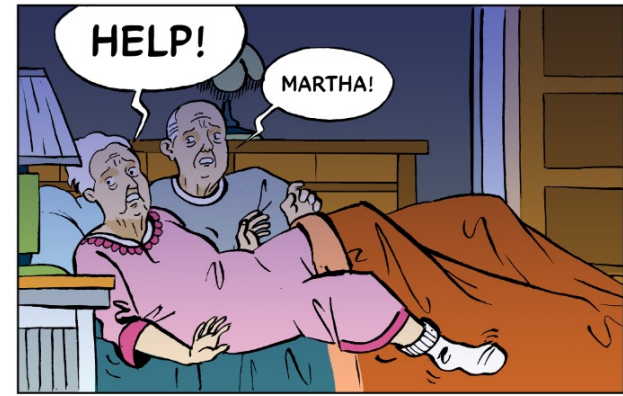
- Positive experiences – feeling of giving back, confidence in care quality, personal development, sense of meaning/purpose, etc.

AND ALSO

- High Stress
- Lost Work Hours/Job
- Decline in Physical and Mental Health

Caregiving Impact

- Informal caregiving associated with higher incidence of depression, anxiety, pain, hypertension, diabetes, and reduced QOL (Janson et al., 2022)
- Unpaid family caregivers lose \$522 billion in wages annually (Chari et al., 2015)
 - Leaving the workforce to care for a family member doubles the chances that a woman will end up in poverty (ASA, 2022)
- Productivity – 23.3% of ~8.8 mil caregivers reported absenteeism or presenteeism (Keita Fakeye et al., 2023)
 - Among those affected, est. \$5,600 annualized loss in productivity
 - Direct economic impact to the US is \$44 billion; combined with indirect impacts to \$264 billion (BCBS, 2021)



NCP Guidelines

Clinical Practice Guidelines for Quality Palliative Care

4th edition



Recognizing the changes to the practice of palliative care in all care settings, the **National Consensus Project for Quality Palliative Care** defines palliative care as follows:

Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, **their families and caregivers.** Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient **and the family.**

- Domain 1: Structure and Processes of Care
 - Criteria 1.2.3: The initial assessment includes conversations with the patient, family caregivers, clinicians, and others according to the patient's preferences
 - Criteria 1.2.4: The initial assessment ... is documented, and includes:
 - (i) Social and cultural factors and caregiving support, including caregiver willingness and capacity to meet patient demands
- Domain 2: Physical Aspects of Care
 - Criteria 2.2.7: The IDT assesses patient and/or caregiver cognitive and physical ability to manage medications and meet caregiving needs
 - Criteria 2.3.6: Caregivers are assessed, trained, and supported to provide safe and appropriate care to the patient, including medication administration, safe transfers, and use of medical equipment
- Etc.

Palliative Care Supports Caregivers by:

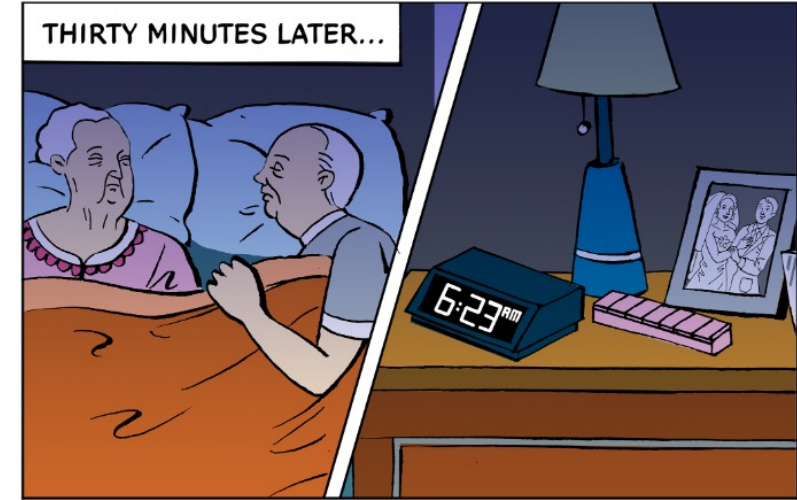
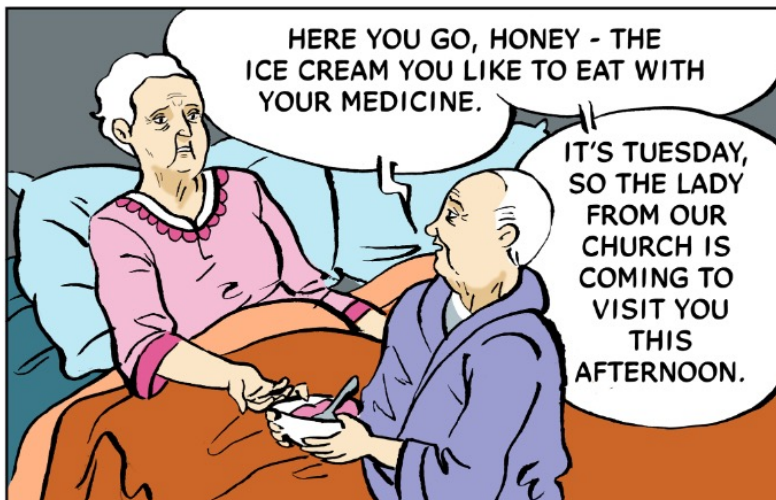
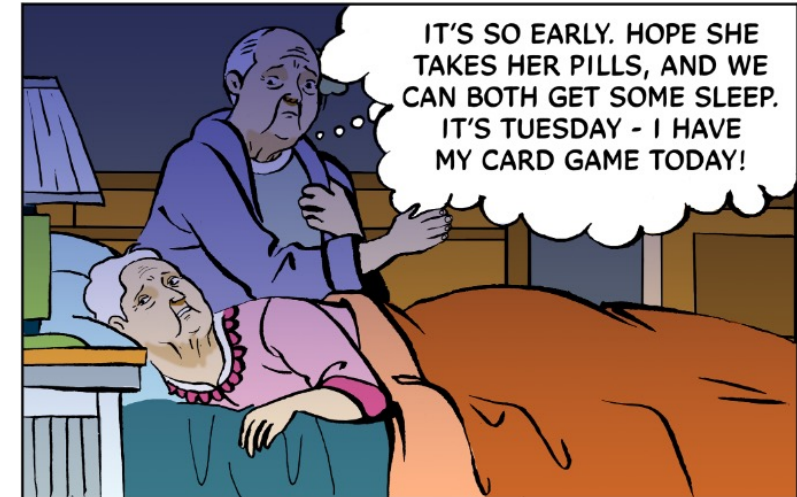
- Ensuring the caregiver stays informed
- Providing useful tools and resources
- Helping manage stress



Palliative Care Impact for Caregivers

- Statistically significant effect on overall caregiver quality of life, mental well-being, anxiety, and depression (Chow et al., 2023)
- Early involvement of pal care led to improvement in caregivers' psychosocial symptoms (El-Jawahri et al., 2017)
- Telemedicine in pal care reduced caregiving burden and anxiety of informal caregivers (Yang et al., 2024)

Martha and Bernard (with Palliative Care)



Supporting Caregivers of People With Serious Illness: A State Policy Perspective

July 31, 2024



Salom Teshale, Senior Policy Associate
Aging and Disability Team
steshale@nashp.org

About NASHP

The National Academy for State Health Policy (NASHP) is a nonpartisan organization committed to developing and advancing state health policy innovations and solutions.

NASHP provides a unique forum for the productive exchange of strategies across state government, including the executive and legislative branches.



Why is supporting family caregivers important?

- 53 million family caregivers provide care in the U.S. ([NAC and AARP](#))
- Family caregivers provide an est. \$600b worth of care ([AARP](#))
- Family caregivers support their loved ones in receiving care at home from people they know and trust
- Caregiver priorities: receiving training for complex care tasks, and information on navigating financial and health care systems ([“In Their Own Words: Caregiver Priorities and Recommendations,” LeadingAge LTSS Center at UMass Boston and Community Catalyst, 2021](#))

What current policy activity supports family caregivers?

- National activity
 - The RAISE Act and the 2022 National Strategy to Support Family Caregivers
 - [Medicare coverage of family caregiver training](#)
- State policy activity
 - Educational campaigns, outreach/awareness, and state task forces
 - Developing caregiver training opportunities
 - Respite

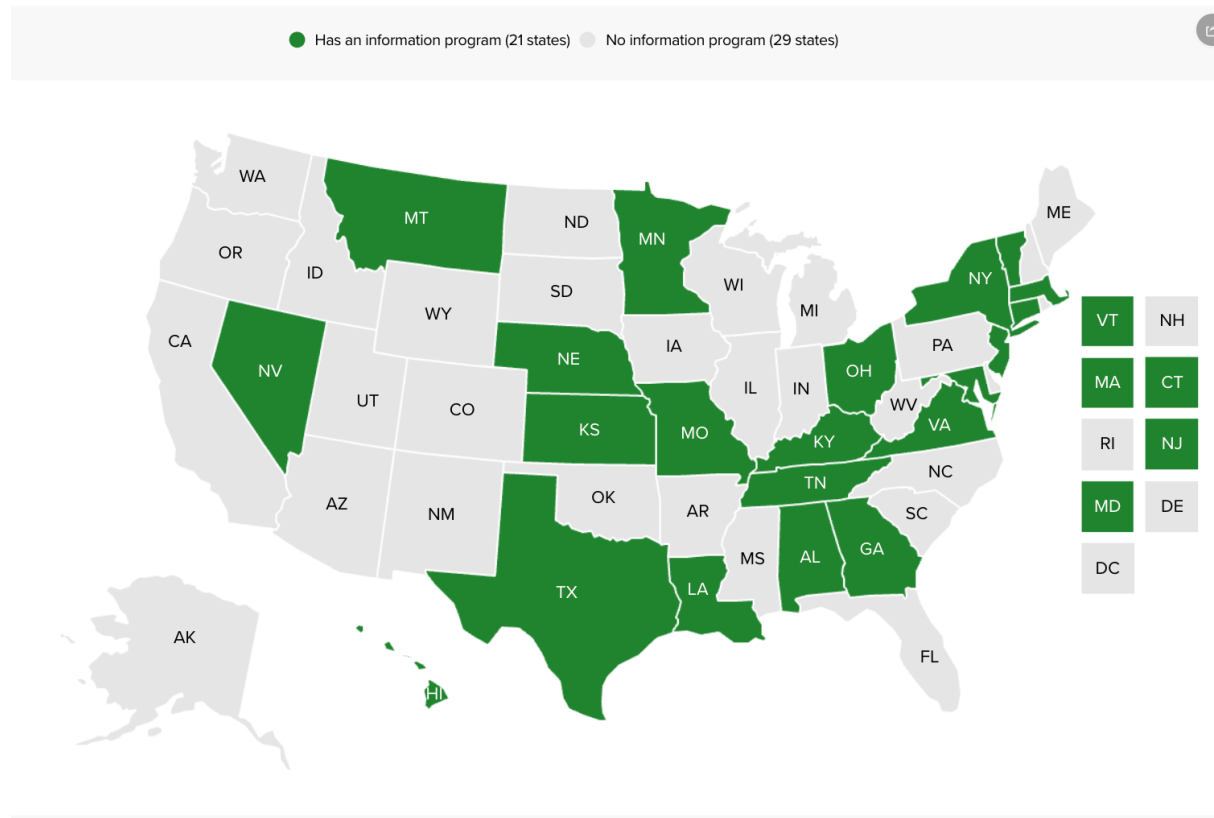
Policy activity supporting family caregivers

- Educational outreach
 - TX: [Supportive Palliative Care webpage](#)
 - GA: [What is Palliative Care? webpage](#)
- Developing caregiver training and caregiver support opportunities
 - MN: [Caregiver Consultants](#) program and [caregiver training](#) supports; [Stroke Patient Transitions of Care Toolkit](#)
 - WI: [Alzheimer's Family and Caregiver Support Program](#)

Policy activity supporting family caregivers

- Respite
 - Washington State
 - Oklahoma

States with Palliative Care Information Programs



Palliative care helps people with serious illness by reducing symptoms, stress, and hospitalizations — and increasing quality of life



By helping people better manage symptoms and make decisions about their care, research shows that palliative care services can lead to **positive outcomes**:

- ↓ Lower [service utilization and more cost savings](#) during the last three months of life
- ↓ 37% reduction in [Intensive Care Unit](#) admissions
- ↓ Lower [total costs of care](#)

Key Takeaways: Opportunities to support caregivers

- Assess caregivers for their needs and burden
- Provide opportunities for caregiver training
- Highlight to health care teams that the caregiver is part of the team (e.g. training on communicating with caregivers)
- Provide access to respite
- Provide outreach about and access to other caregiver support services

The RAISE Act Family Caregiver Implementation and Technical Assistance Center

HOME < AGING AND DISABILITIES < FAMILY CAREGIVING

TOPIC

Family Caregiving

The RAISE Act Family Caregiver Implementation and Technical Assistance Center



SHARE

Across the nation, state health programs depend on caregivers who provide critical support to help relatives, friends, and neighbors age in place while contributing about [\\$600 billion in unpaid health care services](#). To better support family caregivers, Congress passed the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) in 2018, which established the Family Caregiving Advisory Council tasked with creating the country's first national Family Caregiver Strategy. NASHP supports the council's

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nashp.org/family-caregiving

Featured Content



[Resources for Family Caregivers](#)



[The Family Caregiving Advisory Council and Faculty](#)



[Council Meeting Materials and Resources](#)



[State Resources](#)



[Resolve Care](#)



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SupportCaregiving.org



**SUPPORT
CAREGIVING**

Fulfilling the National Strategy to
Support Family Caregivers in Your Community

RESOURCE GUIDES ▾

ABOUT

WHO WE ARE



A new, first-of-its-kind [National Strategy to Support Family Caregivers](#) provides hundreds of actions that federal, state, and local governments, businesses, and communities can take to support caregivers.

Explore the resource guides on this site to find out what you can do to help caregivers achieve the balance and stability they need for their families – and for themselves.



nashp.org

What You Can Do

We all can work together to lighten the load for family caregivers. Explore the resource guides on this site for strategies that you can take to better support family caregivers.

Each guide provides concrete actions for a specific source of potential caregiver support – check back here as more are added!

Resources for:

[Family Caregivers >](#)

[Employers >](#)

[Funders >](#)

[Managed Care Plans >](#)

Resources for State Officials:

[Respite Care >](#)

[Direct Care Workforce >](#)

[State Policy Strategies >](#)

Resource Guide Examples



Respite Care Resource Guide

Respite care is a service typically delivered in the home or a community, faith, or facility-based setting that provides short-term relief for caregivers. It is one of the most desired services by caregivers who report that they need a break.

The Challenge

Despite the demand for this service, many family caregivers do not receive it. Challenges include a lack of trust of unknown providers to provide care, especially in homes; difficulty in finding and paying for quality providers; and rigid program policies that limit the types of respite providers (e.g., those that do not allow for family, friends, and known providers to provide respite).

A Historic Opportunity

The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SORG) developed a [National Strategy to Support Family Caregivers](#) that is now ready for implementation. Released to Congress in September 2022, this comprehensive strategy identifies actions for the federal government to take and lays out actions for states, communities, health care systems, long-term support and service providers, researchers, employers, philanthropic organizations, and many others to support family caregivers. Respite care is a key component of this strategy.

State Action Guide

The ARCH National Respite Network and Resource Center created a Learning Collaborative of state administrators and their partners. In partnership with the National Academy for State Health Policy (NASHP), the Learning Collaborative created this roadmap for states that want to implement the respite actions identified in the National Strategy. The roadmap can support states interested in building or expanding respite care for family caregivers by offering the following policy strategies and promising practices.

Supporting Caregivers in the Workplace



Addressing caregiving responsibilities while in the workplace will likely affect most — if not all — workers at some point. It is estimated there are [53 million people](#) providing informal, often unpaid care to loved ones in the United States. Without proper support, these workers must juggle significant familial and professional responsibilities that can either hinder their ability to work or completely remove them from the workforce. The loss of income connected to family caregiving amounts to an estimated [\\$522 billion each year](#).

Employers that wish to help their workers with caregiving responsibilities may not know where to begin. The [National Strategy to Support Family Caregivers](#) — developed jointly by two U.S. advisory councils, with extensive input from the public — includes nearly 500 actions that can be adopted at every level of government and across the public and private sectors. As HR professionals, [SHRM](#) members drive positive workplace policies that create better workplaces and better worlds. Organizations need to assess their ability and capacity to offer support for their workers.

As a starting point, SHRM recommends HR practitioners take the following three steps:

- 1. Design benefits that reflect the needs of your workers with caregiving responsibilities.** While every employer is not able to offer the same benefits, offering benefits that would appeal to workers with caregiving responsibilities is a way to attract and retain top talent while enabling the worker to remain in the workplace. Shaping benefits to accommodate these workers will signal the organization's support of caregivers. While differences in organizational size, industry and profit-level will affect the level of benefits, below are some suggestions to consider:
 - a. Flexible work arrangements** such as allowing family caregivers to use flexible work hours, compressed work weeks, paid leave programs that allow for "life events," telework or structuring job descriptions around tasks that can be completed remotely at flexible times of day.
 - b. Financial wellness benefits** — including access to emergency funds, financial planning, and tuition and student loan assistance — offer an important promise of financial health and security. They can also be welcome incentives when choosing a new workplace, as caregivers often face financial costs associated with the direct cost of care, loss of income due to missed work and diminished earning capacity due to prolonged absences from the workforce.
- 2. Financial wellness programs** typically seek to improve employees' "financial literacy" by addressing challenges and include programs like webinars, online articles, interactive tutorials, in-person meetings and/or virtual "lunch 'n learn" sessions.
- 3. Additional benefits** such as dependent care flexible spending accounts; health care offerings that allow for telemedicine; subsidized or unsubsidized childcare centers or programs; eldercare centers or programs; employee assistance programs (EAPs) and other referral services; and emergency child/eldercare benefits.



Resource Guide for Family Caregivers

The [2022 National Strategy to Support Family Caregivers](#) provides a first-ever roadmap to improve access to information, services, and resources for family caregivers of all ages — from youth to grandparents. The National Strategy was presented to the U.S. Congress in 2022. Although the National Strategy alone will not create or expand services, and additional work is needed to increase access to resources, many resources are currently available. This guide presents a "how to" for family caregivers to learn about some of the existing resources that align with the areas of focus outlined in the National Strategy.

Resources that Raise Awareness and Outreach for Caregiver Needs

Some resources are designed to help family caregivers manage personal challenges they face. Resources include:

- Take care of [your own health and well-being](#) because caregiving, particularly if you are caring for a person with Alzheimer's disease or a related dementia, can be rewarding but overwhelming.
- [Support those](#) who are experiencing mental health challenges by reaching out to them, asking them how they are doing and if you can help.
- [Stay socially connected](#) and prevent loneliness and isolation.
- Join the [Act on RAISE campaign](#) to help accelerate the implementation of the National Strategy to Support Family Caregivers.

Resources about Being a Member of the Care Team

Family caregivers are often called upon to deliver complex medical care with little to no training, but these online resources can help:

- Access helpful online training for caring for people with [dementia, cancer, and rare diseases](#), as well as caring for [older adults](#) and doing [caregiving from a long distance](#).
- Help with [medications and medical devices](#).
- Collaborate more effectively with [professional caregivers](#).

SupportCaregiving.org

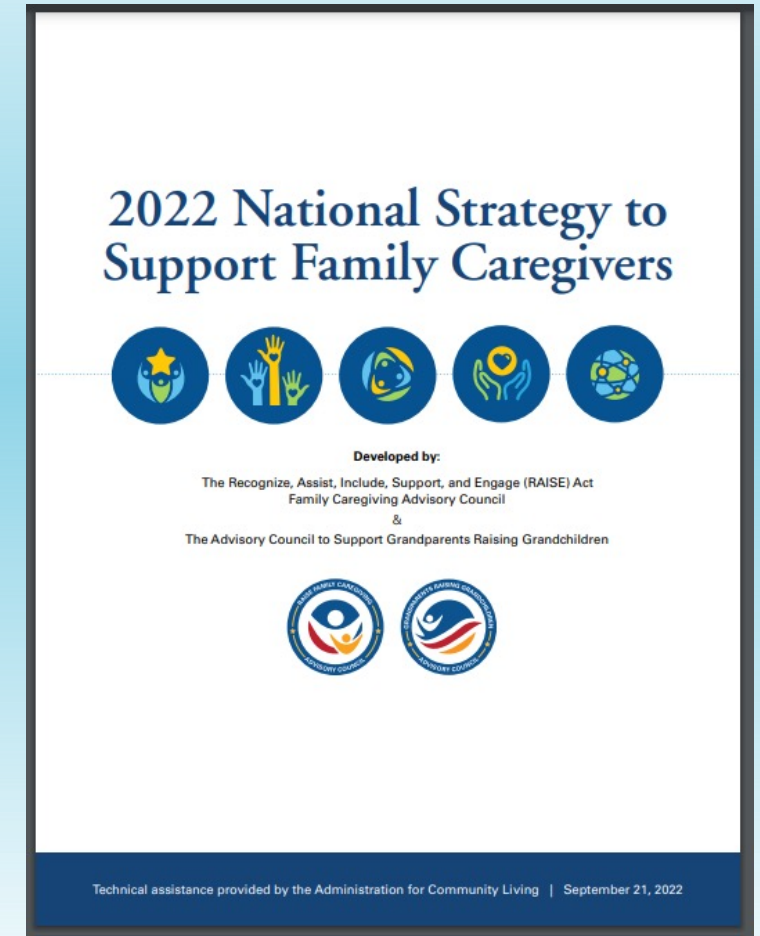


nashp.org

The National Strategy to Support Family Caregivers

- Released in 2022 – nearly 350 federal government actions, over 150 state and private sector actions

<https://acl.gov/CaregiverStrategy>



Audience Question

What do you see as the highest priority area to better support the needs of caregivers right now?

Questions?

Questions

Comments

Feedback



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55 West 125th Street

13th Floor

New York, NY 10027

347-802-6231

capc.org

Resources/References

- <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>
- <https://ryanhouse.org/>
- <https://childrensrespitehomes.org/>
- <https://www.johnhartford.org/>
- <https://nashp.org/palliative-care/>
- <https://supportcaregiving.org/>

Resources/References (cont'd)

- <https://getpalliativecare.org/palliative-care-helps-the-caregiver-too/>
- <https://nashp.org/policy/aging-and-disabilities/family-caregiving/>
- <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- <https://www.aarp.org/caregiving/>