C-TAC
COALITION TO TRANSFORM ADVANCED CARE

NATIONAL ALLIANCE FOR CAREGIVING

NOT JUST VISITORS: INTEGRATING FAMILY CAREGIVERS IN CARE DELIVERY AND DESIGN

On behalf of C-TAC and the National Alliance for Caregiving, we are truly grateful to the Elea Institute for their generous grant, which makes this work possible and strengthens our mission to better serve caregivers and families.

Released 09/2025

Background

> ***"I have taken my mom to probably 100 doctor appointments, and no one ever asked me about my health… it seems Medicare needs to educate doctors."*** *Family Caregiver,*
> *Public Comment on the National Strategy to Support Family Caregivers*

Essential Insights

- **Family caregivers provide essential, high-value care—yet remain undertrained, unsupported, and largely excluded from care delivery systems.** Despite contributing an estimated $600 billion in unpaid labor annually, many caregivers of seriously ill individuals face significant emotional and financial strain, receive little or no training, and lack access to support.

- **Policy and payment reform offer a timely opportunity to better integrate and support caregivers.** With bipartisan momentum behind initiatives like the Alleviating Barriers for Caregivers Act (ABC Act), and the National Strategy to Support Family Caregivers, along with promising models like CMS's GUIDE, there is a clear path to embed caregiver supports into health care delivery—particularly for populations with serious illness.

Behind the Issue

The U.S. population is aging rapidly, with the number of adults aged 65 and older expected to grow by 47%—rising from 58 million in 2022 to 82 million by 2050. As people live longer and increasingly wish to remain at home or in the community, the need for caregivers will also increase. This demand is especially urgent and multifaceted for individuals with serious illness, who often require complex, continuous, and personalized care. Reflecting this growing need, the number of family caregivers supporting older adults, people with serious illness, and individuals with disabilities has surged by 45%—from 43 million Americans in 2015 to 63 million in 2025.

Caregiving takes many forms. Some individuals receive care from professional caregivers such as home health aides, personal care attendants, or other direct care workers who are typically employed by health care organizations or agencies and operating within a defined regulatory structure. But due to significant workforce shortages and personal preference, many people rely instead on unpaid caregivers, including family members and close friends (subsequently referred to as family caregivers). These family caregivers, who reflect nearly 25% of the U.S. population, provide critical support—particularly for people with serious illness—yet they often do so without compensation, training, or formal recognition.

According to a 2023 AARP report, the economic value of family caregiving is estimated at $600 billion annually. Yet despite this enormous contribution to the health care system, these caregivers face considerable burdens, especially when caring for seriously ill individuals. Challenges include high emotional and physical stress, financial insecurity, and limited access to guidance on managing medical and social needs.

Tackling these challenges demands tailored strategies that account for the distinct experiences of family caregivers, especially those caring for loved ones with serious illness. Traditional professional development approaches such as career ladders or apprenticeship programs may not fully meet the needs of these caregivers. Instead, new investments must prioritize training, respite, emotional support, and flexible financial resources to sustain and expand this essential workforce.

Importantly, momentum is building now for policy and programmatic innovations related to family caregiving, just as the need becomes more urgent. Bipartisan initiatives such as the Alleviating Barriers for Caregivers Act (ABC Act) and the RAISE Family Caregivers Act of 2017 have elevated the issue nationally. Additional efforts, including the National Strategy to Support Family Caregivers, have reinforced the urgency of transforming healthcare delivery. In particular, Goal 2 of the Strategy emphasizes the importance of health and social care organizations meaningfully engaging family caregivers, making system-level change not just necessary, but timely and actionable.

This federal focus comes at a critical juncture, as states face mounting fiscal pressures from the wind-down of pandemic relief funds, reduced tax collections, and forthcoming Medicaid enrollment and coverage changes. With Medicaid's capacity to finance caregiver supports increasingly constrained, it will be essential for all payers, including Medicare fee-for-service and Medicare Advantage, to support models that include caregiver components. This shared responsibility highlights the urgency of incorporating caregivers more systematically across a range of payment and care models.

In response, the Coalition to Transform Care and the National Alliance for Caregiving engaged experts and examined promising practices to inform action at this pivotal moment. This brief summarizes the most pressing challenges identified through those conversations and outlines emerging opportunities to integrate caregiver support into current health care payment and care models.

Key Challenges:

> ***"The hardest part for me is you really do become a tech in a way. You have to do things like the port, and I deal with things like the dosage of the medication, and it wasn't easy."*** *—Nancy, Family Caregiver, New Jersey*

Limited familiarity among family caregivers with best practices in caregiving

Most family caregivers receive little to no training in the medical or logistical tasks they are expected to perform, ranging from wound care and medication management to navigating insurance and coordinating services. This lack of preparedness is particularly problematic for caregivers supporting individuals with serious illness, who often require complex care over extended periods. A 2025 NAC/AARP survey found that while 55% of family caregivers perform medical/nursing tasks, only 22% received any training for these responsibilities.

Even more concerning, just 11% of caregivers received formal training to assist with activities of daily living (ADLs) or behavioral management, despite 65% helping with at least one ADL and 84% assisting with three or more Instrumental ADLs (IADLs). Nearly one in four caregivers (23%) report difficulty performing these tasks, yet when training is provided, 96% of caregivers feel well-prepared, highlighting both the critical gap and the proven value of caregiver preparation.

> *"I had to give up a prosperous career and took jobs to work around their schedule. I took a 90% pay cut and lived out of my savings, which has been depleted."*
>
> *—Maylia, Family Caregiver, California*

Caregivers face significant challenges in maintaining employment or meeting other obligations while supporting caregiving

Caregivers typically face substantial financial hardship, especially when supporting seriously ill loved ones who require daily or round-the-clock care. Many reduce work hours, use personal savings, or leave the workforce entirely. According to the AARP Valuing the Invaluable Report, the unpaid labor of family caregivers was valued at $600 billion annually, yet this contribution comes with deep personal costs. A separate National Alliance for Caregiving report found that over 20% of caregivers had to take a leave of absence, while 10% lost their jobs due to caregiving responsibilities. These challenges are even more acute for caregivers of seriously ill individuals, who often cannot plan around episodic or crisis-based needs.

While some states have introduced reimbursement for caregivers through Medicaid, and select Medicare Advantage plans have begun offering financial supports, Medicare's original structure does not currently allow for direct caregiver reimbursement—posing a significant barrier to broader financial relief. Federal legislation would be required to make such support available within traditional Medicare, complicating efforts to provide or incentivize more accessible, nationwide assistance.

Training alone might not incentivize or support adequate, high-quality caregiver engagement

While caregiver training programs are critical, they are rarely sufficient on their own. Effective caregiver support requires a system of wraparound resources, including flexible financing, care navigation, respite, and clinical inclusion. One study found that training alone did not reduce caregiver burden unless paired with emotional support and systemic engagement. For caregivers of people with serious illness, these supports are especially important due to the complexity and emotional intensity of the caregiving role.

> ***"We [family caregivers] are under-rated, and I think the world has no idea what we do. Being a caregiver is the hardest role."***
>
> *—Maylia, Family Caregiver, California*

Caregiver burden is significant and while proactive planning strategies like advance care planning exist, these tools are largely oriented around individuals experiencing illness rather than caregivers

Caregiver stress and burden are widespread, particularly among those supporting individuals with serious illness, functional decline, or cognitive impairment. According to the NAC and AARP Caregiving in the US report noted previously, 40% of caregivers report high emotional stress, and nearly one in four describe their own health as fair or poor. For those caring for individuals with serious illness, the emotional and logistical toll is even greater due to intense, round-the-clock responsibilities and frequent care transitions. Despite the prevalence of burnout, most existing supports focus narrowly on the care recipient, with few resources tailored to caregivers' own well-being or anticipatory grief.

Caregivers remain underrecognized in healthcare models

Despite their essential role, family caregivers are rarely seen as part of the care team. They are typically excluded from care planning discussions, discharge instructions, and quality improvement processes. This lack of visibility undermines both caregiver and patient outcomes. A National Academies report emphasized the need for formal caregiver inclusion in care teams and reimbursement structures. More recent policy frameworks, such as those included in the National Strategy to Support Family Caregivers, highlight the missed opportunity to engage family caregivers as active partners in improving care quality, particularly in high-need populations.

The Guiding an Improved Dementia Experience (GUIDE) Model represents a promising step toward addressing this gap. Launched by CMS in 2024, GUIDE explicitly recognizes care partners as integral members of the dementia care team, providing them with training, respite services, and a 24/7 support line. This model demonstrates how care delivery models can be redesigned to formally incorporate family caregivers, offering a blueprint for expanding this approach to other serious illness populations. By providing dedicated resources for caregiver support services, GUIDE validates the essential role of family caregivers and creates a sustainable framework for their inclusion in care delivery. Critically, within the GUIDE Model, family caregiver support is required and not an optional support.

Key Challenges:

The table below outlines strategies and investment areas for healthcare partners and policymakers to consider when embedding family caregiver supports into healthcare payment and care models to address the key challenges discussed above:

Healthcare Payment Structure	Detail	Current Examples	Options for Integrating or Enhancing Caregiver Supports
Fee-for-service (FFS) – Accountable Care Organizations (ACOs)	These models are designed to serve a relatively broad population, but may include sub-populations with serious illness care needs.	• Medicare Shared Savings Program • ACO REACH	• Allow ACOs to use global budgets flexibly to support caregivers (e.g., transportation, food, in-kind goods). • Incorporate caregiver training and needs assessments into ACO workflows. • Track and reward ACO performance for caregiver engagement (e.g., inclusion in care planning, reduced burnout).
FFS – Specialty Care Models	These models, by definition, focus on specific sub-populations or populations experiencing a specific clinical experience (e.g. surgery) and may be exclusively focused on populations with serious illness.	• Kidney Care Choices • Oncology Care Model • Transforming Episode Accountability Model (TEAM)	• Mandate structured care planning that includes caregivers. • Include reimbursable caregiver training as a core benefit. • Support caregiver stipends or non-monetary incentives (e.g., care coordination, in-kind supports). • Develop research pilots that test impact of caregiver support on outcomes (e.g., hospitalizations, adherence).
FFS	Refers to transactional health care payments	• Medicare Physician Fee Schedule • Part B Coding	• Continue to expand CPT codes for caregiver training services (CTS) (especially virtual) and promote wider adoption among eligible healthcare providers. • Promote wider adoption of the utilization of caregiver risk assessments during eligible visits. • Encourage inclusion of caregiver-reported needs in clinical documentation or care quality metrics.
Plan-based approaches	Medicare Advantage	• Special Supplemental Benefits for the Chronically Ill (SSBCI)	• CMS should strengthen data collection and public reporting requirements for MA supplemental benefits to ensure these widely marketed benefits actually serve beneficiaries. • Encourage or require MA plans to offer supplemental benefits that directly support family/unpaid caregivers of enrollees with serious illness, dementia, or functional impairment. Examples of supports: • Respite care • Caregiver training and education • Transportation or home modifications that ease caregiver burden • Access to a care manager or coach

Conclusion

As demographic pressures intensify and serious illness care becomes more complex, the role of family caregivers will only grow in significance. Without targeted investment and supportive policy infrastructure, our caregiving system will buckle under mounting pressures: unmet needs, financial hardship, and critical workforce shortages.

Yet this moment presents unprecedented opportunity. Policy momentum is building with bipartisan and public awareness is rising as one in four Americans now serve as family caregivers. Innovative care models like GUIDE are demonstrating how to meaningfully integrate and support caregivers as essential members of the care team.

Strategic investment now can catalyze transformative change, creating sustainable systems that recognize family caregivers as partners, improve outcomes for seriously ill patients, and reduce long-term healthcare costs. By acting decisively at this inflection point, we can build a care infrastructure that honors the vital contributions of family caregivers while ensuring they have the training, support, and resources needed to sustain this essential work.

About CTAC

The Coalition to Transform Advanced Care (C-TAC) is a national, bipartisan alliance of over 200 organizations dedicated to improving care for people with serious illness and their families. C-TAC works across health systems, policy, and communities to ensure that individuals receive person-centered, equitable care aligned with their values and needs. The organization advances this mission through policy advocacy, delivery system reform, public engagement, and cross-sector collaboration. C-TAC also leads initiatives to integrate family caregivers into care models, promote culturally appropriate care, and support innovation that improves quality of life for those facing advanced illness.

About NAC

The National Alliance for Caregiving (NAC) is a catalyst for change, transforming how the United States recognizes, supports, and values its more than 63 million family caregivers providing complex care for older adults, people with a serious illness, or a disability. Through our nationally recognized caregiving research and advocacy, we drive policy, system, and culture change to elevate family caregivers as a national priority. NAC fosters partnerships across aging, disability, healthcare, philanthropy, and the private sector with the goal of making family caregiving more sustainable, equitable, and dignified

Acknowledgements

C-TAC and the National Alliance for Caregiving are grateful for the support of the Elea Institute through the Partnership to Improve Quality of Life for Patients and Caregivers Impacted by Serious Illness. This report was prepared by Hope Glassberg, President, Decipher Health Strategies, in collaboration with staff from C-TAC and the National Alliance for Caregiving.