

Advancing Access, Affordability, and Innovation Through a Family Caregiver Lens

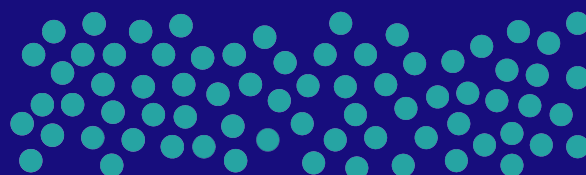
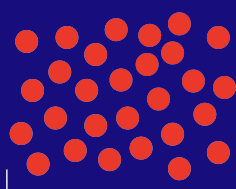
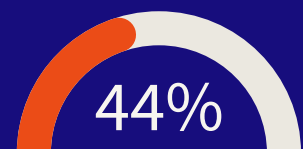
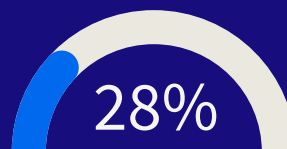
2026 Policy Priorities

Our nation's 63+ million family caregivers are essential partners in care to patients across the spectrum of diseases and conditions. Not only are family caregivers patients themselves, but they play also a critical role in helping patients through diagnosis, follow treatment plans, manage and administer medications, monitor symptoms and side effects, coordinate care across multiple providers, and ensure continuity of care at home. Despite their essential contributions, family caregivers often face significant barriers including financial strain, navigating fragmented systems, little education and support, and limited inclusion in care planning. This policy agenda focuses on addressing these barriers and strengthening caregiver engagement to improve patient outcomes.

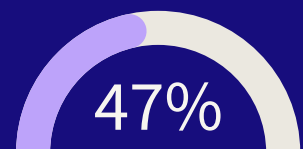


What the *Data* Show

The National Alliance for Caregiving's Caregiving in the US 2025 research, conducted in partnership with AARP, illuminates the emotional, physical, and financial toll shouldered by today's 63+ million family caregivers – along with the persistent barriers they face accessing affordable, coordinated care. These findings are not abstract statistics; they reflect the daily realities of families stretched thin by a fragmented healthcare system. NAC grounds its policy agenda in this evidence, advancing solutions that directly target the access and affordability gaps caregivers encounter every day.



28% of lower-income caregivers (under \$50,000 household income) cannot afford basic expenses.



Improving Access to Quality Healthcare

Family caregivers navigate complex healthcare systems on behalf of their care partners and themselves yet face persistent barriers to accessing appropriate care. We advocate to:

- **Reform burdensome prior authorization and step therapy protocols** that delay access to critical treatments and force caregivers to spend excessive time on administrative tasks.
- **Expand Medicare coverage** of additional in-home health benefits for beneficiaries and their family caregivers.
- **Expand access to innovative screening and preventive services** that reduce the burden of serious illness and chronic conditions on family caregivers and those they care for.
- **Expand telehealth** access for the delivery of family caregiver support, training services, and care coordination, particularly for caregivers in rural and underserved communities.
- **Reduce administrative burden** on family caregivers navigating Medicare, Medicaid, and related programs through tailored engagement and education.
- **Expand caregiver navigation programs** that provide professional guidance to help caregivers understand benefits, coordinate care, and make critical treatment decisions.

Improving Affordability of Complex Care

Nearly half of all family caregivers face negative financial impacts such as going into debt, depleting savings, and struggling to afford care. Addressing affordability is essential to sustaining family caregivers and the people they care for:

- **Eliminate copay accumulators, copay maximizers, and alternative funding programs** that prevent caregivers and their care recipients from accessing needed treatments and realizing the full benefit of manufacturer assistance programs.
- **Reduce out-of-pocket costs** for prescription drugs and special treatment through reforms to cost-sharing structures that disproportionately burden family caregivers managing complex, chronic conditions.
- **Reform 340B program** to ensure drug discounts are directly benefiting the patient. Reducing these expenses will lessen the financial burden on family caregivers navigating complex care.

Advancing Innovation and Caregiver Inclusion

Family caregivers are crucial contributors to innovation. As treatment options become more specialized and often more complex, family caregivers are even more vital. Family caregivers are not just supporters; they are key partners in ensuring that the benefits of innovation reach patients safely and effectively. We support:

- **Strengthen Center for Medicare and Medicaid Services (CMS) and Food and Drug Administration (FDA) recognition of caregiver burden and hardship** in regulatory decision-making positioning caregivers as integral members of the patient's healthcare team.
- **Advance patient and caregiver engagement** in drug development process including clinical trial design.
- **Encourage the FDA to issue guidance requiring the inclusion of caregiver-reported outcomes and caregiver burden assessments** in clinical trial design for therapies that will be administered at home.
- **Support the collection of real-work evidence** that captures caregiver impacts including time burden, training requirements, and quality of life as a part of post-market surveillance and coverage determinations for complex therapies.



Examples of Legislation NAC Supports to Advance Access, Affordability & Innovation

Alleviating Barriers for Caregivers (ABC) Act

The bipartisan ABC Act would reduce the administrative burden family caregivers face when navigating Medicare, Medicaid, and related federal programs. Family caregivers spend significant time managing paperwork, coordinating benefits, and cutting through bureaucratic barriers - time better spent on care. The ABC Act streamlines these processes, ensuring caregivers can focus on what matters most while accessing the supports and services their families depend on.

Alzheimer's Screening and Prevention (ASAP) Act

The bipartisan ASAP Act would give the Secretary of Health and Human Services authority to approve Medicare coverage of blood test screenings for dementia - a step that could reshape the caregiving journey for millions of families.

HELP (Help Ensure Lower Patient) Copays Act

The HELP Copays Act would require that manufacturer copay assistance counts toward patients' cost-sharing requirements, protecting caregivers and their care partners from arbitrary insurance barriers that drive up costs and complicate access to essential treatments. This legislation directly addresses a critical affordability gap that disproportionately burdens family caregivers navigating specialty medications and complex treatment regimens.



About the National Alliance for Caregiving

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