



**National Patient
Advocate Foundation**

The Patient's Voice | *since 1996*

Addressing the Burdens Associated with Serious Illness: Policy Solutions for Patients and Caregivers

**The 11th Annual National Conference of Caregiver Advocates
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Our Mission

To bring patient voices to health system delivery reform by promoting equitable access to affordable, quality healthcare through advocacy action and public and private partnerships.



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Patient Advocate Foundation



501(c)(3) national non-profit which provides professional case management services to Americans with chronic, life threatening, and debilitating illnesses.

Seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment, and preservation of their financial stability.

NPAF Policy Priorities



EQUITABLE ACCESS

“Repeal and Replace” Activity
Affordable Care Act

Medicaid Eligibility

Coverage Issues:
Benefit Design and
Utilization
Management

AFFORDABILITY

Medical Debt and
Balance Billing
Protections

Cost of Living
Burdens

Limiting Out-of-
Pocket Costs

QUALITY HEALTHCARE

Value-Based Care
Delivery

Palliative Care and
Quality of Life

A black and white photograph of two hands, one younger and one older, forming a heart shape. The hands are positioned in the center of the frame, with the fingers of each hand curving towards the center to create the heart's outline. The background is plain white.

Is Family Caregiving the Next Public Health Crisis?

Social, Psychological and Financial Burden on Caregivers of Children with Chronic Illness: A Cross-sectional Study.

Khanna AK¹, Prabhakaran A², Patel P², Ganjiwale JD³, Nimbalkar SM^{4,5}.

Caregivers of patients with amyotrophic lateral sclerosis: investigating quality of life, caregiver burden, service engagement, and patient survival.

Burke T^{1,2}, Galvin M³, Pinto-Grau M^{3,4}, Lonegan K^{3,4}, Madden C³, Mays I³, Carney S^{3,4}, Hardiman O^{3,5}, Pender N^{3,4}.

A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities

Jennifer L. Wolff, PhD; Brenda C. Spillman, PhD; Vicki A. Freedman, PhD; Judith D. Kasper, PhD

Roles of Changing Physical Function and Caregiver Burden on Quality of Life in Stroke

A Longitudinal Dyadic Analysis

Gianluca Pucciarelli, Ercole Vellone, Serenella Savini, Silvio Simeone, Davide Ausili, Rosaria Alvaro, Christopher S. Lee, Karen S. Lyons

Patient and Caregiver Burdens

Caregivers

Emotional stress

Financial strain

Job retention

Decreased quality of life / inability
to complete activities of daily
living

Patients

Emotional stress

Financial strain

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Medical Debt Protections

The Issue

- **1 in 4 Americans** affected by medical debt, and accounts for more than half of all bankruptcies
- Affects **all populations** regardless of age, insurance status, or ethnicity
- Is **not predictive** of a patient's future credit worthiness
- Can result in the **loss of employment** or home for many patients
- Can **impact a patient's credit score** for years long after the debt has been settled

Advocacy Actions

Federal

- Medical Debt Relief Act
- Comprehensive Consumer Credit Reporting Act of 2016

State

- Out-of-network bills / Surprise medical bills

Cost of Living Burdens: Transportation

The Issue

- A **lack of transportation to health care providers** constitutes one of the **most significant barriers to care** for many patients in both urban and rural settings
- Research shows that the **lack of access to affordable transportation** disproportionately **affects lower-income, elderly, women and minority** populations
- In a survey of low-income adults, **25 percent** of missed appointments were due to transportation issues
- In a PAF survey, **60 percent** of patients were dependent on a family member, caregiver, or friend as a means of transportation

Advocacy Actions

- BRIDGE Coalition - a cross-sector and cross-industry group of stakeholders with the goal of connecting the worlds of healthcare and transportation
- Supporting community programs, i.e. Rides to Wellness

Improving Quality of Life

The Issue

- **Gaps persist in** professional, public, and policymaker **understanding** about the definitions, availability, and value of integrating **palliative care** and other support services.
- Community-based palliative care remains very **limited** or **unavailable**.
- The **specialist palliative care workforce is inadequate** to reach all patients and families in need across the entire disease trajectory.

Advocacy Actions

Federal

- Patient Quality of Life Coalition
- Palliative Care Hospice Education and Training Act (PCHETA)

State

- Palliative care model legislation

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Addressing the Burdens for Patients and Caregivers

Work together to **raise awareness**

Develop policies that lead to innovative solutions

Patients, families, and caregivers must be a part of the multi-disciplinary care team, health care decisions, and intervention strategies

Put patients and families at the heart of health delivery reform by **advancing person-centered care**



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THANK YOU

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