



National  
Alliance for  
Caregiving

Cancer  
Caregiving  
COLLABORATIVE

# Financial Toxicity and Cancer Caregiving

Data from Caregiving in the U.S. 2020 demonstrates that caregiving can result in financial strain with substantial short-term and long-term financial consequences. Almost half of all caregivers report at least one financial impact such as stopping or dipping into savings, taking on debt, and having trouble paying bills.<sup>1</sup> The financial strain of caregiving is particularly troubling for those caring for someone diagnosed with cancer.

Cancer caregivers experienced greater financial toxicity compared to non-cancer family caregivers.<sup>2</sup> The term financial toxicity is used to describe how out-of-pocket costs (e.g., copayments, deductibles, and coinsurance) associated with cancer treatment can cause financial hardship for a patient and their family.<sup>3</sup> The level of financial toxicity are not equitably distributed, with low income families, those from diverse racial and ethnic backgrounds, experiencing higher financial hardship.<sup>3</sup>



## KEY INSIGHT

Financial toxicity is a critical issue for family caregivers, particularly those caring for someone with cancer – one of the most expensive medical conditions to treat in the United States. The financial strain of cancer care extends far beyond immediate monetary concerns, impacting both the quality of life and long-term health of patients and their family caregivers long after diagnosis, requiring urgent and equitable solutions.

*“ We essentially put the cost of a mortgage in his veins, which, if I had not had top-notch health insurance it would have been just one among the things that financially destroyed me... Also it would have prevented him from getting the care that he needed.”*

– Laura, Family Caregiver



Learn more about  
Laura's cancer  
caregiving journey

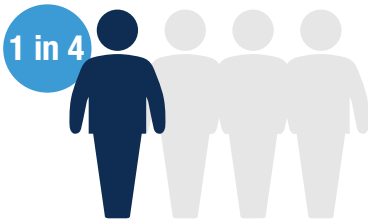
<sup>1</sup>National Alliance for Caregiving & AARP. (2020). Caregiving in the U.S. 2020. [Report]. Retrieved June 14, 2024, from <https://www.caregiving.org/research/caregiving-in-the-us/>.

<sup>2</sup>Longacre, M.L., Weber-Raley, L., & Kent E.E. (2021). Cancer caregiving while employed: Caregiving roles, employer assistance, and preferences for support. *Journal of Cancer Education*, 36(5): 920-932. doi: 10.1007/s13187-019-01674-4.

<sup>3</sup>National Cancer Institute. (2024). Financial Toxicity (Financial Distress) and Cancer Treatment (PDQ) – Patient Version. Retrieved January 1, 2025, from <https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq>.



## DATA SPOTLIGHT



Nearly one in four family caregivers go into debt because of their caregiving responsibilities.<sup>1</sup>



One in ten people with medical debt accumulated those expenses while providing care for someone else.<sup>7</sup>

Financial toxicity affects both the caregiver and the person they are caring for in the following ways:

- Financial toxicity has been associated with decreased quality of care such as cancer patients skipping treatments or not taking their medication as directed due to its costs.<sup>4,5</sup>
- An increase in financial toxicity can lead to experiencing lower quality of life (e.g., worse psychological and physical well-being, and self-esteem, and decreased social support) for both the patient and caregiver.<sup>4</sup>
- Financial toxicity may lead to adverse work impacts (e.g., disruptions, job loss, reduced hours),<sup>4,5</sup> high levels of debt, risk of bankruptcy, and adverse financial events (e.g., inability to pay bills, delinquent mortgage payments, foreclosure).<sup>3</sup>

While the literature on the financial hardships on cancer survivors is well documented, there are still knowledge gaps about the financial hardship on cancer caregivers, including studies that look at the indirect family costs through the cancer continuum and interventions to address these gaps.<sup>6</sup>

## Greater Recognition and Advocacy on Financial Toxicity of Caregiving

Family caregivers are the backbone of our healthcare system, often shouldering tremendous financial strain to provide care. Despite the critical financial support caregivers provide, they often lack access to the necessary resources and support systems to effectively manage their caregiving responsibilities – including its financial demands and impacts. The need and urgency to address this is evident among those caring for someone with cancer.

In response, the National Alliance for Caregiving (NAC) advocates for policies and practices that promote the economic inclusion and financial well-being of family caregivers in communities and at work. In alignment with the [National Strategy to Support Family Caregivers](#), NAC works to ensure financial and workplace security for caregivers, enabling them to provide care without jeopardizing their long-term financial health.



## IMPACT SPOTLIGHT

**In 2024, NAC successfully mobilized its network partners across cancer, disability, aging, and patient advocacy sectors to achieve a regulatory win: barring medical debt from credit reports and prohibiting lenders from using medical information in credit decisions. This victory marks an important step toward ensuring better financial outcomes for both family caregivers and those they support.**

<sup>4</sup>Shankaran, V., Li, L., Fedorenko, C., Sanchez, H., Du, Y., Khor, S., Kreizenbeck, K., & Ramsey, S. (2022). Risk of Adverse Financial Events in Patients with Cancer: Evidence from a Novel Linkage Between Cancer Registry and Credit <https://doi.org/10.1200/JCO.21.0163>

Records. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, 40(8), 884–891. <https://doi.org/10.1200/JCO.21.01636>

<sup>5</sup>Hastert, T. A., Ruterbusch, J. J., Nair, M., Noor, M. I., Beebe-Dimmer, J. L., Schwartz, K., Baird, T. E., Harper, F. W. K., Thompson, H., & Schwartz, A. G. (2020). Employment outcomes, financial burden, anxiety, and depression among caregivers of African American cancer survivors. *JCO Oncology Practice*, 16(3), e221–e233. <https://doi.org/10.1200/JOP.19.00410>

<sup>6</sup>Salazar, M. M., Khera, N., Chino, F., & Johnston, E. (2024). Financial hardship for patients with cancer and caregivers at end of life in the USA: narrative review. *BMJ Supportive & Palliative care*, 14(1), 25–35. <https://doi.org/10.1136/spcare-2023-00455>

<sup>7</sup>Lopes, L., Kearney, A., Montero A., & Brodie M. (2022). Health Care Debt in the U.S." *The Broad Consequences of medical and dental bills*. FKK. Retrieved February 5, 2025, from <https://www.kff.org/report-section/kff-health-care-debt-survey-main-findings/>

# Catalyzing Change: Cancer Caregiving Collaborative

NAC's [Cancer Caregiving Collaborative](#) convenes a diverse coalition of stakeholders — including patient advocacy groups, healthcare leaders, researchers, and family caregivers— to expand access to high-quality training, education, and support services for cancer caregivers. This is being achieved by addressing the financial burden of caregiving by advocating for smart and equitable economic policies and practices.

## 2025 Recommendations

### Financial Inclusion

- Advocate for policies that promote economic security and workforce participation, including comprehensive paid family and medical leave.
- Lower the out-of-pocket costs associated with complex care by establishing a national refundable caregiver tax credit.
- Address the toxic impacts of debt and debt collection practices that family caregivers experience as they navigate complex healthcare and support systems.

## Core Strategies for Driving Action

The Collaborative advances these priorities and recommendations by focusing on the following core strategies:



### Peer Learning and Resource Sharing

We bring partners together across the cancer care continuum including family caregivers, patient advocacy, research, health systems, and drug development to learn about emerging trends, research, and policy developments relevant to caregiver training services (CTS) and financial support services (FSS). We facilitate knowledge sharing, resource development, and peer-to-peer connections to support the implementation of CTS in health system settings.



### Policy Education and Advocacy

We educate and mobilize cancer care stakeholders about relevant CTS and FSS policies and practice change to support family caregivers through sign-on letters and public comment opportunities.



### Storytelling

We amplify the voices of cancer caregivers to highlight critical challenges and gaps in cancer care support.

### About the National Alliance for Caregiving

Since 1996, the National Alliance for Caregiving (NAC) has been a catalyst for change, transforming how the United States recognizes, supports, and values our 53 million family caregivers providing complex care. Through our nationally recognized research and our advocacy for the first-ever National Strategy to Support Family Caregivers, we drive the policy, system, and culture change needed to make family caregivers a national priority. With more than 50 members, we build partnerships across aging, disability, healthcare, philanthropy, and the private sector to make caregiving more sustainable, equitable, and dignified.