

The Cancer Caregiving Challenge

An estimated 18 million cancer survivors are currently living in the US. This number is projected to increase to 22.5 million by 2032.¹ However, a cancer diagnosis does not just affect the individual.

Family caregivers² play a critical role throughout an individual's cancer journey – from diagnosis, treatment, in-between, and during the end-of-life stage. Family caregivers help with symptom monitoring, medication management, and other complex medical and nursing tasks. This often leads them to experience great emotional distress, poorer physical health, and significant financial challenges.³ Despite the reliance on and demands of caregivers they are generally under-supported by the health care system.⁴

Data on the availability, adoption, and implementation of interventions to support family cancer caregivers is scarce; however, two recent national surveys underscore the inconsistency of supports programs and services available to family caregivers in the cancer care system.^{5,6}

- A 2023 survey of cancer centers revealed that a quarter did not have any family caregiver programs and only a few reported having programs on training in medical or nursing tasks (22%) or programs focused on caregiver self-care (20%).⁵
- A 2017 survey of oncology clinics showed that only 64% of the sites reported having supportive care services available to caregivers and less than a quarter offered general training or educational classes for caregivers.⁶

“I sort of joke that I have a master’s degree in medicine because I had to figure out how to speak this language and how to speak for [my care recipient] in a way that people would listen. And I often heard from doctors, and they were like, ‘oh, are you a doctor?’ and I’m like, ‘no, I’ve just had to learn how to speak your language so that you’ll listen to me!”

– Cancer Caregiver

¹American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2022-2024*. Atlanta: American Cancer Society; 2022.

²This document uses the National Strategy to Support Family Caregivers definition for caregivers: “an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation.”

³National Alliance for Caregiving (2016) *Cancer Caregiving in the U.S.: An intense, episodic, and challenging care experience* National Alliance for Caregiving https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf

⁴Thomas, T. H., Campbell, G. B., Lee, Y. J., Roberge, M. C., Kent, E. E., Steel, J. L., Posluszny, D. M., Arida, J. A., Belcher, S. M., Sherwood, P. R., & Donovan, H. S. (2021). Priorities to improve cancer caregiving: report of a caregiver stakeholder workshop. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 29(5), 2423–2434. <https://doi.org/10.1007/s00520-020-05760-y>

⁵Odom, J. N., Applebaum, A., Bakitas, M. A., Bryant, T., Currie, E., Curry, K., Donovan, H., Fernandez, M. E., Ferrell, B., Azuero, A., Gray, T. F., Hendricks, B. A., Meier, D., Nightingale, C., Reinhard, S., Sannes, T. S., Sterba, K., & Young, H. M. (2023). Availability of Family Caregiver Programs in US Cancer Centers. *JAMA network open*, 6(10), e2337250. <https://doi.org/10.1001/jamanetworkopen.2023.37250>

⁶Nightingale, C. L., Sterba, K. R., McLouth, L. E., Kent, E. E., Dressler, E. V., Dest, A., Snively, A. C., Adonizio, C. S., Wojtowicz, M., Neuman, H. B., Kazak, A. E., Carlos, R. C., Hudson, M. F., Unger, J. M., Kamen, C. S., & Weaver, K. E. (2021). Caregiver engagement practices in National Cancer Institute Clinical Oncology Research Program settings: Implications for research to advance the field. *Cancer*, 127(4), 639–647. <https://doi.org/10.1002/cncr.33296>

The Opportunity: Cancer Caregiving Collaborative

The Cancer Caregiving Collaborative, powered by the National Alliance for Caregiving, is a multiphase cross sector initiative to address the unmet needs of cancer caregivers through research, policy change, and practice change. Notably, there are many important and longstanding cancer related efforts, however, family caregivers are not the primary focus. The Collaborative will serve as a consistent forum that convenes and mobilizes cancer and caregiving ecosystem stakeholders.

Aligned with NAC's mission of improving the lives of family caregivers, the Collaborative focuses on uplifting and supporting family caregivers in cancer care. The Collaborative will work to ensure family caregivers are valued members of the cancer care team and champion policies to ease the financial burden of cancer. By addressing both the health team integration and financial aspects of caregiving, this initiative strives to create a more comprehensive and equitable cancer care system that recognizes and supports the invaluable contributions of family caregivers.

Priorities

1

Healthcare Integration

Advocate for equitable integration of family caregivers into cancer care teams by optimizing reimbursement pathways. This will increase access to high-quality training, educational resources, and support services.

2

Financial Health

Address the financial burden of cancer caregiving by advocating for smart and equitable economic policies.

Why is this important?

Millions of family caregivers across the nation dedicate themselves to the well-being of the individuals they are caring for living with cancer. Yet, these individuals often face a lack of support and resources, leaving them feeling overwhelmed, emotionally drained, and in a precarious financial situation. The Collaborative aims to change this by:

- Identifying and prioritizing the unmet needs of cancer caregivers.
- Centering cancer caregivers through the Collaborative's governance, priorities, and efforts.
- Developing and advocating for solutions that address these critical needs, ensuring their voices are heard and translated into policy, research, and practice changes.
- Building a network of champions for cancer caregivers to shape policy and practice improvement efforts.

“Too often, caregivers feel isolated and invisible, in addition to unsupported. Integrating caregivers onto healthcare teams and ideally, identifying and addressing their unmet needs, will address these issues and have a significant and positive impact on the experience of caregivers and ultimately, on the experience of the patients for whom they provide care.”

– Allison J. Applebaum, PhD, Cancer Caregiving Collaborative Executive Committee

Leadership

The Collaborative's **Executive Committee** and **Steering Committee** represent key stakeholders across the cancer continuum including patient advocacy organizations, cancer researchers, and healthcare leaders with personal and professional connections to cancer caregiving.

EXECUTIVE COMMITTEE

Tara Anglim, EdD, LCSW-R, Peconic Bay Medical Center
Allison J. Applebaum, PhD, Memorial Sloan Kettering Cancer Center
Abena Apau Buckley, MBA, Empowered Potential International*
Elizabeth Franklin, PhD, MSW, Sanofi

Laura Makaroff, DO, American Cancer Society
Jason Resendez, National Alliance for Caregiving
Alexandra Zaleta, PhD, CancerCare

**Denotes caregiver representative*

STEERING COMMITTEE – ORGANIZATIONAL PARTNERS



STEERING COMMITTEE – ADVISORY BOARD MEMBERS

Heather Badt, MBA, LSS, Cancer Support Community *
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**Denotes organizational members of the steering committee
Steering Committee list up-to-date as of May 30, 2024.*

COLLABORATIVE FUNDERS



About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving (NAC) is a national membership coalition that brings together more than 50 national healthcare companies and nonprofits, care innovators, caregiving advocacy organizations, and financial services leaders to advance a common agenda of building health, wealth, and equity for America's 53 million family caregivers. From championing our nation's first-ever national caregiving strategy to releasing new data insights on the realities of caregiving, NAC works tirelessly to make caregiving more sustainable and equitable through agenda-setting research, programming, and policy change.