



Caregiving Without a Roadmap: Insights from Cancer Caregivers

February 2026



Executive Summary

Family caregiving is often portrayed as an act of compassion and love, but that context is incomplete and often comes at a significant personal cost. Yet reliance on family caregivers has grown due to the rising number of cancers' diagnoses and survivors; despite important scientific developments in diagnosis and treatment, the systems designed to support them remain fragmented and insufficient.

In response to this urgent public health need, the National Alliance for Caregiving (NAC), in partnership with CancerCare, convened two virtual listening sessions with cancer caregivers from across the U.S. in September 2025 to deepen the understanding of their experiences, barriers and gaps in support, and opportunities for improvement.

Participants described a landscape where they are essential to positive patient outcomes yet systematically excluded from adequate training or financial protection. From a daughter learning to juggle an array of medications and a feeding tube, to a wife lying about her ability to pay so that her husband can receive lifesaving treatment, caregivers are providing skilled labor, carrying emotional and financial weight, and filling the gaps in our healthcare system – at great personal costs.

The discussion revealed three overarching themes: 1) caregivers are often thrown into complex medical roles with little or no preparation and forced to learn tasks through “trial and error”; 2) the financial toxicity of cancer extends far beyond medical bills, forcing families to make difficult-to-impossible tradeoffs between their own health and long-term economic security and their family member’s immediate survival; and 3) access to caregiver support is constrained by systemic barriers, including administrative red tape and exclusionary eligibility requirements.

“It’s like being thrown into a job you didn’t apply for with no training, no pay, no support, and no days off.” – R.H.

This report synthesizes these firsthand experiences into actionable insights for the cancer caregiving community. The findings underscore that caregivers are not merely “helpers” – they require formal recognition and integration into healthcare teams, systemwide support, and direct financial interventions. The insights gathered from our listening sessions are clear and an urgent call for systemic integration of caregivers into cancer care delivery, policy reform, and payment models.



Key Takeaways

- **Learning Through “Trial and Error:”** Cancer caregivers routinely perform complex medical tasks, from wound care to managing feeding tubes, with little to no formal training. They described relying on internet searches to backfill knowledge gaps due to limited or lack of formal training by healthcare professionals. Caregivers reported wanting to be recognized and included in care planning by the healthcare team from the start, provided with clear information about their role, duties, and expectations, and supports that are accessible, comprehensive, and practical.
- **The Compounding Financial Toll of Cancer:** While the cost of cancer treatments is a known financial burden, caregivers emphasized the compounded strain of these expenses when combined with their “life happening” alongside cancer. Indirect costs such as transportation, property taxes, home maintenance, and deferred medical and dental care, among others, were serious sources of financial and emotional strain. Caregivers highlighted the need for comprehensive support, including financial navigation services, direct financial relief, and programs that address basic needs and social determinants of health (e.g., housing).
- **Systemic Barriers and Red Tape:** Accessibility of existing support resources is impeded by restrictive eligibility criteria. Caregivers cited barriers related to specific diagnostic or therapeutic requirements, asset limits that disqualify caregivers, especially older adults, from public benefits like Medicaid or Supplemental Nutrition Assistance Program (SNAP), and immigration status. Caregivers require streamlined access to support, unification of inconsistent resources, and broadening of restrictive eligibility criteria.

Overview

A family caregiver is an unpaid person, such as a family member, friend, or neighbor, who provides support to someone with a chronic illness, disability, or other long-term health needs. In cancer, caregivers provide intensive support: they manage complex medical tasks, navigate fragmented care systems, and experience significant emotional and financial strain.¹ As cancer incidences continue to rise nationwide with an estimated 2 million new diagnosis projected in 2026, increasing numbers of family members and friends are stepping into vital caregiving roles.² Couple this growth with the now 18.6 million cancer patients and survivors in the U.S.,² and the urgency for systems to recognize, prepare, and support cancer caregivers has never been greater.

NAC's Cancer Caregiving Collaborative is a multi-sector initiative, working to close the critical gaps in support by addressing the unmet needs of cancer caregivers. With more than 30 partners, the Collaborative focuses on strengthening caregiver support through two primary priorities: healthcare integration (education, training, navigation) and financial health (economic stability, financial navigation, workforce protection).

In partnership with CancerCare, a member of the Collaborative, NAC hosted two virtual listening sessions with cancer caregivers. Founded in 1944, CancerCare is a national nonprofit organization that has supported millions of people affected by cancer through free counseling, support groups, educational resources, advocacy, and direct financial assistance.

Purpose

Aligned to the strategic goals of the Cancer Caregiving Collaborative, the purpose of the listening sessions were to:

- Better understand the lived experience of diverse cancer caregivers.
- Identify systemic barriers that create gaps in care, training, and support for cancer caregivers.
- Elevate cancer caregivers' voices to inform the Collaborative's priorities in healthcare integration and financial health.
- Ensure that emerging solutions are grounded in cancer caregivers' real needs and perspectives.

Information gleaned through these listening sessions will help inform the Collaborative's strategic work and drive system level change to empower and support family caregivers across the cancer care continuum.

Methodology

Two 90-minute virtual listening sessions were held in September 2025 with a total of 107 participants:

- Session 1 explored medical and nursing tasks, whether caregivers received formal training for these tasks, and the impact of these experiences.
- Session 2 centered on the financial impact of caregiving, including both direct costs related to cancer treatments and indirect costs related to impacts of caregiving on work, childcare, and other responsibilities.



¹National Alliance for Caregiving. (2016). *Cancer Caregiving in the U.S.: An Intense Episodic, and Challenging Care Experience*. https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf

²American Cancer Society. (2026). *Cancer Facts & Figures 2026*. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2026/2026-cancer-facts-and-figures.pdf>

Each session followed the same format:

- A 35-minute moderated panel with three adult caregivers caring for family members with pancreatic, colon, breast, and hematologic (leukemia) cancers.
- A 25-minute group breakout discussion with session participants (3-10 people per group) for reflection and peer dialogue, followed by a 10-minute full group reflection.
- A graphic recorder who visually interpreted key themes and insights in real time, translating the discussion into two posters (See page 8).

This report was developed by analyzing the panel transcripts, breakout room transcripts, chat reflections, and visual summaries. Themes were synthesized to identify recurring and cross-cutting themes and categorized within the Collaborative's priority areas of healthcare integration and financial health.

SESSION 1:

Learning Medical Tasks Through Trial and Error

“None of this obviously came with a roadmap. And I figured this out through trial and error, piecing things together day by day...” - A.K.



National data reflect a deep mismatch between what caregivers are asked to do and the preparation they receive. Throughout the U.S., 55% of caregivers are performing medical and nursing tasks typically performed by healthcare professionals. Yet only 22% of caregivers report receiving formal training.³ Among those providing care, 1 in 5 caregivers say they find these tasks difficult. For caregivers who receive training, almost all (96%) say it prepared them better for the tasks.⁴ Furthermore, 64% of caregivers report experiencing high emotional stress related to caregiving responsibilities with 38% rating their caregiving highly emotionally stressful. This reality was strongly echoed during the first listening session.

Caregivers repeatedly described little or no preparation during critical points of care or important interactions with the healthcare team. They cited feeling like they were “thrown into medical and nursing responsibilities with only brief demonstrations, or none.” Specifically, caregivers recalled discovering at discharge that they would be responsible for complex medical or nursing tasks, and spending time immediately after working to reconcile conflicting medication lists and feeding tube instructions.

“[I’ve been in] marketing my whole life and then realizing I had to crush up meds to put in her J-tube with having zero training. Yeah, like, you know, two minutes before we were discharged from the hospital as well.” - H.D.

“I was taught how to feed my husband by hand through his feeding tube after we were discharged. It was, like, the last thing. It was a 60-second experience, and I learned on the way out the door.” - C.S.

Other caregivers shared similar experiences, describing the complexity and need to learn medical terminology, medications management, wound care, post-surgical tasks, and which specialists were responsible for each part of treatment. The lack of training can create risky and even dangerous situations.

“My husband has an open wound, and I have been the caretaker of the wound for 5 years. This is so far from my capabilities, but I do it.” - B.B.

³AARP and National Alliance for Caregiving. (2025). Caregiving in the US 2025. <https://doi.org/10.26419/ppi.00373.001>

⁴CancerCare. (2025). The Health Insurance Maze: How Cancer Patients Get Lost in the Red Tape of Utilization Management. <https://www.cancer.org/redtape>

Caregivers also described the need to learn how to navigate the health system itself – hospital processes, who to call, how and when to access emergency care, and how to advocate for their family members. For those caregivers whose primary language was not English, the absence of culturally and linguistically accessible materials intensified stress and added barriers, leading to inequities. Collectively, the limited or lack of role preparation from the health systems created an emotional strain. Caregivers spoke openly about the weight of this responsibility and the uncertainty of caring for a family member with little guidance. As one caregiver shared:

“I still live with that fear – that I’m not doing something that I should be doing, or I’m doing the wrong things.” – D.G-T.

They also emphasized that these tasks were part of a much larger emotional and logistical load. Caregivers shared how they were pulled into multiple directions because of competing responsibilities. They described navigating family dynamics, breaking difficult news, caring for children or other loved ones, dealing with grief, and the financial impact of caregiving.

“I never realized there was a role in that I was having to be the bearer of bad news to the patient... and what a weight that is on the person to have to do that.” – A.K.

To manage these overwhelming responsibilities, caregivers relied on online resources and peer support groups. Throughout the session, caregivers emphasized the value of peer support as a primary source of validation, emotional support, and practical guidance; often filling gaps left by formal care systems.

“[There is an] emotional impact of being a caregiver. You’re automatically thrown into not just being a caregiver, but there’s so many unspoken expectations and roles that have to be assumed, that we don’t even know, right? Like, we don’t even know where to start, because there’s so many different roles, and we’re working with a broken system... I think that’s the most impactful thing as an emotional burden. As well, in dealing with burnout.” – S.J.

To fill the gaps, caregivers proposed a designated point of contact (such as a caregiver liaison or social worker), plain language materials, integration of caregiver information into patient portals, and ongoing peer support networks for shared experience and guidance.

SESSION 2:

The Financial Weight Caregivers Carry

Caregiving in the U.S. 2025 data show that nearly half of caregivers reported experiencing at least one major financial impact and 47% experience at least two different financial challenges.³ Negative financial impacts include stopping or using savings, taking on more debt, leaving bills unpaid, paying bills late, putting off retirement, or planning not to retire. For those caring for someone with cancer, the financial impact can be more devastating and multifaceted, especially among low-income families and those from diverse racial and ethnic backgrounds.¹ This truth was evident throughout the first listening session.

“When my husband lost his job, it impacted me so much because all the money was gone. All the savings we had, everything my husband worked so hard for, even what I had worked so hard for, every bit of that savings was gone.” – T.S.

“I’m still working on building that [my savings] back up and paying off the debt that came out of all of that [caregiving].” – S.B.

Caregivers spoke about the layered and compounding financial impact that came with caring for family members with cancer. They cited medical costs such as copays, specialized equipment, wound care supplies, and mounting non-medical expenses including transportation to appointments, parking fees, meals away from home, lodging during treatment, and childcare. They also reported concerns over the burden of property taxes, home repairs and maintenance, and even pet care. Caregivers described how the demands of care disrupted their employment, compounding financial strain through reduced work hours, job loss, early retirement, and shrinking household income, often forcing them to rely on credit cards to cover basic needs.

“When you’re diagnosed with a long-term disease such as this [cancer], knowing that you can’t afford it unless you get help, and trying to decide whether you’re going to go forth with treatment and completely financially ruin yourself, or whether you’re just going to let nature take its course. It’s... appalling.” – B.B.

These financial challenges led to difficult decisions about treatment and care, highlighting the deep connection between affordability, access to treatment, patient outcomes, and caregiver impact. One caregiver shared that some seniors are advised to get a divorce to qualify for state benefits, while another reported food insecurity and how a sudden \$2,000 medication copay forced her husband to ration medication, which affected his health negatively. Other caregivers mentioned how they had to tradeoff basic necessities (e.g., food purchases) to afford the care of their family members. In some cases, caregivers reported feeling they had to make dire decisions in the moment: One caregiver revealed that she misrepresented her financial situation to ensure her husband could continue receiving treatment if assistance was not approved.

“We couldn’t afford that extra \$2,000, and my husband stopped taking his medication every day.” – T.S.

Caregivers also described administrative red tape, resource fatigue, and eligibility barriers to access support. Although caregivers acknowledged the availability of resources, many described the process of identifying and accessing them as overwhelming. They cited a patchwork of inconsistent resources across patient advocacy organizations, pharmaceutical rebates, or state funded support. They spoke about the very specific criteria for resources, such as not qualifying based on their place of residence, immigration status, or specific medications. Some caregivers also expressed feeling humiliated and feeling that they had to “beg” for assistance or when they repeatedly encountered program criteria they could not meet.

29%

of cancer patients report diagnostic delays, and 40% experience treatment delays due to their most recent insurance approval process.⁴

“There’s a lot of red tape... thinking about certain grants, it was like, okay, if it wasn’t the U.S. citizenship, it was, if you’re not taking this specific chemotherapy medication, or this specific immunotherapy medication, then you’re not eligible for this specific program. So, there wasn’t anything that really came through...” – S.B.

Caregivers repeatedly reflected on the sacrifices they made when time, energy, or money was scarce – often at the expense of their own wellbeing. Many caregivers delayed medical care due to costs, while others struggled to maintain their homes or meet basic needs. One caregiver shared postponing a dental appointment she could not afford; another described how financial and time constraints prevented her from keeping up with home maintenance. Caregivers emphasized that these tradeoffs accumulate over time and affect their health and financial stability.

“There are direct costs associated with caring for another person, and then there are costs that start... in terms of your own health. The implications of health challenges that might be related or unrelated, simply because life is happening.” – A.A.

Access issues compound these challenges. For example, recent CancerCare research on insurance administrative red tape found that half (49)% of patients and their families had to get directly involved in navigating prior authorization, just one of many administrative barriers that consume the limited time and energy of family caregivers.⁴ And, among those involved, half (51%) lost up to 1 business day, 27% lost up to 2-3 business days, and more than 1 in 10 (12%) lost a full business week or more of their lives to fighting just a single incidence of insurance red tape – time that could instead be focused on treatment, recovery, caregiving support, and family responsibilities.

To address these burdens, caregivers highlighted the importance of systemic support such as financial navigation, sufficient paid leave, caregiver grants or stipends, respite, and meaningful assistance with housing, transportation, food, and other basic needs. Without this support, caregivers are left absorbing financial, practical, and emotional shocks with long-term consequences to their family members’ outcomes, their own health, and economic stability.

Urgent Priorities in Cancer Caregiving

Cancer caregivers reflected moments of joy in their role, yet these were eclipsed by the heavy challenges and unmet needs of providing care and support to a loved one. Despite family caregivers being an essential member of the care team, the health system today continues to treat them as outsiders. The following are practical insights into what caregivers need to be successful and feel supported in their roles:

- 1. Being recognized and included in the care of their family members from the start.** Caregivers expressed the need to be recognized as part of the medical care team and be provided training and support from the beginning of their family members' cancer experience. This support should include preparation for the medical, logistical, and emotional responsibilities they are expected to shoulder.
- 2. Early, accessible, comprehensive, and practical cancer caregiver education, training, and support.** Caregivers described learning through trial and error. They stressed the need for timely, repeated, and accessible information, such as step-by-step instructions for complex medical tasks. Even when education and training were provided, caregivers found the training often cursory or delivered at a time when it was difficult to absorb details (e.g., at discharge). The emotional weight of their role was also overwhelming. Caregivers expressed the need for tools to support care coordination and make healthcare navigation easier, such as integrated caregiver education within existing systems like patient portals.
- 3. Comprehensive support for the medical, insurance, and financial aspects of the cancer caregiving experience.** Caregivers shared that the costs and administrative burdens associated with cancer impacted treatment adherence, employment, emotional health, and the caregivers' own health. They emphasized the need for help navigating insurance red tape, understanding eligibility, and identifying resources.
- 4. Support that accounts for care context and social determinants of health.** Caregivers emphasized that effective solutions must consider factors such as language access, cultural relevance, transportation, housing stability, and employment flexibility. Without addressing these systemic barriers, support within the healthcare system alone cannot meet caregivers' needs.

Other needs mentioned include sustainable implementation of caregiver assessment and education, workplace flexibility and job protection, expanded peer and community support networks, and increased public awareness and caregiver-centered policies.

Conclusion

The caregiver experiences shared during the September 2025 listening sessions paint a vivid picture of the realities of cancer caregiving – one where caregivers are overextended and under supported, despite their resourcefulness and commitment to family members. These discussions reveal that their resilience is often born out of necessity because the healthcare system, family and medical leave policies, and the broader policy landscape around them does not provide the support they need.

The insights in this report confirm that the status quo is unsustainable. Family caregivers cannot continue to operate as an unsupported, untrained extension of the healthcare workforce without suffering long-term health and financial consequences. The recommendations emerging from these sessions include formal recognition and training, as well as financial support that consider caregivers' cultural, economic, and social context. As the Collaborative continues to drive system change, these voices will serve as the compass for driving policy and healthcare system improvements to ensure cancer caregivers have the tools they need to care for their family members.



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Listening Session Posters

YOUR STORY MATTERS: UNDERSTANDING GAPS IN MEDICAL & NURSING TASK TRAINING FOR CANCER CAREGIVERS

YOUR VOICE HELPS US CREATE CHANGE

EXPERIENCE

- EMOTIONS & DYNAMICS**
 - Inverted Roles
 - Having Tender & Life-Changing Conversations
 - Emotional Support
 - Burden
 - Self Person Taking Care of
 - Frustration
- TRaversing THE SYSTEM THROUGH TRIAL AND ERROR**
 - Health System
 - Doctors Office
 - Emergency Services
- THROWN INTO IT WITH NO TRAINING**
 - Discharge After Surgery
 - Cleaning Ports
 - Took a CNA Course!
- COMMUNICATION**
 - Advocacy
 - Language
 - Asking Questions
- INFORMATION GAPS**
- UNCERTAINTY**
 - Doing the Day to Day When the Day to Day Changes
- BURNEOUT** (D-E-P-R-E-S-S-E-D)
 - Isolation
 - Balancing Other Responsibilities
 - Alienation
 - Fear of Unknown
 - Ungering Emotional Toll

IMPROVEMENTS

- INTEGRATION INTO HEALTH SYSTEM**
 - Plan & Conversation Including Caregiver from Beginning
 - Standardization Across Centers
 - Institutionalize Caregiver Support
- CAREGIVER COMMUNITY**
 - Coordination
 - Proactive Engagement
 - Support
 - Fill Knowledge
 - Advocates & Point People for Caregivers
- TRAINING**
 - Technical Skills
 - Information & Education
 - Inclusion
- ROADMAP**
 - Improved Access / Bridging the Care Gap
 - Navigation Information
 - Resources
 - Roles & Expectations
- SOCIAL CHANGES**
 - Being a Caregiver Isn't Unique!
 - Expectation That You'll Become One

NATIONAL ALLIANCE FOR CAREGIVING (NAC) LISTENING SESSION: SEPTEMBER 15, 2025 - GRAPHIC RECORDING BY RIO HOLADAY

YOUR STORY MATTERS: UNDERSTANDING THE FINANCIAL CHALLENGES OF CANCER CAREGIVING

CAREGIVER EXPERIENCES

- MULTIPLIER EFFECTS**
 - We're Each Others' Caregivers
 - If We're Not of, There's a Direct Impact on Patient
 - It's Appalling
 - Letting Go of Things I Take Pride In
- EMOTIONAL SUPPORT**
- WHILE CANCER HAPPENS, LIFE HAPPENS TOO**
- BEING A CAREGIVER SHOULDN'T FORCE ANYONE INTO FINANCIAL HANDSHIP**
- THE SYSTEM ISN'T WORKING FOR EVERYONE**
- FAMILY CAREGIVERS AREN'T JUST HELPERS, THEY'RE ESSENTIAL PARTNERS**
- SYSTEMIC**
 - Formalizing Caregiver Role & Process
 - Comprehensive Support
- FINANCIAL**
 - DIRECT**
 - Caregiver Stipend
 - Home Medicine
 - INDIRECT**
 - Home Repairs
 - Car Repairs
 - Transportation
 - Pet Program
 - Property Taxes
 - Gas
- CAREGIVERS**
- FINANCIAL TOXICITY**
 - Nursing Wound Care
 - Medical Bankruptcy
 - It Was Just Me and My Savings
- MINDSET**
 - Asking for Help... & Being Asked?
 - Thinking Outside the Box
 - Determination
 - Maintain Dignity & Sanity!
- CAREGIVER HEALTH**
 - Therapy
 - Exercise
 - Your Wellbeing Matters
 - There is Hope!
- IF YOU'RE GOING TO ASK FOR HELP, ASK FOR HELP FOR YOURSELF TOO**
- FINANCIAL TOLL**
 - Can't Afford X-Rays for My Teeth
 - Catching Up
 - Debt That Comes from Not Having Assistance
- TRADEOFFS & SACRIFICES**
 - Decisions
 - Get Treatment and Ruin Self Financially
 - Let Nature Take Its Course
- PHYSICAL**
 - Red Tape & Access to Services
 - Equal Local Knowledge
 - Accessible
 - Overwhelming to Find Resources
- WE DESERVE SUPPORT**

NATIONAL ALLIANCE FOR CAREGIVING (NAC) LISTENING SESSION: SEPTEMBER 29, 2025 - GRAPHIC RECORDING BY RIO HOLADAY

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ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

The National Alliance for Caregiving 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. Learn more at [caregiving.org](https://www.caregiving.org).

ABOUT CANCERCARE

For over 80 years, CancerCare has empowered millions of people affected by cancer through free counseling, resource navigation, support groups, educational resources, advocacy, and direct financial assistance. Our oncology social workers improve the lives of people diagnosed with cancer, caregivers, survivors and the bereaved, by addressing their emotional, practical and financial challenges. To learn more, visit [cancercare.org](https://www.cancercare.org).

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