



# Cancer Caregiving Collaborative

## Workshop Summary and Proceedings

Wednesday, October 25, 2023  
Washington, DC

*The National Alliance for Caregiving (NAC) is a membership-based organization catalyzing system change to build health, wealth, and equity for the 53 million family caregivers in the United States.*



## Event Context and Purpose

The [National Alliance for Caregiving](#) (NAC) Cancer and Caregiving Collaborative (Collaborative) Design Workshop was held on October 25, 2023 (convened as part of the inaugural NAC [Caregiver Nation Summit](#) held on October 25-26, 2023, in Washington, DC).

The Collaborative is building upon the following previous cancer and caregiving reports and workshops:

- [Cancer Caregiving in the US: An Intense, Episodic, and Challenging Care Experience](#) (2016);
- [National Strategy to Support Family Caregivers](#) (2022); and
- [Family Caregiving for People with Cancer and Other Serious Illnesses: Proceedings of a Workshop](#) (2023).

NAC is serving as the convener and catalyst to drive action around an aligned research, policy change, and practice change agenda based on the gaps and opportunities identified by its Collaborative members and partners.

### Key focus areas include:



#### Research

Identify research priorities, synthesize existing data, and generate new data insights on cancer caregiving.



#### Policy Change

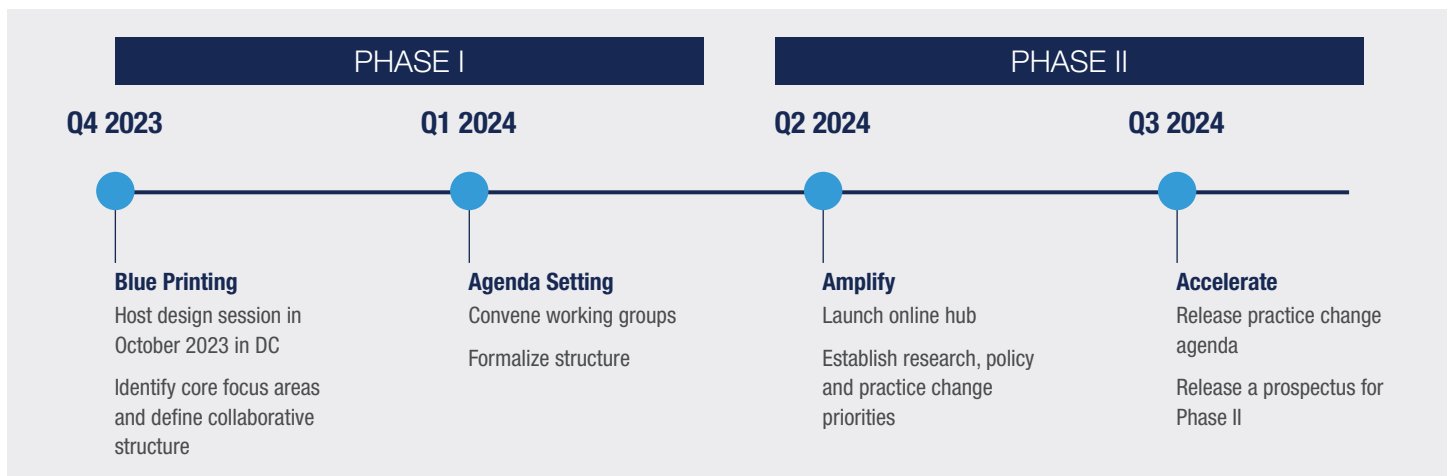
Develop and advance a common policy agenda to address the challenges that cancer caregivers face.



#### Practice Change

Identify and champion practice improvements to support cancer caregivers.

The NAC Collaborative Design Workshop was the kickoff event of a multi-phase, multi-year effort by NAC. The initial phases of the Collaborative activities and tactics in 2023-2024 are envisioned to include:



The Design Workshop agenda included plenary presentations followed by a breakout brainstorming session in which attendees were separated into three working groups: research, policy change, and practice change.

## Key Takeaways

There was consensus from attendees that a collective and continuous effort is needed to improve the experience, health outcomes, and support services available to cancer caregivers. Additional key takeaways from the Design Workshop are listed below. NAC will now move forward with the Design Workshop attendees to:

- Define the key, critical existing research gaps and align a strategy to fill these gaps.
- Assess the landscape of cancer caregiving care coordination and navigation programs and identify the educational, health system, and reimbursement gaps that could be addressed.
- Identify caregiver and health care professional training and education needs and how to best fill these gaps.
- Identify key “low hanging fruit” opportunities in the policy realm, particularly policy changes that would have the most impact for caregivers and could be more easily accomplished.
- Develop models to articulate how additional reimbursement support to practitioners to provide caregiver education would help improve patient outcomes and reduce overall health care spending and key opportunities to ensure more education throughout the cancer journey is supported by payers.
- Adapt existing patient-focused shared decision-making frameworks to create a framework focused on the caregiver.
- Ensure existing efforts are aware of the cancer and caregiving efforts being taken forward by the Collaborative and leverage opportunities for these efforts to help implement and scale these key priorities.

There was consensus from attendees that a collective and continuous effort is needed to improve the experience, health outcomes, and support services available to cancer caregivers.

## Design Workshop Attendees

**Forty stakeholders** representing the cancer care ecosystem, including patient advocates, academic researchers, health care professionals, and industry, participated in the Cancer Caregiving Collaborative Design Workshop. (See the appendix for the list of attendees and the organizations they represent). NAC will also identify and reach out to additional stakeholders who were unable to attend the Design Workshop for their engagement and participation moving forward.

### Speakers

- **Allison J. Applebaum, PhD**, Director, Caregivers Clinic, Memorial Sloan Kettering Cancer Center;
- **Fawn A. Cothran, PhD, RN, GCNS-BC, FGSA**, Hunt Research Director, National Alliance for Caregiving;
- **Erin E. Kent, PhD, MSc**, Associate Professor, Health Policy and Management, University of North Carolina at Chapel Hill, Cancer Prevention and Control;
- **Jason Resendez**, President and CEO, National Alliance for Caregiving; and
- **Ranak Trivedi, PhD**, Associate Professor, Division of Public Mental Health and Population Sciences, Dept of Psychiatry and Behavioral Sciences, Stanford University; Director of Caregiving and Family Systems, Stanford Center for Asian Health Research and Education.

## Opening Remarks

The Collaborative Design Workshop was kicked off by Jason Resendez, NAC President and CEO, who articulated the key aim of the Collaborative was to drive collaboration across the cancer and caregiving continuum to make cancer caregiving more sustainable, dignified, and equitable.

Mr. Resendez noted that the goals of the Collaborative Design Workshop included the following:

- **Establish baseline awareness of the needs of cancer caregivers among key stakeholders in the cancer care ecosystem**, including industry, academic researchers, health care professionals, and patient advocates.
- **Inform the development of core priorities for the Collaborative** across research, policy change, and practice change.
- **Identify mission-aligned stakeholders and partners across the cancer care continuum** to support family caregiver-oriented research, policy change, and practice change efforts.

Before the plenary presentations, Mr. Resendez shared a short video with the Workshop participants regarding the cancer caregiving journey of Abena, a cancer caregiver based in Washington, DC.

Abena was a caregiver for her husband, who was diagnosed with a brain tumor. She shared that it took some time to understand what it meant to be a caregiver. She took care of all her husband's needs while also caring for her children, at the cost of her own health and well-being. Towards the end of her husband's life, Abena was responsible for the medical tasks caring for him at home, which required her to stop working. While it was an honor to care for her husband, the cost was high, and support was hard to find.

Abena's video highlighted several of the issues the Collaborative will seek to address and reinforces the challenges that cancer caregivers face every day. Abena's video is available via the following link: <https://youtu.be/-VkJJzE6ms>



While it was an honor to care for her husband, the cost was high, and support was hard to find.



## Cancer Caregiving Landscape Presentations

To set the stage before the participants joined the research, policy change, and practice change breakout groups, the following expert presentations were given:

### Cancer Caregiving in the U.S.

**Fawn A. Cothran, PhD, RN, GCNS-BC, FGSA**

Dr. Cothran highlighted the *Cancer Caregiving in the U.S. report* (published in June 2016 as a collaborative effort among NAC, the National Cancer Institute, and the Cancer Support Community). This report highlighted the experiences of 111 caregivers providing unpaid informal care in the US to a relative or friend diagnosed with cancer and compared characteristics, experiences, and needs to those of caregivers who provide care for some other primary reason.

It was highlighted that the cancer caregivers spent significantly more hours per week in providing care than their non-cancer caregiving counterparts with the average number of hours providing care of 32.9 hours (compared to 23.9 hours in the non-cancer caregiving population). Additionally, 50% of the cancer caregivers reported they were under high stress (compared to 37% of the non-cancer caregivers) and that they were more involved in helping to support activities of daily living compared to the non-cancer caregiving group.

These cancer caregivers also have significant responsibilities in interacting with their care partner/care recipient's health care providers (82%), monitoring their care and condition (76%), and advocating on behalf of their care partner/care recipient (62%).

### The Urgent Need to Address Cancer Caregiving Disparities

**Ranak Trivedi, PhD**

Dr. Trivedi highlighted the inequities in cancer incidence and mortality while noting that there are undocumented disparities due to a lack of disaggregated data, and the fact that we are missing the capture of diverse experiences and cultures.

She provided two examples of research efforts looking to provide more data and understanding around these inequities in cancer caregiving:

- **Project ENABLE Cornerstone:** determining the effectiveness and evaluate costs of a multi-component, lay coach-led care navigator intervention for under-resourced family caregivers (which is a Type I hybrid implementation-effectiveness randomized control trial which includes 294 African American and/or rural family caregivers of patients with newly diagnosed advanced care).
  - Key findings: high rates of depressed mood, stress burden, and quality of life



- **South Asian Family Approaches to Disease (SAFAD):** focused on South Asian survivors of breast cancer and caregivers (given the high rate of HER-2 positive breast cancer in this population) and the fact that these caregivers are more likely to seek caregiver supports, non-English resources, and help navigating the health care system.
  - Key findings: a number of unmet psychosocial and home- and community-based services programs were highlighted, including emotional distress, fear of recurrence and disease progression, fear of disclosure, loneliness, reluctance to join conventional support groups, and seeking culturally attuned self-management supports.

Dr. Trivedi concluded her talk by highlighting some key calls to action:

- Research: improve funding to understand cultural differences, prioritize data disaggregation in surveys and administrative data, and develop culturally and linguistically responsive interventions, programs, and services.
- Policy: policies that support diverse family and caregiving structures and home and community-based services that overcome barriers.

## Opportunities to Support Cancer Caregivers along the Caregiving Continuum

*Allison J. Applebaum, PhD*

Dr. Applebaum highlighted both the findings from the Cancer Caregiving in the U.S. report (which Dr. Cothran had also featured) as well as the NAC report *Caring for the Carers: A Spotlight Brief on Supporting the Mental Health of Family Caregivers*. She then highlighted the unique challenges driving mental health outcomes in caregivers of patients with cancer, including: the sudden nature of the diagnosis, the fact that some cancers are genetically transmitted, the shift of cancer care to the home, and the fact that changes in patient functioning can often occur rapidly.

She noted that the Caregivers Clinic at Memorial Sloan Kettering Cancer Center provides psychosocial support to cancer caregivers. Since 2011, 408 caregivers have received psychodiagnostic visits and subsequently gone on to receive 4,136 follow-up individual psychotherapy sessions in the Clinic. Medication management has also been provided to 244 caregivers, as have been 98 couples/family sessions and three support groups.

Dr. Applebaum also presented recent data on the availability of family caregiver programs in U.S. cancer centers, with about 75% of cancer centers providing at least one program and numerous other supports available. She highlighted critical gaps in the identification, distress screening, and needs assessments for caregivers, and recommended that the creation of medical records for caregivers would allow for a repository for these data and an infrastructure to support the provision of psychosocial care.

She ended her talk with a call to action regarding the need to mitigate caregiver distress at each phase of the caregiving trajectory:

- Capitalize on the CARE Act as an opportunity to trigger a constellation of steps that will allow for the early identification of caregivers in need and triage to appropriate interventions and care.
- Create separate medical records for caregivers at the point of caregiver identification.
- Treat each follow-up cancer care “event” as an opportunity to evaluate caregiver wellbeing.
- Provide continuity of connection and care, which is necessary when patients no longer receive medical care (i.e., survivorship, hospice); and
- Emphasize that bereavement care is caregiver care.

~75% of cancer centers provide at least one family caregiver program.

## Making the Invisible, Visible: Cancer Caregiving Research in North Carolina and Beyond

*Erin E. Kent, PhD, MSc*

Dr. Kent began her talk by noting there were an estimated 18.1 million cancer survivors in the U.S. currently (and that it was projected this number would reach 26 million by the year 2040). Additionally, she pointed to 2022 data which shows there are approximately 3.4 million cancer caregivers and that 16.6% of U.S. adults reported responsibilities for caregiving.

The unique aspects of cancer that impact caregivers and families include:

- Complexity: rapid health deterioration, multi-modal therapies and complex decision-making, recurrence/fear of recurrence and complications.
- Financial toxicity: Families with an adult cancer diagnosis have higher odds for any medical debt, especially for those with medical out-of-pocket costs [P Richard, et al. The Financial Burden of Cancer on Families in the United States. International Journal of Environmental Research and Public Health (2021), 18(7), 3790, <https://doi.org/10.3390/ijerph18073790>].
- Care burden: Cancer versus non-cancer caregivers report higher levels of activities of daily living assistance and caregiving hours per week (Cancer Caregiving in the US 2016 report).

However, despite these impacts and statistics, direct services for caregivers are rarely provided.

To serve as a catalyst to bring together North Carolina faculty, students, trainees, and other colleagues, the [Caregiving Collaboratory](#) was created to share ideas and opportunities related to caregiving research, policy work, community engagement, and pedagogy, training and practice.

She highlighted several research efforts in North Carolina focused on rural patients and caregivers she is involved with. The focus on the rural setting stems from local population needs which focused on rural patients and caregivers (given that 40% of the population of North Carolina is rural and the estimate that cancer diagnoses in the rural population age 65 and older will increase 24% over the next 10 years).

On the care delivery front, Dr. Kent highlighted enCompass Carolina, a coach-assisted program targeted to rural cancer caregivers which is designed to help identify social support needs and connect caregivers to needed people and resources. This platform was adapted from eSNAP, a lay navigator-delivered social support mapping intervention developed by Dr. Maija Reblin (University of Vermont). enCompass Carolina provides coaching to help maximize social support to caregivers and their care recipients in the following dimensions: in-home, informational, communication and coordination, financial, emotional and spiritual, and transportation and delivery.

enCompass  
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recipients

Dr. Kent concluded her talk by highlighting a number of design solutions needed to improve cancer caregiving research:

- Better measurement and harmonization of variables that matter to understanding and improving caregiving experiences.
- More funding and coordination of research resources (e.g., establishing an Office of Caregiving Research with the NIH Office of the Director).
- Establish a pipeline of transdisciplinary caregiving researchers.
- Focus on implementing what we know works.
- Focus on inclusive design with underserved populations; and
- Continue to partner and iterate with caregivers (given one size does not fit all).



## Breakout Session and Report Outs

For the final part of the Design Workshop, the attendees were separated into three breakout groups (research, policy change, and practice change) which were each facilitated by NAC staff.

The common themes, opportunities, and take aways that emerged across the three breakout groups are highlighted below (as well as the topic areas each item falls under, given the interconnected relationship among these three key areas):



RESEARCH

### 1. Research Gaps and Opportunities

The group highlighted a number of gaps in understanding the unique challenges of cancer caregiving for children as well as adults (and the needs of pediatric oncology patients). There are also gaps in knowledge regarding rural areas and the types of support they need (given that direct caregiver support and care are harder to come by). A number of health equity gaps were also identified such as data sets that promote inequity due to how caregivers are defined and other cultural gaps. Identification of existing caregiving data sets and registries were also identified as an opportunity to better understand how caregivers are identified.

*Key Take Away: The Collaborative should define the key, critical existing research gaps and align on a strategy to fill these gaps.*



RESEARCH



POLICY CHANGE

### 2. Care Coordination and Navigation

It was highlighted that the American Cancer Society had developed an online navigation tool which will include a caregiver-to-caregiver component and that multiple supports were needed (for instance, navigators focused on both the health system as well as the caregiver and patient's mental health needs). Reimbursement gaps were also highlighted (particularly in the case of family care navigators).



PRACTICE CHANGE

*Key Take Away: The Collaborative should assess the landscape of cancer caregiving care coordination and navigation programs and identify the educational, health system, and reimbursement gaps that could be addressed (as well as highlighting model programs that could be replicated).*



POLICY  
CHANGE

### 3. Training and Education Opportunities

It was identified that caregivers need training on multiple facets of their caregiving role, including the medical tasks they need to provide as part of their support in their care partner's cancer journey, an understanding of the specific treatment their care partner is receiving (and how that will impact their caregiving role), and how they can receive mental and emotional support themselves. On the health care professional side, it was noted that all practitioners require more training on the needs, importance, and roles of caregivers in the care of their care partners with cancer.

*Key Take Away: The Collaborative should identify caregiver and health care professional training and education needs and how to best fill these gaps.*

PRACTICE  
CHANGEPOLICY  
CHANGE

### 4. Policy Priorities

The key policy priorities identified include working at the state level to expand the Family Medical Leave Act/paid leave and identifying how more "top down" support can be provided for care coordination and navigation. Other opportunities highlighted include quality assessments, expansion of the Social Security definition of disability around certain cancers and needs of community health workers.

*Key Take Away: The Collaborative should identify key "low hanging fruit" opportunities in the policy realm (particularly those policy changes that would have the most impact for caregivers and could be more easily accomplished).*

POLICY  
CHANGE

### 5. Reimbursement Policies

It was noted that payers and health insurers needed a better understanding of how the education and needs of caregivers could ensure a high level of care and that currently there is not adequate reimbursement support for the providers to spend time providing education to caregivers. It was also highlighted that a "Welcome to Cancer" visit (akin to the "Welcome to Medicare" visit) could be developed which would provide education to both patients and their caregivers on the key services available to them (which could help increase patient outcomes).

*Key Take Away: The Collaborative should develop models to articulate how additional reimbursement support to practitioners to provide caregiver education would help improve patient outcomes and reduce overall health care spending (and key opportunities to ensure more education throughout the cancer journey is supported by payers).*

PRACTICE  
CHANGEPOLICY  
CHANGE

### 6. Need for Caregiver-Centric Shared Decision-Making Models

There is a need to create shared decision-making models with a caregiver lens (as most shared decision-making models are patient-focused) that articulates the impact patient decision making has on the caregiver.

*Key Take Away: The Collaborative should adapt existing patient-focused shared decision-making frameworks to create a framework focused on the caregiver (given that most current shared decision-making models are patient- and not caregiver-focused).*

PRACTICE  
CHANGE

RESEARCH

### 7. Opportunities to Leverage Existing Efforts

To help drive the group's cancer and caregiving agenda, it was suggested that existing platforms and efforts such as the American Cancer Society National Navigation Roundtable and Cancer Moonshot should be leveraged to highlight the key cancer and caregiving issues such as care navigation, policy change, and research needs.

*Key Take Away: The Collaborative should ensure existing efforts are aware of the cancer and caregiving efforts being taken forward by the Collaborative (and to leverage opportunities for these efforts to help implement and scale these key priorities).*

POLICY  
CHANGEPRACTICE  
CHANGE

## Next Steps

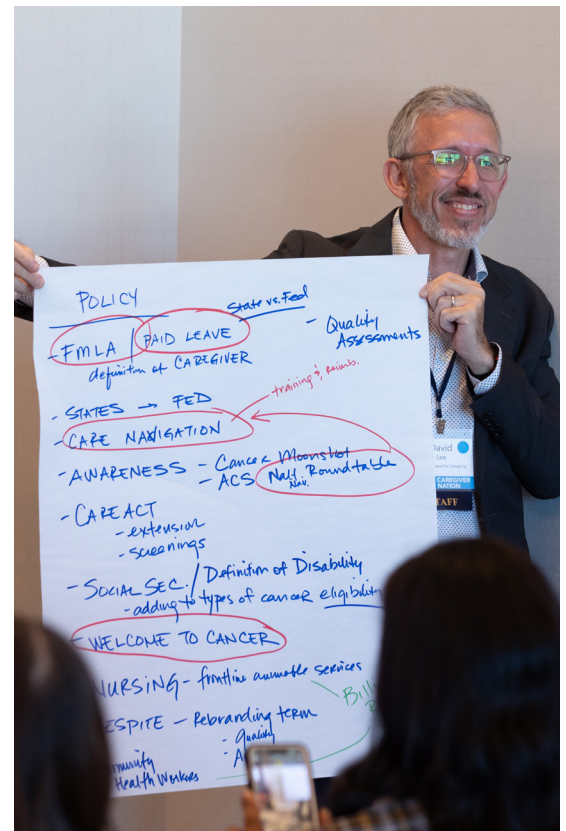
Mr. Resendez thanked everyone for their efforts and thoughts around the action that can be taken to act on the group's shared vision to support cancer caregivers. He noted that the Collaborative was envisioned as a long-term initiative with NAC as the convener and catalyst of this work, in partnership with a broad group of stakeholders.

In 2024, he noted that NAC will stand up the Collaborative's governance structure and workstreams and will sponsor a session in early 2024 to share NAC's thinking on the collaborative organizational structure, specific proposed action agendas, and a report out from the Design Workshop for those who were unable to participate.

## Acknowledgements

The National Alliance for Caregiving thanks all the attendees and presenters for their engagement before, during, and after the design workshop, as well as those stakeholders who engaged with the NAC in the planning phase of the workshop to help frame the conduct and focus of this effort.

Additionally, we recognize the generous sponsorship of the following partners who made the workshop and Cancer Caregiving Collaborative design phase possible: EMD Serono, Bristol Myers Squibb, Sanofi, Pfizer, Merck, Eisai, and 2seventybio.



## APPENDIX:

### NAC Cancer Caregiving Collaborative Design Workshop Attendees

|   |   |  |
|---|---|--|
| Ivy Ahmed, Eisai  | Heidi Donovan, University of Pittsburgh                         | Yadira Montoya, National Alliance for Caregiving             |
| Yewande Akinbami, Patient-Centered Outcomes Research Institute      | Emily Fields, 2seventy bio                                      | Elizabeth Mullin, Cancer Support Community                   |
| Demi Anastasiadis, Sanofi   | Ashley Freedman, National Patient Advocate Foundation           | Chandlyen Nightingale, Wake Forest University                |
| Tara Anglim, North Well Health                                      | Jasmine Greenamy, Bristol Myers Squibb                          | Yiqing Qian, Johns Hopkins University                        |
| Allison Applebaum, Memorial Sloan Kettering Cancer Center (speaker) | Sharon Hamill, CSU Shirley Haynes Institute for Palliative Care | Sarah Rasby, University of Nebraska-Lincoln                  |
| Pamela Barnes, Bristol Myers Squibb                                 | John Hughes, Merck  | Jason Resendez, National Alliance for Caregiving (moderator) |
| Anneliese Barron, One Family Foundation                             | Erin Kent, University of North Carolina (speaker)               | Sally Sachar, Sachar Solutions                               |
| Tom Borck, EMD Serono   | Parvathy Krishnan, Krishnan Foundation                          | Kristen Santiago, Lungevity                                  |
| Tammy Boyd, American Cancer Society                                 | Michael LaMonte, University of Buffalo-SUNY                     | Manan Shah, Bristol Myers Squibb                             |
| Rachel Cannady, American Cancer Society                             | David Lee, National Alliance for Caregiving                     | Rachel Solomon, Sanofi                                       |
| Martin Carrizosa, WellSpring  | Bethany Lilly, The Leukemia & Lymphoma Society                  | Lauren Tokarewich, National Alliance for Caregiving          |
| Zeena Chi, Genentech  | Tabassum Majid, Patient-Centered Outcomes Research Institute    | Ranak Trivedi, Stanford University (speaker)                 |
| Fawn Cothran, National Alliance for Caregiving (speaker)            | Melissa Miller, Cancer Support Community                        | Alexandra Zaleta, Cancer Care                                |
|   |   | Mike Zincone, Pfizer   |