

Strategies and Interventions to Strengthen Support for Family Caregiving

A Workshop

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AGENDA

Thursday, June 5, 2025: 9:00am – 5:00pm

Friday, June 6, 2025: 9:00am – 12:30pm

Keck Center, Room 100
500 5th St NW
Washington, DC

THURSDAY, JUNE 5, 2025

Purpose

- Examine evidence-based interventions and strategies that effectively address the physical, mental, and financial burdens of caregiving for cancer and other serious illnesses, including the role of palliative care.
- Consider interventions that address the range of challenges associated with caregiving: psychological, emotional, physical, and financial/economic, including the increased risk of suicide among caregivers.
- Explore the role of palliative care in interventions to ease caregiver burden.
- Examine the special needs of different caregiver populations (e.g., children, older adults, individuals with disabilities)
- Consider how successful programs can be scaled and spread throughout the United States.
- Explore policy opportunities to support family caregivers, including employer/workplace-based policies and programs.

9:00–9:10

Welcome and Workshop Overview

Peggy Maguire, Cambia Health Foundation, *Planning Committee Chair*

9:10–10:30

SESSION 1: FAMILY CAREGIVING AND THE U.S. HEALTH CARE SYSTEM

Goals:

- Describe the value of family caregivers in the United States and the contributions they make to society, and specifically the health care system, in quantitative and qualitative ways.
- Consider the joys and challenges of caregiving at the various phases of life.
- Reflect on the unique needs of caregivers including psychosocial needs; community support needs (e.g., avoiding social isolation); financial needs; cultural considerations; special populations (e.g., young caregivers, caregivers in the workforce); screening for caregiver wellbeing and targeted interventions for caregivers.
- Explore the range of unmet needs of caregivers at different phases of caring for an adult living with a serious illness, a child living with a serious illness, or an individual experiencing a complex, lifelong disability.

Moderator: **Rita Choula**, AARP Public Policy Institute, *Planning Committee Member*

Experiences and Storytelling from Caregivers for Individuals with a Serious Illness or Lifelong, Complex Disability¹

Karen Brisbon, former caregiver to brother, Alan, and father, Beresford (prostate cancer), and mother, Ruth (breast cancer, congestive heart failure, and dementia)

Jonathan Cottor, National Center for Pediatric Palliative Care Homes, former caregiver to son, Ryan, with a rare disease

Jessica Guthrie, full-time caregiver to mother living with Alzheimer's Disease

Debbi Harris, mother and caregiver to son, Josh, with complex medical needs and disabilities (*virtual participant*)

10:30–10:45 BREAK

10:45–11:45 SESSION 2: NEW CHALLENGES AND OPPORTUNITIES TO SUPPORTING FAMILY CAREGIVERS AT THE STATE AND FEDERAL LEVELS

Goals:

- Consider the national and state level policy landscape for supporting family caregivers for individuals with serious illness and discuss the major challenges and opportunities.
- Examine the connections between federal actions (e.g., RAISE Family Caregivers Act), health systems, states, and employers working to support caregivers and how these efforts can be amplified or adopted widely to address unmet needs of caregivers.

Moderator: **Peggy Maguire**, Cambia Health Foundation, *Planning Committee Chair*

Alison Barkoff, George Washington University, *Planning Committee Member*

Jason Resendez, National Alliance for Caregiving, *Planning Committee Member*

Wendy Fox-Grage, National Academy for State Health Policy

11:45–12:45 LUNCH

¹ The workshop, and this session in particular, will include access to a separate meeting room (Keck 103) for individuals to decompress in private and participate in compassionate dialogue if the conversations raise difficult memories. Feel free to call or text planning committee member and chaplain, Jeffery Garland, at 973-495-3369, if you would like company.

12:45–2:30 SESSION 3: DEEP DIVE ON CAREGIVING POLICIES, PROGRAMS, AND FINANCING

Goals:

- Explore the latest evidence on effective caregiver interventions. Consider how each intervention benefited specific caregiver profiles or phases of caregiving.
- Discuss new opportunities in financing mechanisms for caregiver services and supports (e.g., employer-based programs, Medicare payment for caregiver education, Medicare value-based payments, state-based Medicaid payments, and others).
- Explore employer/workplace-based policies and programs that support caregivers.
- Consider the challenges to broadly implementing proven successful policies and programs.

Moderator: **Jason Resendez**, National Alliance for Caregiving, *Planning Committee Member*

Intervention #1: Paying Family Caregivers

Molly Morris, The Self-Direction Center

Meredith Doherty, University of Pennsylvania (*virtual participant*)

Intervention #2: Respite Care

Kim Whitmore, ARCH National Respite Network and Resource Center

Melissa Zimmerman, Jewish Family Services, Salt Lake City

Intervention #3: Care Coordination and Transitions

Anna Chodos, University of California, San Francisco (*virtual participant*)

Tyler Cromer, ATI Advisory

2:30–2:40 BREAK

2:40–3:40 SESSION 4: WORKING CAREGIVERS – NEEDS AND OPPORTUNITIES

Goals:

- Consider the needs of the one in five employed adults who are also caregivers for older adult loved ones.
- Explore opportunities to support this population through employer/workplace-based policies and programs.

Moderator: **Rebecca Kirch**, National Patient Advocate Foundation, *Planning Committee Member*

Crystal Denlinger, physician executive and caregiver to parents

Shawn Phetteplace, Main Street Alliance

Karen Kavanaugh, Tufts Medical Center, Working While Caring initiative

3:40–3:50 BREAK

3:50—4:50 SESSION 5: YOUNG CAREGIVERS – NEEDS AND OPPORTUNITIES

Goals:

- Consider the unique needs of young carers (children, adolescents, young adults).
- Explore where young carers receive support for themselves and the individuals they care for.
- Discuss the unique challenges young carers face and the opportunities to extend currently effective adult caregiver policies to benefit young carers.

Moderator: **Sharon Hamill**, CSU Shiley Haynes Institute for Palliative Care, *Planning Committee Member*

Feylyn Lewis, Vanderbilt University School of Nursing

Melinda Kavanaugh, University of Wisconsin, Milwaukee

Stephanie Fitzgerald, Lorenzo's House, Chicago (*virtual participant*)

4:50 Closing Remarks – Day 1

Peggy Maguire, Cambia Health Foundation, *Planning Committee Chair*

5:00 END OF DAY 1

FRIDAY, JUNE 6, 2025

9:00—9:10 Welcome and Day 2 Overview

Peggy Maguire, Cambia Health Foundation, *Planning Committee Chair*

9:10—11:15 SESSION 6: Palliative Care Principles and Practices for Family Caregiving²

Goals:

- Explore the role of palliative care in interventions to ease caregiver burden.
- Consider the current and possible future role of palliative care providers in supporting the needs of individuals with a serious illness or lifelong, complex disability and their caregivers (e.g., spirituality, experiences of loss – freedom, income, friends as well as the loss of a loved one's abilities and relationships) and the opportunities for palliative care providers to enhance caregiver supports.

² The workshop, and this session in particular, will include access to a separate meeting room (Keck 103) for individuals to decompress in private and participate in compassionate dialogue if the conversations raise difficult memories. Feel free to call or text planning committee member and chaplain, Jeffery Garland, at 973-495-3369, if you would like company.

Co-Moderators:

Jori Bogetz, Seattle Children's Hospital, *Planning Committee Member*

Sharon Hamill, CSU Shiley Haynes Institute for Palliative Care, *Planning Committee Member*

Lived experience perspectives:

Sarah McCarthy, Boston Children's Hospital, caregiver to daughter with cancer

Lisa Gables, American Academy of Physician Associates, caregiver to parents in rural setting

Palliative care perspectives:

Research: **Abraham Brody**, NYU College of Nursing

Chaplaincy: **John Tastad**, Sharp HealthCare (*virtual participant*)

Psychology: **Ranak Trivedi**, Stanford University

Pharmacy: **Jennifer Ku**, Providence Health (*virtual participant*)

Nursing: **Lynn Reinke**, University of Utah College on Nursing

11:15–11:30 **BREAK**

11:30-12:30 **SESSION 7: Key Opportunities for Improving the Family Caregiving Experience**

Goal: Planning committee members reflect on the workshop presentations and discussions and highlight unique opportunities to improve caregiving experience in the immediate, short, and long-term.

Moderator: **Peggy Maguire**, Cambia Health Foundation, *Planning Committee Chair*

Alison Barkoff, George Washington University

Jori Bogetz, Seattle Children's Hospital

Rita Choula, AARP Public Policy Institute

Rory Farrand, National Alliance for Care at Home (until May 2025)

Jeffery Garland, Association of Professional Chaplains

Sharon Hamill, CSU Shiley Haynes Institute for Palliative Care

Rebecca Kirch, National Patient Advocate Foundation

Kashelle Lockman, Society of Pain and Palliative Care Pharmacists

Jason Resendez, National Alliance for Caregiving

Susan Schneider, Duke University

12:30 **MEETING ADJOURNS**

