

Strategies and Interventions to Strengthen Support for Family Caregiving

A Workshop

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DRAFT 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*

9:10–10:15

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, *Planning Committee Member*

Experiences and Storytelling from Caregivers for Individuals with a Serious Illness or Lifelong, Complex Disability¹ (~1 hour)

Karen Brisbon, caregiver to family members experiencing cancer and dementia

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

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

10:15–10:30 BREAK

10:30–11:30 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 and kinship family (e.g., grandparents raising grandchildren) caregivers 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*

Wendy Fox-Grage, National Academy for State Health Policy

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

11:30–12:45 LUNCH

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.

¹ The workshop, and this session in particular, will include access to a separate meeting room for individuals to debrief and participate in compassionate dialogue if the conversations raise trauma.

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

Intervention #1: Paying Family Caregivers

- **Molly Morris**, Applied Self-Direction
- **Meredith Doherty**, University of Pennsylvania

Intervention #2: Respite Care

- **Kim Whitmore**, Marquette University, National Respite Network and Resource Center.
- **Melissa Zimmerman**, Jewish Family Services, Salt Lake City

Intervention #3: Care Coordination and Transitions

- *TBD*

2:30–2:45 **BREAK**

2:45—3:45 **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*

- **Karen Kavanaugh**, Tufts Medical Center, Working While Caring initiative
- **Crystal Denlinger**, National Comprehensive Cancer Network, caregiver to parents
- **Shawn Phetteplace**, Main Street Alliance

3:45—4:45 **SESSION 5: YOUNG CAREGIVERS – NEEDS AND OPPORTUNITIES**

Goals: Consider the unique needs of young carers (children, adolescents, young adults). Where do young carers receive support for themselves and the individuals they care for? What are the unique challenges young carers face? What are 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*

- **Melinda Kavanaugh**, University of Wisconsin, Milwaukee
- **Feylyn Lewis**, Vanderbilt University School of Nursing
- **Diana Shulla Cose**, Lorenzo's House, Chicago

4:45 **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 Caregiving**

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.

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

Psychology: **Ranak Trivedi**, Stanford University

Pharmacy: **Jennifer Ku**, Providence Health

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: 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, *Planning Committee Member*

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

Rita Choula, AARP, *Planning Committee Member*

Rory Farrand, National Alliance for Care at Home, *Planning Committee Member*

Jeffery Garland, Association of Professional Chaplains, *Planning Committee Member*

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

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

Kashelle Lockman, Society of Pain and Palliative Care Pharmacists, *Planning Committee Member*

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

Susan Schneider, Duke University, *Planning Committee Member*

12:30

MEETING ADJOURNS