NATIONAL ACADEMIES Sciences Engineering Medicine

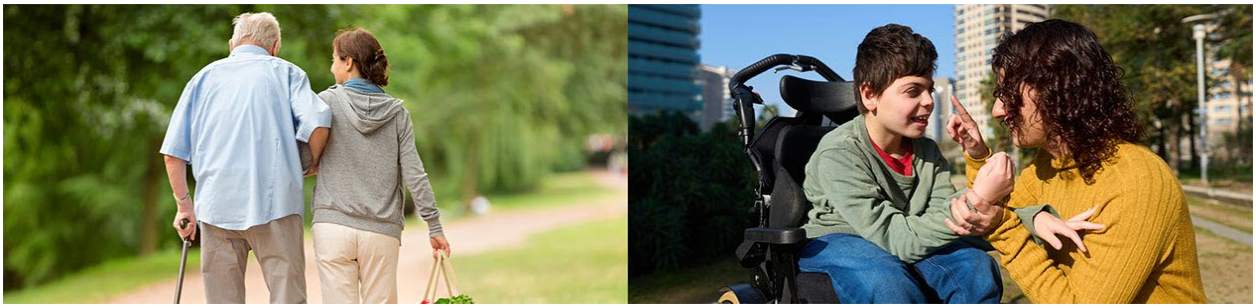
ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

Strategies and Interventions to Strengthen Support for Family Caregiving and to Alleviate Caregiver Burden: A Workshop

June 5, 2025 | 9:00 AM – 5:00 PM EDT |

June 6, 2025 | 9:00 AM – 12:30 PM EDT |

ATTENDEE PACKET



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NATIONAL ACADEMIES Sciences Engineering Medicine

BOARD ON HEALTH CARE SERVICES

Strategies and Interventions to Strengthen Support for Family Caregiving

A Workshop

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 Disability[1]

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 Caregiving**[2]

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

NATIONAL ACADEMIES Sciences Engineering Medicine

Roundtable on Quality Care for People with Serious Illness

Membership Roster

Peggy Maguire, JD (Co-Chair)
Cambia Health Foundation

Philip E. Rodgers, MD (Co-Chair)
University of Michigan Medical School

Jori Bogetz, MD
Seattle Children's Hospital and Research Institute

Brynn Bowman, MPA
Center to Advance Palliative Care

Karen Bullock, PhD, LCSW
Representing the National Association of Social Workers

Jane Carmody, DNP, MBA
The John A. Hartford Foundation

Steven Clauser PhD, MPA
Patient-Centered Outcomes Research Institute

Heather Coats, PhD
Representing the Hospice and Palliative Nurses Association

Zara Cooper
Harvard Medical School
Brigham and Women's Hospital

Rory Farrand, MA, MS, MSN
National Alliance for Care at Home (previously, Hospice and Palliative Care Organization)

Elena M. Fazio
National Institute on Aging
National Institutes of Health

Jeffery Garland, D-Min
Representing the Association of Professional Chaplains

Matthew Gonzales, MD
Representing the Catholic Health Association

Anna Gosline, MPH
Blue Cross Blue Shield of Massachusetts

Corita Grudzen, MD
Memorial Sloan Kettering Cancer Center

Scott Halpern, MD, PhD
University of Pennsylvania
Perelman School of Medicine

Sharon B. Hamill, PhD
CSU Shiley Haynes Institute for Palliative Care

Razia Hashmi MD, MPH
Blue Cross Blue Shield Association

Jessica A. Hausauer, PhD
National Coalition for Hospice and Palliative Care

Susan Hedlund
Sheri and Les Biller Family Foundation

Arif Kamal, MD, MBA
American Cancer Society

Rebecca A. Kirch, JD
National Patient Advocate Foundation

Tom Koutsoumpas
Coalition to Transform Advanced Care (C-TAC)

Kashelle Lockman, PharmD, MA
Representing the Society of Pain and Palliative Care Pharmacists

R. Sean Morrison, MD
National Palliative Care Research Center

Thomas M. Priselac, MPH
Cedars-Sinai Health System

Joseph W. Shega, MD
Representing the American Geriatrics Society

Cardinale Smith, MD, PhD
Mount Sinai Tisch Cancer Center

Wendy-Jo Toyama, MBA
American Academy of Hospice and Palliative Medicine

Shoshana Ungerleider
End Well Foundation
TED Health

Susan Elizabeth Wang, MD
Kaiser Permanente

NATIONAL CANCER POLICY FORUM

National Cancer Policy Forum Membership Roster

Robert A. Winn, M.D. (Chair)
Virginia Commonwealth University

Rohit Bhargava, Ph.D.
Cancer Center at Illinois

Smita Bhatia, M.D., M.P.H.
University of Alabama at Birmingham

Gideon Blumenthal, M.D.
Merck

Chris Boshoff, M.D., Ph.D.
Pfizer Inc.

Christina Chapman, M.D.
Baylor College of Medicine

Gwen Darien
National Patient Advocate Foundation

Crystal Denlinger, M.D., FACP
National Comprehensive Cancer Network

James H. Doroshow, M.D.
National Cancer Institute

S. Gail Eckhardt, M.D., FASCO
Baylor College of Medicine

Christopher R. Friese, Ph.D., R.N., AOCN
University of Michigan

Scarlett Lin Gomez, M.P.H., Ph.D.
University of California, San Francisco

Julie R. Gralow, M.D., FACP, FASCO
American Society of Clinical Oncology

Sarah M. Greene, M.P.H.
Cancer Research Advocate

Roy S. Herbst, M.D., Ph.D.
Yale University

Hedvig Hricak, M.D., Ph.D.
Memorial Sloan Kettering Cancer Center

Chanita Hughes-Halbert, Ph.D.
University of Southern California

Roy A. Jensen, M.D.
University of Kansas; Association of American Cancer Institutes

Randy A. Jones, Ph.D., R.N., FAAN
University of Virginia

Beth Y. Karlan, M.D.
University of California, Los Angeles

Samir N. Khleif, M.D.
Georgetown University; Society for Immunotherapy of Cancer

Ronald Kline, M.D.
Centers for Medicare and Medicaid Services

Shivaani Kummar, M.D., FACP
Oregon Health and Science University

Elena Martinez, Ph.D.
University of California, San Diego

Larissa Nekhlyudov, M.D., M.P.H.
Brigham & Women's Hospital; Dana-Farber Cancer Institute; Harvard Medical School

Cleo A. Ryals, Ph.D.
Flatiron Health

Susan M. Schneider, Ph.D., R.N., AOCN
Duke University

Lawrence N. Shulman, M.D., MACP, FASCO
University of Pennsylvania

Heidi Smith, M.H.S.
Novartis Pharmaceuticals

Amye J. Tevaarwerk, M.D.
Mayo Clinic in Rochester, Minnesota

Katrina Trivers, Ph.D., M.S.P.H.
Centers for Disease Control and Prevention

Robin Yabroff, Ph.D.
American Cancer Society

Christine Mirzayan Science & Technology Policy Graduate Fellow

Lauren Giurini, PhD Candidate
University of Wisconsin-Madison

NATIONAL ACADEMIES Sciences Engineering Medicine

Forum on Aging, Disability, and Independence

MEMBERSHIP ROSTER

CO-CHAIRS

Steve Ewell, M.B.A., M.S.
Executive Director
Consumer Technology Association (CTA) Foundation

Rebecca Stoeckle
Senior Vice President and Director of Health and Technology
Education Development Center

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The Gerontological Society of America

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Associate Professor
Department of Nursing
The College at Brockport SUNY

George Demiris, Ph.D.
PIK University Professor
School of Nursing & Perelman School of Medicine
University of Pennsylvania

Amy Kelley, M.D., M.S.H.S.
Deputy Director
National Institute on Aging
National Institutes of Health

Frank R. Lin, M.D., Ph.D.
Professor, Department of Otolaryngology-Head & Neck Surgery
Johns Hopkins School of Medicine
Director, Cochlear Center for Hearing and Public Health
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Georgia State University

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LeadingAge

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Vice President, Program
John A. Hartford Foundation

Bonnielin K. Swenor, Ph.D., M.P.H.
Director, The Johns Hopkins Disability Health Research Center
Associate Professor
The Wilmer Eye Institute, Johns Hopkins School of Medicine
Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health

Erwin Tan, M.D.
Director, Thought Leadership – Health
AARP

Fernando Torres-Gil, Ph.D.
Professor
Director, Center for Public Research on Aging
Luskin School of Public Affairs
University of California, Los Angeles

Strategies and Interventions to Strengthen Support for Family Caregiving and to Alleviate Caregiver Burden: A Workshop

Speakers Biosketches

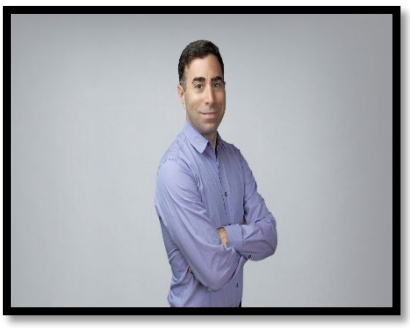
Karen Brisbon
Patient/Caregiver Advocate

As a Patient/Cancer Caregiver Advocate, my passion is to help families who are currently going through a cancer journey. My experience as a Caregiver for my mother during her fight against breast cancer and for my brother and Father who both fought Prostate Cancer emphasized how different each cancer journey can be which really puts focus on the need to have different services available for caregivers.

I have been a volunteer with the American Cancer Society in NJ/FL for the past 6 years supporting various fundraising events. I am a trained community volunteer for the ACS CARES Program (Community Access to Resources, Education and Support) focusing on giving someone who has been diagnosed with cancer with the non-clinical support with programs and services that fit their specific journey.

I have worked with the American Cancer Society Patient and Family Advisory Council which focused on Patient Navigation Support, Caregiver Support Services, Medical Health Content and Cancer Support and I am currently a member of the Mount Sinai Cancer Health Equity Research Center Community Advisory Board which focuses on reducing health inequalities in cancer care and lessening the burdens of cancer among underserved communities.

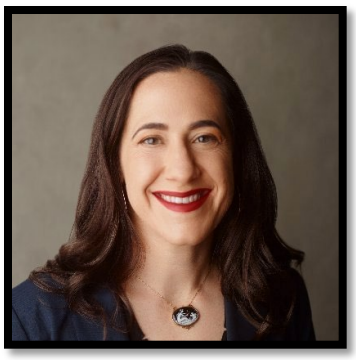
Caregiving is a life changing event with many different phases and each patient/caregiver journey will be very different. My passion is sharing my personal experience as a caregiver and advocate with patients and families as they go through their respective cancer journey. The availability of programs and services are extremely vital to everyone's journey and enables the caregiver to be the advocate for their family to ensure their loved one receives quality, dedicated, compassionate cancer care.



Ab Brody, PhD, RN, FAAN
New York University

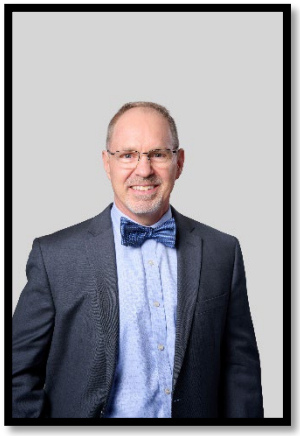
Ab Brody, PhD, RN, FAAN, is the Mathy Mezey Professor of Geriatric Nursing, Professor of Medicine and Associate Director of the Hartford Institute for Geriatric Nursing at NYU. He is a leading expert in developing the science of pragmatic trials, focused primarily on implementation of evidence-based, technology assisted, practices in geriatrics

and palliative care in the real world, in particular to address the needs of high risk, high need populations. He has developed the Aliviado Health program that seeks to help interdisciplinary clinical teams across settings to provide high quality, team-based care to persons living with dementia and their care partners and a companion AI assisted symptom management mHealth app for caregivers.



Anna Chodos, MD, MPH
Department of Medicine, UCSF

Dr. Anna Chodos is a Professor of Clinical Medicine in the Division of Geriatrics and the General Internal Medicine at Zuckerberg San Francisco General and the Division of Geriatrics at the Department of Medicine at UCSF. Her clinical work is in outpatient specialty care in geriatrics and dementia care. She leads two national programs to educate practicing providers on age-friendly care for people with dementia and their caregivers, especially for those who receive care in our nation's safety net health care systems. Dementia Care Aware trains primary care clinicians and teams on how to provide dementia care that starts with an early detection approach. Caregivers as Partners in Care Teams trains health care teams across setting on how to identify, engage, and support caregivers as members of the care team.

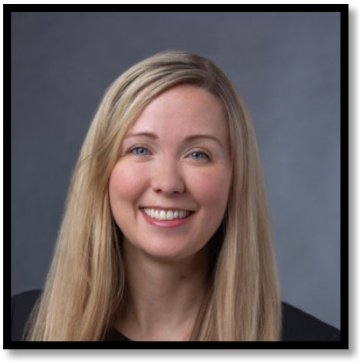


Jonathan Cottor, MBA, MPH
National Center for Pediatric Palliative Care Homes

Jonathan Cottor is a devoted father whose journey with his son Ryan, diagnosed with Spinal Muscular Atrophy at 9 months old, profoundly shaped his life. Ryan defied expectations, living an extraordinary 17 years until his death in December 2018. Inspired by their experience, Jonathan and his wife co-founded Ryan House, a pioneering children's respite, palliative, and hospice care home in Phoenix, Arizona.

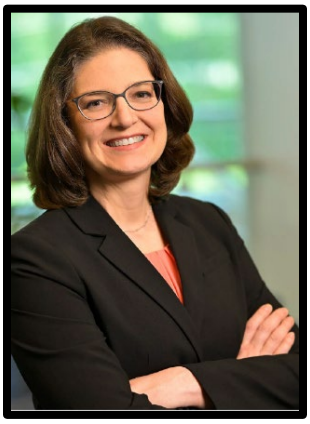
After a 30-year career in corporate marketing and leadership, Ryan's death became the catalyst for Jonathan to align his work with his passion. He earned a Master of Public Health (MPH) from the Johns Hopkins Bloomberg School of Public Health, specializing in policy and advocacy, along with a certificate in Maternal and Child Health.

Jonathan is now a recognized national thought leader in pediatric palliative care. He has been instrumental in building a coalition of community-based pediatric palliative care home models, culminating in the creation of the National Center for Pediatric Palliative Care Homes and its flagship initiative, Children's Respite Homes of America.



Tyler Cromer, MPA
ATI Advisory

Tyler Overstreet Cromer leads ATI Advisory's Complex Care Programs, Policy, and Research Practice and has nearly two decades of experience in health policy, budget, research, and consulting to public and private leaders. Cromer serves a national expert on complex care policy topics across health and social needs, including Medicare Advantage, PACE, home care, and caregiving. Prior to joining ATI, Cromer served as a senior executive at the White House Office of Management and Budget (OMB), providing oversight and expertise for budget development and execution across the Department of Health and Human Services (HHS). She was involved in many value-based care reforms, having led efforts at OMB related to the Center for Medicare and Medicaid Innovation (CMMI) from its inception until her arrival at ATI. Cromer serves a national expert and frequent speaker on complex care policy topics across health and social needs, including Medicare Advantage, PACE, home care, and caregiving. Cromer received her Master of Public Administration from the Maxwell School at Syracuse University and her bachelor's degree from Wake Forest University.



Crystal Denlinger, MD, FACP
National Comprehensive Cancer Network

Crystal Denlinger, MD is a practicing medical oncologist; a physician executive leading a global nonprofit dedicated to advancing equitable access to high-quality cancer care; a daughter, sister, and aunt; and a long-term informal caregiver for both of her parents during their journeys with cancer and dementia. She has experience in home-based parental caregiving as well as providing informal care for a parent living in a long-term care facility, in addition to her role as a medical oncologist providing formal care to those living with and through gastrointestinal cancers. She took up ballroom dancing during her caregiving journey as an outlet for well-being in 2020.

Meredith Doherty, PhD, LCSW
University of Pennsylvania

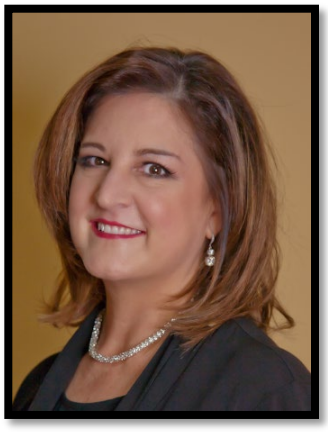
Dr. Doherty is an Assistant Professor at the School of Social Policy and Practice at the University of Pennsylvania where she conducts mixed-method, community-engaged research to understand the relationship between economic security and health. She draws upon her professional experience as a clinical social worker in safety-net health systems to develop, implement, and evaluate psychosocial and financial interventions for families facing serious and chronic illness. Dr. Doherty applies her expertise in the fields of psychosocial oncology, palliative and end-of-life care, health services research and social work leadership. Dr. Doherty received her MSW from the Silver School of Social Work at New York University, her PhD in Social Welfare from the CUNY Graduate Center and was Co-Chief Research Fellow in Psycho-Oncology at Memorial Sloan Kettering Cancer Center. Dr. Doherty is a Senior Fellow at the Leonard Davis Institute of Health Economics and faculty at Penn Center for Cancer Care Innovation. She is lead investigator of the Guaranteed Income and Financial Treatment (GIFT) Trial, the first randomized controlled trial to examine the impact of unconditional cash transfers on Medicaid beneficiaries with advanced cancer and their caregivers. At SP2, Dr. Doherty teaches courses in health policy and social work/nonprofit leadership.

Stephanie Fitzgerald, MA
Lorenzo's House, Chicago

For 30+ years, founded and led social impact organizations– schools, a statewide strategic philanthropy and a leadership development organization. She brings strategic thinking; facilitative leadership; operations and process improvement; diversity, equity and inclusion; people development; and experience as a mother of four and as a carer to family members with Alzheimer's to this role. BA Harvard University, MA University of Illinois & MA University of Delaware.

Wendy Fox-Grage
National Academy for State Health Policy

Wendy Fox-Grage is a senior policy fellow on NASHP's Aging and Disability team, working on long-term services and supports, family caregiving, and palliative care. She joined NASHP in September 2019. Previously, she worked as a senior strategic policy advisor for the AARP Public Policy Institute for 15 years and as a program principal for the National Conference of State Legislatures for nearly 10 years. She started her career as a Congressional Fellow for the U.S. Senate Special Committee on Aging. She has a BS in human development and social policy from Northwestern University and Master's degrees in both gerontology and public administration from the University of Southern California.



Lisa Gables, CPA
American Academy of Physician Associates

Lisa M. Gables, CPA, is an association executive with extensive experience in healthcare and aging services. She was named chief executive officer of the American Academy of PAs (AAPA) in September 2020 after serving as interim CEO since June 2019.

In 2024, Gables founded HealthFORCE, a national alliance of leaders committed to addressing the root causes of the healthcare workforce crisis. The HealthFORCE vision is a future where every individual in the United Staes can swiftly, affordably, and reliably access quality, safe healthcare.

Jessica Guthrie, MEd
Millenial Caregiver, Advocate

Jessica C. Guthrie, M.Ed is a visionary leader reshaping the caregiving landscape through lived experience as her mother's Alzheimer's caregiver and over a decade of executive leadership expertise. As founder of Career & Caregiving Collide™ and Jessica C. Guthrie Caregiving Consultancy, she champions dignified, empathetic care while helping organizations create innovative support strategies for family caregivers. A nationally recognized advocate, Jessica bridges the gap between corporate initiatives and real caregiver experiences, ensuring diverse family voices drive meaningful change in care solutions.

Debbi Harris
Family Voices of Minnesota

Debbi Harris works as a systems specialist for Family Voices of Minnesota, consulting to help families navigate the complex health care infrastructure. She has been a family leader for the Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity (CMC), as well as a former Director in Executive Leadership on the Board of The Arc of the United States. Harris has worked with the national Workers Advisory Group (WAG) for Paid Leave and the National Caregiver Advocacy Collaborative of the National Alliance for Caregiving and has contributed to workgroups on transition from pediatric to adult medicine, community advisory boards regarding equity in access to federal waivers, a direct care workforce shortage committee for her home county, and two pediatric bioethics committees. Her family's story was featured in the RAISE Act Initial Report to Congress 2021, as well as the Better Life Lab: Crisis Conversations, Family Caregiving Podcast, with journalist Brigid Schulte. Harris was the 2021 guest lecturer for the Volk Lecture in Medical Humanities, Cincinnati Children's Hospital.

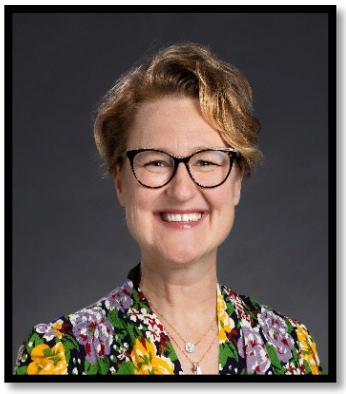
Harris is a writer of Narrative Medicine and has published in Today's Caregiver magazine, Kaleidoscope, Existere: Journal of Literature and Arts, at Salon.com, JAMA Pediatrics, the Journal of Pediatric Rehabilitation Medicine, Complex Care Journal, the NHPCO Pediatric E-Journal and AAP Pediatrics, and others. The Harris family's story is featured at TreatPeopleLikePeople.org, sponsored by the Minnesota Governor's Council on Developmental Disabilities.

Harris lives in the Twin Cities area of Minnesota with her husband Victor, a retired USMC officer, where they care for their son Josh, who has complex medical needs and significant disabilities.

Karen Kavanaugh, MSW
Tufts Medical Center

Karen Kavanaugh leads the Working While Caring initiative at Tufts Medical Center, an initiative designed to engage employers in developing and evaluating solutions for employee caregivers and to strengthen the effectiveness research on workplace policies and practices for employee caregivers. Previously, she was Chief, Strategic Initiatives at the Rosalynn Carter Institute for Caregivers where she launched Working While Caring and co-led the development of a new framework for organizing the complexity and variation in care, RCI's profiles in caregiving experiences. Kavanaugh was previously with The Pew Charitable Trusts where she led several projects focused on state policy reform including early childhood home visiting, safe and effective pharmaceutical compounding, and d household financial security. She also worked for Michigan Governor Jennifer Granholm helping to advance the state's

human services and transportation policy agendas, coming to that work following several years in community development in Detroit, Michigan.



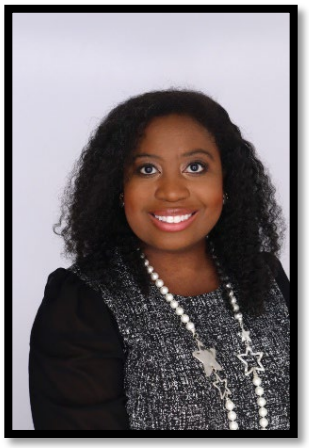
Melinda Kavanaugh, PhD, LCSW
University of Wisconsin - Milwaukee

Dr. Kavanaugh is a Professor of Social Work and a Licensed Clinical Social Worker (LCSW), with clinical expertise in health care professional education and caregiving research. Funded by federal, state, and non-profit organizations, Dr. Kavanaugh conducts translational research, including YCare, a multidisciplinary youth caregiving skills and support protocol for young carers in ALS, cancer, Alzheimer's disease, and spinal cord injury and traumatic brain injury in the military connected and Veteran community. Dr. Kavanaugh's research is community engaged, partnering to create targeted programs and support for children, youth and young adults as caregivers. Additionally, Dr. Kavanaugh's research informed a series of books for children, young adults, families and schools, including a graphic novel translated into 11 languages. Dr. Kavanaugh is also president of Global Neuro YCare, an international non-profit, focused on developing language and culturally accessible programs and supports for health care professionals, children, youth, and families in neurological disorders around the globe, including the animated short film, "LUKi & the Lights", helping children and families understand and talk about ALS/MND.

Jennifer Ku, PharmD, BCPS
Providence Health & Services

Dr. Jennifer Ku is a palliative care clinical pharmacist and a board-certified pharmacotherapy specialist caring for patients in the South Puget Sound region. Within Providence Health & Services, she delivers palliative care as part of a transdisciplinary team to patients hospitalized at two community hospitals and ambulatory patients seen at an outpatient palliative care clinic. She holds several system-wide and institutional committee appointments within Providence and currently serves as the Advocacy Co-Chair for the Society of Pain and Palliative Care Pharmacists. Prior to joining Providence, she practiced or received training in hospice and palliative medicine at various geographical locations in the United States including MedStar Georgetown University Hospital, University of Iowa Hospitals & Clinics, and the Iowa City VA Medical Center. Her areas of expertise include medication stewardship within hospice and palliative medicine, transdisciplinary teamwork, and interprofessional education. Dr. Ku also serves as a Clinical Assistant Professor at the University of Washington School of

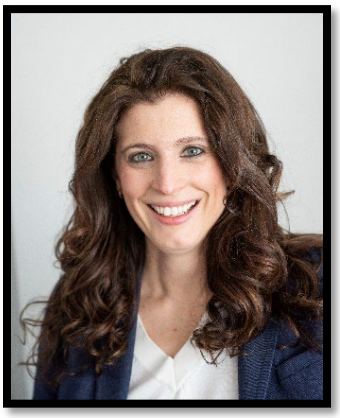
Pharmacy. She graduated with her Pharm.D. from the University of North Carolina Eshelman School of Pharmacy, completed a residency in pharmacy practice at University of Utah Health and completed a residency in pain management and palliative care at University of Iowa College of Pharmacy.



Feylyn Lewis, PhD
Vanderbilt University

A native of Nashville, Tennessee and a Vanderbilt University alumna, Dr. Lewis grew up as a youth caregiver for her disabled mother. Her experience with caregiving, disability, and living life on the margins led her on a path of global research and advocacy. She has a Master's degree in Clinical Mental Health Counseling and a PhD in Social Work. Her research focuses on mental health and resiliency in youth and young adult caregivers, and she conducts research in the US, Europe, UK, and Australia. Dr. Lewis currently works as the Assistant Dean of Student Affairs at Vanderbilt University School of Nursing, where she is responsible for providing vision, leadership and strategic planning for student affairs programming that delivers holistic wellness formal support services, student life and community engagement.

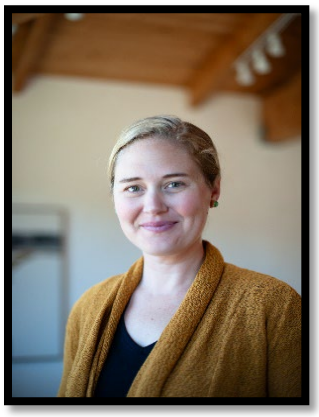
Outside of work, she serves as the Vice-President of Diversity, Equity, Inclusion, and Belonging in the Junior League of Nashville, a board member for the Tennessee Caregiver Coalition and the Brighton and Hove Carers Centre (United Kingdom), and co-chairs the Congressionally appointed PCORI Healthcare Delivery and Disparities Research Advisory Panel, and she sits on numerous other international advisory boards. She currently resides in Nashville where she continues to provide care for her mother.



Sarah McCarthy, PhD, MPH, LP
Boston Children's Hospital

Dr. McCarthy is the Director of Psychology of the Robert's Program on Sudden Unexpected Death in Pediatrics at Boston Children's Hospital. As a researcher, she has published over 50 peer reviewed articles in high impact journals including the New England Journal of Medicine, Pediatrics, and JAMA Pediatrics, and her work has been funded by AHRQ, PCORI, and multiple internal awards. Findings from her research have informed, and more importantly, humanized the way we care for children with serious medical illness and their families during their illness and into bereavement. In service of this objective, Dr. McCarthy has also bravely shared her lived experience as a mother to her late daughter, a young child with cancer who died of complications from her treatment. Dr. McCarthy's courageous exploration has illuminated the tremendous burdens of caring for a

child with a serious illness within our health care system and identified urgent research priorities to improve the family experience and patient outcomes. Dr. McCarthy's advocacy for how we can better care for children with serious illness and their families inspires her scholarly writing, funded projects, invited presentations to national and international meetings, and her writing for the public as a fellow of the Academy of Health and the OpEd project.

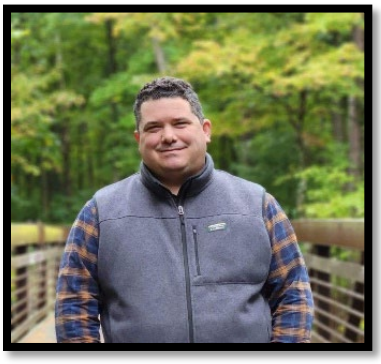


Molly Morris, MSW
The Self-Direction Center

Molly Morris is the Co-Founder of The Self-Direction Center, a new nonprofit dedicated to championing self-directed home and community-based services across the United States. With over 15 years of experience in health and human services systems, Molly is recognized for her expertise in self-directed care models, stakeholder engagement, and policy implementation.

As Vice President at Applied Self-Direction (ASD), Molly led initiatives impacting programs serving the over 1.5 million Americans who self-direct their services nationwide. She provided technical assistance to state agencies and managed care organizations while monitoring emerging trends in self-direction, including the impact of COVID-19 on service delivery models. Under her leadership, ASD launched a Participant Council to incorporate the expertise of people with lived experience and established the National Self-Direction Policy Workgroup, bringing together leaders in Financial Management Services, creating collaborative spaces for diverse stakeholders to drive meaningful policy change.

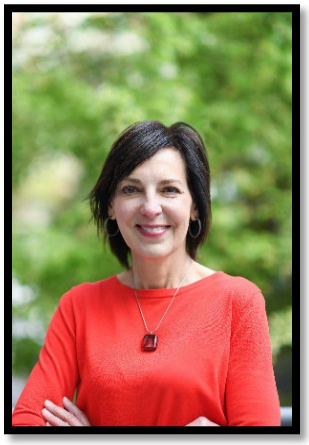
Previously, Molly worked at the National Resource Center for Participant-Directed Services at Boston College, supporting initiatives to expand self-direction to diverse populations. Molly holds a Master of Social Work from Boston College and a Bachelor of Science in Psychology from the University of Mary Washington.



Shawn Phetteplace
Main Street Alliance

Shawn Phetteplace is a strategic campaign leader and National Campaigns Director at Main Street Alliance, where he oversees national advocacy initiatives, grassroots organizing, and coalition-building efforts to empower small business owners. With over 17 years of experience in political organizing, government relations, and volunteer mobilization, Shawn previously spent six years at the ONE Campaign, where he

played a key role in passing major bipartisan legislation. He has extensive experience lobbying lawmakers, engaging the media, and managing multi-state campaigns. Passionate about economic justice and small business advocacy, Shawn continues to drive impactful policy change at the intersection of business and progressive values.

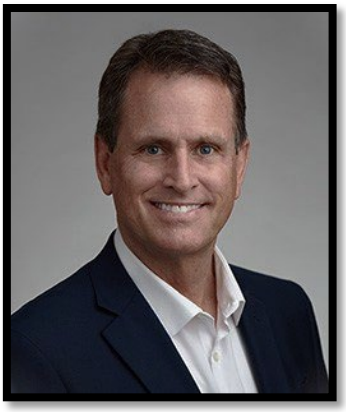


Lynn Reinke, PhD, ANP-BC, FAAN, FPCN
University of Utah, College of Nursing

Dr. Reinke received her PhD from the University of Washington School of Nursing in 2008. She completed a Post-Doctoral Fellowship in Health Services R&D at the VA Health Care System in Seattle. Recognizing the importance of research informing health policy, she was a Health and Aging Policy Fellow from 2016-2017. She served as a Co-Director of the UW Palliative Care Graduate Certificate Program from 2019-2021. In January 2022, Dr. Reinke assumed the position of the Claire Dumke Ryberg, RN, Presidential Endowed Chair for Palliative and End of Life Care at the University of Utah, College on Nursing. In 2024, she was appointed Director of the Center for Family Integrated Healthcare within the College of Nursing.

Dr. Reinke's clinical practice and program of research focuses on improving the delivery of palliative and end-of-life care for patients and their families with serious illnesses. Her studies, funded by NIH, VA, and Foundations, are designed to test nurse-led interventions on assessing and supporting family caregiver needs and on improving the quality of clinicians' end-of-life communication skills.

Dr. Reinke was selected in the inaugural cohort of the Cambia Sojourns Scholars Leadership Program in 2014. She is a Fellow in the American Academy of Nursing and served as the 2024 President for the Hospice & Palliative Nursing Association and Foundation.



John Tastad, MA
Sharp HealthCare

John Tastad, MA is the coordinator for Spiritual Support Services at Sharp HospiceCare, and the coordinator for the Advance Care Planning program at Sharp HealthCare. Now in his 24th year at Sharp, John's academic training includes undergraduate studies at Bushnell University and graduate studies at Fuller Theological Seminary and the University of San Diego. John is past chair of the San Diego Coalition for Compassionate Care and is actively involved in Bioethics at Sharp and in the community. John has spoken on topics related to, Spiritual Care, Advance Care Planning and Bioethics for many national, state and local academic institutions and organizations. John runs and reads a lot, and he is the proud dad of three amazing men and a beautiful five-year-old grandson.

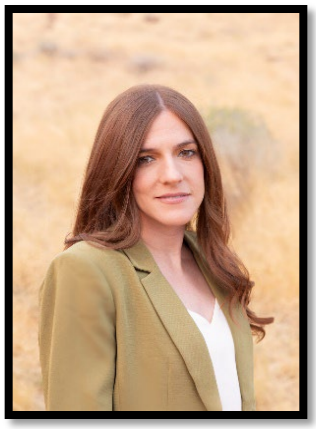
Ranak Trivedi, PhD, MA, MS
Stanford University

Ranak Trivedi, PhD, is a clinical psychologist and investigator with the HSR&D Center for Innovation to Implementation, in Palo Alto, California and an assistant professor of Dept. of Psychiatry and Behavioral Sciences, Stanford University. Dr. Trivedi's work is focused on understanding how families and patients can better collaborate to improve health outcomes for both. Her work has addressed the barriers and facilitators of chronic illness self-management, and developing family centered self-management programs that address the needs of both patients and their family members. Dr. Trivedi's work has highlighted the need of improving assessment and treatment of mental illnesses in primary care settings. She has been funded by the VA and NIH. Dr. Trivedi is a past recipient of an HSR&D Career Development Program award and leads the VA National Caregiver Research Interest Group.

Kim Whitmore, PhD, RN, CPN
Marquette University College of Nursing

Kim Whitmore, PhD, RN, CPN has more than 25 years of experience working with communities, families, caregivers, and individuals with disabilities across the lifespan. Currently, Dr. Whitmore is an Assistant Professor in the College of Nursing at Marquette University. The overall goal of her research program is to promote health equity and support positive outcomes for family caregivers. Dr. Whitmore received an Honors Bachelor of Science Degree and a Master of Science Degree in Nursing from Marquette University and a Doctor of Philosophy in Nursing Research from the University of Wisconsin- Milwaukee.

Dr. Whitmore is also a research consultant with the ARCH National Respite Network and Resource Center and leads the National Committee for Advancement of Respite Research.



Melissa Zimmerman, MSW
Jewish Family Service

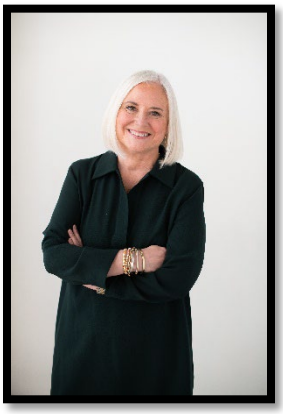
Melissa Zimmerman joined Jewish Family Service of Utah as Executive Director in March 2024. She is honored to lead an organization dedicated to strengthening individuals and families of all backgrounds through four core service areas: support for older adults and caregivers, affordable mental health counseling, emergency financial assistance, and the on-site Alex & Sally Lebwohl Food Pantry, which served nearly 29,000 people in 2024.

With 17 years of experience in the nonprofit sector, Melissa brings a deep commitment to community-based care. Prior to joining JFS Utah, she served as Chief Behavioral Health Officer at Jewish Family and Children's Services in Tucson, Arizona.

Melissa holds a bachelor's degree in psychology from the University of Arizona, where she graduated summa cum laude, and a Master of Social Work from the University of Denver. In 2020, she was recognized as one of Southern Arizona's 40 Under 40 Next Great Leaders.

Strategies and Interventions to Strengthen Support for Family Caregiving and to Alleviate Caregiver Burden: A Workshop

Planning Committee Biosketches



Peggy Maguire, JD
Cambia Health Foundation

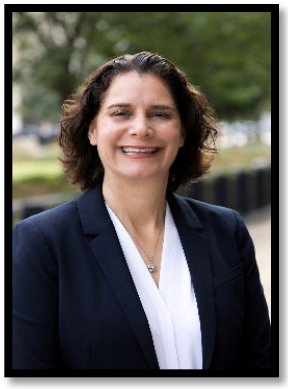
Peggy Maguire is the President of Cambia Health Foundation, where she works with a wide array of stakeholders to advance whole person health. Under her leadership, the Foundation has purposefully invested over $131 million to transform healthcare through innovative programs like the Sojourns® Scholar Leadership Program, which has supported 10 cohorts of emerging palliative leaders over the past decade to improve the care and quality of life for people with serious illnesses and their caregivers.

Peggy has spearheaded several significant initiatives at the Cambia Health Foundation such as the establishment the Cambia Palliative Care Center of Excellence at University of Washington and the creation of the Cambia Endowed Chair of Pediatric Palliative Care at Oregon Health and Sciences University's Doernbecher Children's Hospital. Peggy also led the way for an endowed fund for palliative care innovation at the University of California, San Francisco, where she continues to serve on an annual review committee.

Peggy co-chairs the Roundtable on Quality of Care for People with Serious Illness at National Academies of Sciences, Engineering and Medicine. She also chairs the Western States Regional Board of the American Heart Association and the national Grantmakers in Aging Board of Directors. Peggy is a member of the International Women's Forum and a senior fellow with the American Leadership Forum of Oregon.

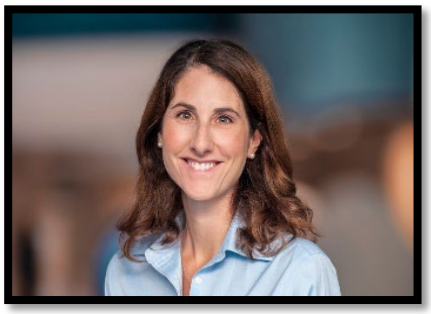
Peggy has received numerous accolades and awards, including a 2025 Presidential Citation from the American Academy of Hospice and Palliative Medicine in recognition of her significant contributions to the field of hospice and palliative medicine. In 2024, she was named an Executive of the Year by the Portland Business Journal. Peggy received Honorable Mention for Innovation at the 2019 Top Women in Healthcare Awards. In 2017, Portland Monthly Magazine honored Peggy with a Light a Fire Award for Extraordinary Board Service; she received an Athena Award from Dress for Success Oregon in 2016; was named a Woman of Distinction by the Girl Scouts of Oregon and Southwest Washington in 2015; and a Woman of Influence by the Portland Business Journal in 2014.

Peggy joined Cambia in 1997 and has held several key positions including vice president of legal services and senior vice president/chief of staff to the CEO prior to her current role. She holds a BA from Lawrence University, a JD from Northwestern School of Law of Lewis & Clark College, and a Certificate from the Executive Program at Stanford University's Graduate School of Business.



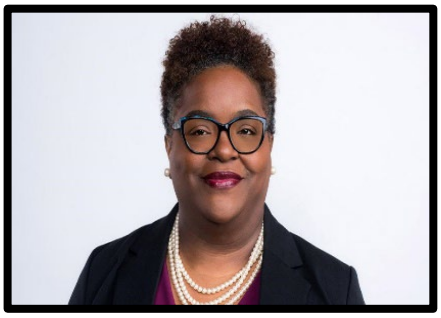
Alison Barkoff, JD
The George Washington University Milken Institute School of Public Health

Alison Barkoff is the Harold and Jane Hirsh Associate Professor of Health Law and Policy and Hirsh Program Director at the George Washington University Milken Institute School of Public Health. Prior to joining GW, she led the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services from January 2021 to October 2024, where she served as the advisor to the HHS Secretary on aging and disability policy, oversaw national disability and aging programs, and led cross-agency initiatives related to long-term services and supports (LTSS), family caregiving, direct care workforce, civil rights, housing, healthy aging and elder justice. Under hear leadership, ACL led the development of the first-ever National Strategy to Support Family Caregivers. Earlier in her career, she served in leadership roles in the federal government and non-profit advocacy. For more than 25 years, Ms. Barkoff has focused on legal and policy advocacy to improve the lives of people who face the most significant challenges in accessing health care and other critical community services and is a nationally recognized expert on LTSS, disability and aging policy, Medicaid and civil rights. She has testified before Congress and the U.S. Commission on Civil Rights.



Jori Bogetz, MD
University of Washington School of Medicine; Seattle Children's Research Institute

Jori F. Bogetz, MD, is an Assistant Professor of Pediatrics at the University of Washington School of Medicine, the Director of Research at the Treuman Katz Center for Pediatric Bioethics and Palliative Care, and an attending physician in pediatric palliative care at Seattle Children's Hospital. Dr. Bogetz completed her pediatric residency and an Academic General Pediatrics Fellowship at Stanford University and a Pediatric Hospice and Palliative Medicine Fellowship at Harvard/Boston Children's Hospital. Her research focuses on improving care for children with severe neurological impairment and their families through interventions that support high quality communication and family-centered care. Dr. Bogetz has published >50 papers in peer reviewed journals and contributed to 4 foundational textbooks in her field. Dr. Bogetz has received funding for her research from the National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Cambia Health Foundation, the National Palliative Care Research Center, the Seattle Children's Research Institute, and the Lucile Packard Foundation for Children's Health.



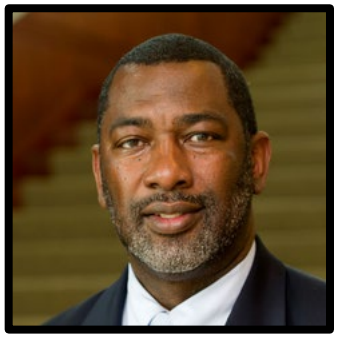
Rita Choula, MA
AARP Public Policy Institute

Rita B. Choula, MA is the Senior Director of Caregiving with the AARP Public Policy Institute. She leads and provides content expertise on family caregiving initiatives throughout AARP and externally. Her work bridges policy and research to practice, centered on identifying and supporting the needs of family caregivers elevating the unique nature of each caregiving experience. In collaboration with clinical experts and key stakeholders, Rita leads the development of policy and practice solutions that enable health care and social service providers to better recognize the diverse needs of family caregivers and provide supports to them across settings. Rita holds a Master's degree in the Management of Aging Services from the University of Maryland Baltimore County. She is a currently a member of the Board of Directors for the Association of Frontotemporal Dementia (AFTD) and the National Alliance for Caregiving (NAC). She is also a member of the Gerontological Society of America (GSA), American Society on Aging (ASA), and the National Academy of Social Insurance (NASI).

Rita is a recipient of the CARE 100 List of the Most Influential People in Care of 2020 and the National Hispanic Council on Aging Caregiving AARP Award of 2019. Rita is a former family caregiver to her mother of fifteen years while caring for two young children.

Rory Farrand, MS, MA, MSN
National Alliance for Care at Home, *until May 2025*

Rory Farrand was most recently the Vice President of Palliative and Advanced Care at the National Alliance for Care at Home (formerly NHPCO), with over 20 years of experience in healthcare leadership. Her expertise spans palliative care, geriatric psychiatry, clinical training and operations, Alzheimer's/dementia care, and innovative program development. Prior to joining the Alliance, she served as National Director of Palliative Care at VITAS Healthcare, where she led initiatives to enhance palliative care services, developed community-based programs, and advocated for regulatory advancements. Rory's also served as Vice President of Medical Management at Centene Corporation, where she led national programs focused on palliative care and social determinants of health, and as both RVP of Clinical Operations, then VP of Clinical Learning & Development at Aspire Health. She is a board-certified adult nurse practitioner with an MSN in geriatric health, an advanced practice certificate in palliative care, and degrees in psychology, behavioral neuroscience, and art therapy. Rory is an active member of HPNA and the Gerontological Advanced Practice Nurses Association, and frequently speaks to various coalitions and organizations on topics related to Serious Illness. She has been a member of NASEM's Serious Illness Roundtable since 2022.

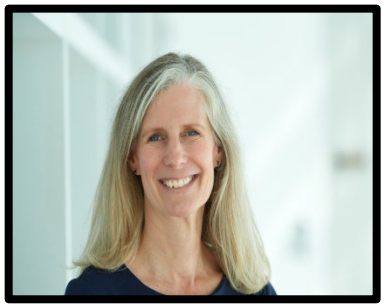


Jeffrey Garland, DMin
Association of Professional Chaplains

Rev. Dr. Jeffery T. Garland has served as a board-certified chaplain and a Palliative Care and Hospice Advanced Certification with the Association of Professional Chaplains for more than 25 years. Since 2000, Garland has worked full-time as a chaplain with Visiting Nurses Home Health Hospice and Palliative Care in West Orange, New Jersey. Garland works with homecare, facilities, and general inpatients units. His expertise would be working in predominantly urban neighborhoods providing educational and medical information on hospice and palliative care. Garland has served as the president of Association of Professional Chaplains from 2020-2021. He currently serves on the National Hospice and Palliative Care Organization. Garland has also worked with the National Academies Sciences, Engineering, and Medicines as part of the Association of Professional Chaplains. Garland is an adjunct professor at Seton Hall University teaching Christianity and Ethics.

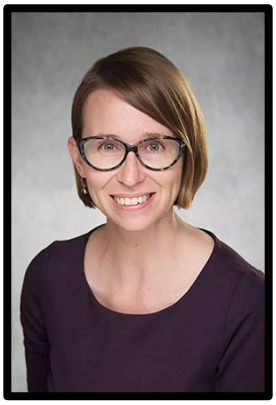
Sharon Hamill, PhD
California State University Shiley Haynes Institute for Palliative Care

Sharon B. Hamill received her Ph.D. in Social Ecology from the University of California, Irvine in 1990. She is the Executive Director of the CSU Shiley Haynes Institute for Palliative Care. She has been a Professor of Psychological Sciences/ Child and Adolescent Development at CSU San Marcos for 28 years. Her interests include the development of personal and social responsibility among adolescent and emerging adult caregivers, multi-generational families of Alzheimer's Disease patients, and ethnic group differences in caregiving. A primary focus of her research program and teaching is on promoting quality of life through palliative care in order to decrease suffering in patients and their caregiving families. Dr. Hamill is a former WASC Commissioner, a past recipient of the Harry E Brakebill Distinguished Professor Award for excellence in teaching, research and service, and a recipient of the California State University Faculty Innovation and Leadership Award. Dr. Hamill is currently a member of the NASEM Roundtable on Quality Care for People with Serious Illness and The National Alliance for Caregiving Cancer Collaborative Steering Committee.



Rebecca Kirch, JD
National Patient Advocate Foundation

Rebecca Kirch, JD, is EVP Policy and Programs for the National Patient Advocate Foundation (NPAF). As a leading health policy expert and advocate in her field, Rebecca is dedicated to advancing person-centered solutions that make the healthcare system work for all of us. She previously directed quality of life and survivorship initiatives with the American Cancer Society to integrate palliative care, psychosocial support and rehabilitation services with disease-directed treatment. Known for her expertise in patient and caregiver research engagement, Rebecca currently serves in leadership roles on several academic projects funded by NIH and PCORI. She co-founded Patient Advocate Foundation's Patient Insight Institute and is also board chair for Care Camps Foundation that supports pediatric oncology camps for children and families.



Kashelle Lockman, PharmD, MA
Society of Pain and Palliative Care Pharmacists

Kashelle Lockman is a Clinical Associate Professor and instructional design consultant in the Office of Consultation and Research in Medical Education, Department of Internal Medicine, at the University of Iowa Carver College of Medicine. Prior to joining OCRME, she was faculty at University of Iowa College of Pharmacy for 8 years in the SOLACE Palliative Care Collaborative, where she co-designed and directed a palliative care certificate and practiced as a palliative care pharmacist within the Iowa Healthcare outpatient palliative care clinic.

Dr. Lockman serves as a Trustee for the Society of Pain and Palliative Care Pharmacists (SPPCP) and represents SPPCP on the NASEM Roundtable on Quality Care for People with Serious Illness.

Dr. Lockman is a 2019 Cambia Health Foundation Sojourns Scholar and has received several teaching awards, including the 2019 American College of Clinical Pharmacy New Educator of the Year and a 2023 University of Iowa Office of Teaching, Learning, and Technology ICON All Star award.

Dr. Lockman earned a Bachelor of Science in biology at the College of Charleston, Doctor of Pharmacy from the University of Maryland, and Master of Arts in Instructional Systems Development from University of Maryland Baltimore County.

Jason Resendez
National Alliance for Caregiving

Jason Resendez is a nationally recognized care advocate. He currently serves as the President and CEO of the National Alliance for Caregiving, where he leads research, policy, and programmatic initiatives to build health, wealth, and equity for America's 53 million family caregivers. In 2023, Jason was named one of the most consequential leaders in health and medicine by STAT News.

Prior to joining NAC, Jason was the founding executive director of the UsAgainstAlzheimer's Center for Brain Health Equity where he pioneered the concept of Brain Health Equity through peer-reviewed research, public health partnerships, and public policy. In 2020, Jason was named one of America's top influencers in aging by PBS's Next Avenue alongside Michael J. Fox and Surgeon General Dr. Vivek Murthy. He has been quoted by The New York Times, The Washington Post, The Wall Street Journal, STAT News, and Univision on issues related to caregiving and health equity. Jason is from South Texas and graduated from Georgetown University.

Susan Schneider, PhD, RN, AOCN
Duke University

Dr. Schneider, earned PhD, MS and BSN degrees in Nursing. Currently she is an Associate Professor Emeritus at Duke University. She is a Past President of the Oncology Nursing Society and an Advanced Oncology Certified Nurse.

Dr. Schneider has over 40 years of experience as a clinical nurse, advanced practice nurse and researcher caring for individuals with cancer. In these roles she has both implemented and conducted clinical trials at three comprehensive cancer centers. She has expertise in conducting phase I pharmaceutical trials and has been a primary investigator for funded supportive care trials.

As a researcher, she focused on developing interventions to manage symptom distress to improve cancer patients' quality of life and increase survival. Such interventions hold significant potential for enhancing an individual's ability to adhere to treatment regimens and cope with the disease. She has received funding from the National Institutes of Health, the American Cancer Society and the Oncology Nursing Society Foundation.

Dr. Schneider has devoted her teaching career to the development of oncology nurse leaders. Examples of her program development skills include obtaining funding for innovative models of educating advanced practice oncology nurses at two universities. She received the Excellence in Cancer Nursing Research Award and Excellence in Cancer Nursing Education Award from the Oncology Nursing Society. She was selected as a Fellow in the American Academy of Nursing. Dr. Schneider served on the Biden Cancer Initiative Board.

Dr. Schneider uses her extensive clinical knowledge to advocate for quality care for the cancer population. As a support group leader, she assists individuals with metastatic cancer to make decisions about clinical trials and supportive care. As a leader of a professional organization, she is an experienced advocate for cancer research funding and patient access to care. She has been a member of the National Cancer Policy Forum since 2019.

Background Readings

1. ARCH Resources
2. The Care That Saved Me
3. Reflections On Caregiving Policy: Progress, Challenges, And Opportunities
4. The Role of Spirituality in Palliative Care: A Conversation With Tracy A. Balboni
5. Minnesota Paid Leave makes time for the moments that matter

ARCH Resources

Annotated Bibliography of Respite and Crisis Care Services, 6th Edition
https://archrespite.org/research/annotated-bibliography-of-respite-and-crisis-care-services

ARCH Innovative and Exemplary Respite Services Program Initiative
https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services/

ARCH Innovative and Exemplary Respite Services Evaluation Initiative
https://archrespite.org/i-and-e-data-briefs-2024/

ARCH Respite Research Initiative
https://archrespite.org/research/respite-research-consortium/

2024 Respite Research Summit Proceedings
https://archrespite.org/research/respite-research-summit-proceedings/

Publications of the Committee for Advancement of Respite Research
https://archrespite.org/research/carr-publications/

1) **Measuring the Value of Respite**
   https://archrespite.org/library/measuring-the-value-of-respite/

2) **Recommended Common Data Elements for Respite Research**
   https://archrespite.org/library/cde-white-paper/

National Respite Care Provider Training and Toolkit
https://archrespite.org/library/national-respite-care-provider-training-and-replication-toolkit/

Empowering Lifespan Respite Care Program Leadership in Implementation of the National Strategy to Support Family Caregivers
https://archrespite.org/library/empowering-lifespan-respite-care-program-leadership-in-implementation-of-the-national-strategy-to-support-family-caregivers/

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disease despite uncertainty about their efficacy, performed new kinds of diagnostic testing, and traced contacts. Those of us on the front lines requested commitment and collaboration from colleagues, who kept us informed about the disease statistics and reported important outcome measures. Ultimately, we know the disease will not disappear. But though outbreaks will recur, disease preparedness, strong leadership, and effective decision making will help mitigate the severity of MVD and its tragic consequences.

Disclosure forms provided by the author are available at NEJM.org.

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The Care That Saved Me

Sarah McCarthy, Ph.D.

I am a pediatric psychologist at a large academic medical center and a health services researcher. Beyond my professional identity, I am the mother of twin girls, Molly and Emma. In April 2020, Molly was diagnosed with two cancers, and by 2021, a third cancer had emerged. She died in 2022 at the age of 5. The day my daughter died, a nail-painting station was set up in the pediatric intensive care unit (PICU).

I never chose to have my personal and professional lives become inextricably linked. I wish I were writing this essay solely as a clinician and researcher. But given my reality, I've chosen to lean into the knowledge I wish I didn't have. Although I don't find meaning in Molly's illness or her death, I believe I can find meaning in sharing what I have learned and how I have changed. I am a better clinician and a different researcher than I was in 2020 — a truth that is difficult to accept because I would give anything to be who I was before. These experiences have made me rethink clinical practice and research in service of children with serious illnesses.

As a clinician, I have identified four practices that I now prioritize in my work, emerging from Molly's illness and death and my bereavement.

First, strive to illuminate the patient's personhood. Toward this end, I now write my notes differently. During Molly's ICU stay, rounds began with, "Molly is a 5-year-old girl with a history of ALL and neuroblastoma now MDS who was proactively intubated…." In my mind, I always added: "Molly is an energetic and creative 5-year-old girl. She loves playing the ukulele, writing plays with her twin sister, snuggling, and listening to books read aloud. She dislikes shift changes and has been known to set off her alarms to bring the nurses back." Though I don't include this level of detail in my clinical notes, I do make sure to include information that helps me and other clinicians see each patient as an individual,[1] illuminating their unique personhood.

Second, make an effort to understand life outside the hospital. My experience with Molly underscored the importance of seeing the child and their family members as people both inside and outside the hospital. I now ask children questions like, "What do you want your health care team to know about you?" and "What makes you happy?" and "If you weren't at the hospital today, what would you be doing?" I document their answers in the medical record. This information allows me and others to connect with patients and their families on a deeper level, providing context about their unique life circumstances that may affect their ability to cope with the demands of treatment.[2]

Third, cultivate practical compassion. When I met with families in the past, I always provided an assessment and offered evidence-based interventions aimed at alleviating distress. Though I still do these things, my approach looks

different now. First, I ask parents when they last ate, drank something other than coffee, or slept. If a parent has not eaten or slept, I pause my interview and offer to help meet these immediate needs before continuing. Doing so sometimes disrupts my schedule, and I know that as clinicians, we are often pressed for time and balancing multiple demands. But taking these small steps to recognize and address basic needs allows me to see the families I care for as humans and prioritize their sleep and nourishment.

Fourth, learn how to sit with darkness, while allowing for light. I have learned from grief. I am more comfortable sitting with darkness, anger, and gut-wrenching pain. I go to those dark places to be present with others who are in them, to bear witness. To not turn away from their pain, from their big uncomfortable emotions. I don't try to fix a pain I know is unbearable, but I let parents know that they are not alone, that their love for their child is seen and their grief is witnessed. I also allow myself to put that darkness down for a bit to continue functioning, to smile and laugh, to be present, to connect. This work now sustains me in new ways. I have shifted from practicing with empathy — hurting for my patients — to practicing with compassion, seeing their hurt and responding, sometimes with a specific intervention and always by seeing them, being present with them, recognizing our shared humanity.

As a researcher, I have shifted my approach because of my experience with Molly. I now choose only projects likely to have direct effects that advance the priorities of patients and their families. This focus is not negotiable for me anymore; I am committed to centering my research on the voices of people with direct experience of serious illness and bereavement. I therefore have to actively collaborate with and budget for these partners and use nontraditional methods to illuminate the often-unseen experiences of patients and caregivers.

As a psychologist, I have learned that small interventions can have substantial impact. After Molly's death, I worked with two PICU nurses to develop and test an intervention for alleviating parent-caregivers' fatigue.[3] It involved educating parents and staff about caregiver fatigue, as well as training staff on caregiver support, including the provision of practical items (such as sleep masks and shower steamers) as part of a "parent code cart" — all of which helped staff notice and respond to parents' suffering. After we had deployed the intervention for 6 months, we found that staff members' compassion had increased, their feelings of depersonalization had decreased, and they had greater confidence in their ability to assist families. Both staff and parents described the care as more personal and connected than it had previously been.

A few days before Molly died, I returned to the PICU around 3 a.m. to find my daughter's room filled with people. Seeing my panic, one of the primary nurses grabbed my hand. "It's OK," she reassured me. "We are just giving her a manicure. We know she likes to be fancy. Red and blue, her favorites." As tears rolled down my cheeks, I marveled that a team who had only known Molly when she was intubated and heavily sedated could see her so well. The day she died, we brought Molly's twin sister, Emma, to the hospital to say goodbye. Outside Molly's room, a nail-painting station was set up for Emma. For over an hour, I watched as Molly's nurses, social workers, doctors, respiratory therapists, and others sat down with Emma to have their nails painted. To talk with Emma about Molly. To share stories. To listen. To love. These were not billable interactions; there is no procedure code for compassion or connection. To this day, this sweet kindness is what I think of when I remember the worst day of my life.

The biggest thing I have learned is this: our work matters. Those small acts of kindness and moments of connection, seeing the children for who they are, make a difference. Patients and families do not forget them. And during the absolute hardest times, these acts sustain them.

It has been 4 years since Molly became ill and 2.5 years since she died. I have dug deep and still struggle to make sense of what happened to my child and to our family. Amidst the darkness, I have found a tiny point of light: the best medical care in the world, the most advanced science, could not save Molly, but the compassionate care that our family received saved me.

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Reflections On Caregiving Policy: Progress, Challenges, And Opportunities

Alison Barkoff

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As Congress and the Trump administration develop their health care agendas in the coming months, the challenges of accessing and providing care for people needing assistance with activities of daily living are critical issues that must be addressed. As the late Rosalynn Carter famously noted, caregiving affects all of us, as one day we all will provide care, receive care, or both.

More than 53 million Americans provide an estimated $600 billion of unpaid care <https://www.aarp.org/pri/topics/ltss/family-caregiving/valuing-the-invaluable-2015-update/> annually to family members who are aging or have a disability, helping them remain in their own homes and communities. Families often have to step in when they cannot access paid care due to long waiting lists <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2024/> for Medicaid, the only program that covers home care, and the high costs of privately paying for care. Family caregivers are increasingly expected to take on more care—and more complex medical tasks—with serious consequences to their own health and financial security, including $522 billion in lost income <https://www.rand.org/news/press/2014/10/27.html> nationwide each year and higher rates of physical and mental health impacts <https://journals.lww.com/ajnonline/fulltext/2008/09001/physical_and_mental_health_effects_of_family.9.aspx> due to a lack of training, support, and opportunities for self-care.

Policies to support family caregiving garner strong bipartisan backing, with a recent poll <https://bipartisanpolicy.org/blog/caregiving-poll-june-2024/> showing that 89 percent of Democrats and 79 percent of Republicans support investments in caregiving. Organizations across many sectors—including aging and disability advocates, workforce groups, state and local communities, businesses, and philanthropic organizations—have made caregiving a top priority and are taking action. As we stand at a crossroads at the beginning of a new administration, it's worth taking stock of where family caregiving policy has been and planning for what lies ahead.

National Strategy To Support Family Caregivers

Caregiving historically has not received the national attention it deserves. That changed in 2018, when Congress passed and President Donald Trump signed the bipartisan Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act <https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf> . Among the law's key provisions was its directive to the Administration for Community Living (ACL) to lead the development of the first-ever National Strategy to Support Family Caregivers. To gather input from all stakeholders across the country, the ACL established an advisory council with representatives of the diverse caregiver community—including adult children caring for aging parents, parents caring for children with disabilities, spouses caring for ill spouses, and youth caregivers—together with people receiving care, direct care workers, advocates, researchers, and state officials. Fifteen federal agencies joined the effort.

Then the COVID-19 pandemic hit. When I joined the ACL on the first day of the Biden administration in January 2021, the issue of caregiving had become visible like never before. Daily stories of family members stepping in as older adults and disabled people lost critical supports and as the direct care workforce crisis worsened had a powerful impact on policy makers and the public. The Biden administration then announced it would make strengthening the "care infrastructure" a priority by increasing access to home care, improving conditions for the paid direct care workforce, and better supporting family caregivers. Suddenly, the work to develop the National Strategy became an unprecedented opportunity to shape caregiving policy across the country in real time.

Our efforts culminated with the delivery of the National Strategy to Support Family Caregivers to Congress in September 2022. It was groundbreaking. This was the first time there had been a coordinated effort across the federal government to increase support for family caregivers. The National Strategy included more than 350

commitments from 15 federal agencies to increase access to care and better support caregivers and people receiving care. At the same time, it recognized that federal agencies cannot solve the caregiving crisis alone. The National Strategy made 150 additional recommendations for Congress, state and local government, business, philanthropy, and advocacy and provider organizations to build a stronger infrastructure of support for family caregivers. It also included cross-cutting principles that guided all recommendations, including the need to develop a well-trained and well-paid direct care workforce and the need to place the family and person at the center of all interactions.

Progress In Implementing The National Strategy

We knew the National Strategy had the potential to be an impetus for real change, unlike other reports that are issued with much fanfare and then sit on a shelf. On the day the National Strategy was delivered to Congress, the Department of Health and Human Services (HHS) Secretary Xavier Becerra, who had been a caregiver for his aging father, urged federal agencies to be bold in their implementation, and the White House committed to using its power to advance the caregiving agenda. A few months later, President Joe Biden spoke about the importance of caregiving in his 2023 State of the Union <https://caringacross.org/news/caring-across-statement-on-2023-state-of-the-union/> and then issued the first-ever executive order <https://www.govinfo.gov/content/pkg/FR-2023-04-21/pdf/2023-08659.pdf> related to caregiving in April 2023, directing federal agencies to take steps to support caregivers and increase access to care.

Federal agencies took heed of this call to action. In September 2024, the ACL issued a progress report <https://acl.gov/sites/default/files/2024ProgressReport_StrategyToSupportCaregivers.pdf> on federal implementation of the National Strategy. Nearly every one of the 350 commitments from federal agencies were in progress or had been completed, and agencies had added 40 new actions during the intervening two years. The breadth and reach of the actions were astounding. For example:

- The Centers for Medicare and Medicaid Services issued new payment rules <https://www.cms.gov/newsroom/press-releases/cms-finalizes-physician-payment-rule-advances-health-equity> allowing Medicare to cover training for family caregivers for the first time and issued a new regulation to increase access to Medicaid-funded home care and strengthen the direct care workforce;
- The ACL issued the first-ever regulations governing the national family caregiver program under the Older Americans Act

<https://acl.gov/sites/default/files/oam/2024/OAA_FinalRuleOverview2024.pdf> and invested $22 million to help states, local communities, and the aging networks begin to implement recommendations <https://acl.gov/ncsc> from the National Strategy;
- HHS and the Department of Labor launched an interagency initiative focused on strengthening the direct care workforce <https://acl.gov/DCWcenter> ; and
- The Department of Veterans Affairs significantly expanded <https://www.militarytimes.com/veterans/2022/07/25/expansion-of-va-caregiver-program-to-all-eras-of-service-remains-set-for-october/> its family caregiver support program.

The momentum and progress have gone far beyond federal agency action. A recent report <https://nashp.org/national-strategy-to-support-family-caregivers-progress-and-impact-report-2024/> about state and community progress implementing the National Strategy noted that 72 percent of states have used it to inform their policies in support of family caregivers. The National Strategy has helped drive—and has been driven by—more than $100 million in philanthropic investments in caregiving initiatives, including major investments by The John A. Hartford Foundation <https://www.johnahartford.org/grants-strategy/current-strategies/family-caregiving> , Grantmakers in Aging <https://www.giaging.org/> , and Care for All with Respect and Equity (CARE) Fund <https://carefund.org/> . The National Strategy has fueled advocacy, including the launch of Act on RAISE <https://www.actonraise.org/> , a coalition working to accelerate its implementation and strengthen federal-state coordination in support of caregivers, and it has added energy to Care Can't Wait <https://www.carecantwait.org/> , a campaign advocating for investments in home care, caregiver supports, and paid leave. In short, the National Strategy has been a driver of policy change across the country and has energized the growing national caregiving movement.

Looking Ahead: The Opportunities And Risks

As we look ahead, there are both opportunities to build on this momentum and serious threats that could cause us to lose ground. We have made so much progress in such a short time, yet too many people who need and provide care still cannot get the support they need. As I consider what is ahead for the National Strategy specifically and caregiving generally, I am filled with both cautious optimism and serious concerns.

I am cautiously optimistic that implementation of the National Strategy will continue. Its development already has continued across a change in administrations, proving that it is

apolitical. I hope that new leadership in agencies involved in the National Strategy will recognize its importance and continue to fulfill their commitments. Moreover, states' interest in policies to support caregivers and expand access to care <https://nashp.org/caregiving-state-policy-learning-collaborative/> continues to grow, building on the innovation already happening in many states.

The issue of caregiving continues to be high profile. During the 2024 presidential campaign, both candidates made promises <https://www.usatoday.com/story/money/2024/10/25/trump-harris-2024-election-caregiver-vote/75792138007/> to support family caregivers. Vice President Kamala Harris proposed to significantly expand access to home care through a new Medicare benefit, and President Trump expressed support for tax credits for family caregivers. In the November election, voters supported state initiatives focused on caregiving <https://nationalpartnership.org/2024-legislative-roundup/> , including paid family leave and a state-funded long-term care benefit. Even Hollywood is shining a spotlight on the issue of caregiving, with a documentary <https://wellbeings.org/series/caregiving/> by Bradley Cooper coming out this spring, a new foundation <https://colinfarrellfoundation.org/> started by Colin Farrell, and a nonprofit organization for caregiver education and support <https://wearehfc.org/> founded by Seth Rogan.

Members of Congress on both sides of the aisle have shared their personal experiences with family caregiving. That is one reason why caregiving has enjoyed bipartisan support, as reflected in the many bipartisan caregiving bills introduced in the last session of Congress. In December 2024, Congress passed and President Biden signed legislation to expand and improve supports for caregivers of veterans <https://www.elizabethdolefoundation.org/news/congress-passes-landmark-veterans-legislation-with-key-reforms-for-caregivers> . Members of both parties supported the Credit for Caring Act <https://press.aarp.org/2024-1-31-AARP-Applauds-Introduction-Credit-for-Caring-Act> , which would give caregivers a tax credit to defray out-of-pocket caregiving expenses. Members of the Senate and House reached a bipartisan agreement on provisions to strengthen and expand family caregiving programs as part of the reauthorization of the Older Americans and Lifespan Respite Acts.

But the new political environment has come with new risks, and we have already seen that bipartisan support for caregiving is no longer a guarantee. Despite strong bipartisan support when the legislation expanding caregiver supports was included in the end-of-the year budget bill, these provisions were stripped out of the final legislation after Elon Musk and then President-elect Trump criticized the bipartisan agreement. Not only does

this mean that desperately needed caregiver supports were not expanded, but now these critical programs are at a heightened risk for budget cuts <https://www.forbes.com/sites/howardgleckman/2024/12/23/gop-budget-squabble-puts-the-older-americans-act-at-risk/> . Caregiving stakeholders must be vigilant as President Trump and congressional Republicans call for significant cuts to federal spending when the budget deal expires in March. Cuts to non-discretionary programs could mean cuts to federal programs that support older adults, people with disabilities, and their caregivers. As outlined in the National Strategy, we need more, not less, investment in these critical programs to meet the needs of the growing number of caregivers and people they support.

President Trump and Republican congressional leaders have stated that they plan to use a budget reconciliation <https://www.cbpp.org/research/federal-budget/congressional-budget-will-offer-clues-to-republican-priorities-potential> bill—which is not subject to the filibuster in the Senate—to pass legislation extending the expiring 2017 tax cuts and reducing the federal deficit by making cuts to mandatory programs. With promises to protect Social Security and Medicare, they are targeting Medicaid <https://kffhealthnews.org/news/article/trump-republicans-gop-medicaid-expansion-aca-obamacare-matching/?utm_campaign=KHN%3A%20Topic-based&utm_medium=email&_hsenc=p2ANqtz--k08jEjVn1fCmw7wjEzi8RGbyolWI9OmY4L7VpsnJHVkWnjb0vumoNsXrzvlTtQ0p-Sf2ORNrsK00ijBhu8aYGgACLPg&_hsmi=343681926&utm_content=343681926&utm_source=hs_email> for significant cuts, with proposals <https://ccf.georgetown.edu/2025/01/20/house-budget-committee-circulates-new-detailed-list-of-budget-reconciliation-options-including-draconian-medicaid-cuts-within-house-republican-caucus/> to cut more than $2 trillion from the program. Cuts to Medicaid would mean growing waiting lists <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2024/> and even fewer people accessing the home care they need, worsening of the already dire direct care workforce crisis, and fewer supports for family caregivers <https://www.kff.org/medicaid/issue-brief/how-do-medicaid-home-care-programs-support-family-caregivers/> . Aging <https://justiceinaging.org/cutting-medicaid-harms-older-adults/> , disability <https://healthlaw.org/wp-content/uploads/2024/09/06-Older-Adults-and-PWD.pdf> , and caregiver groups are sounding alarm bells <https://drive.google.com/file/d/1_COKsR_KVwjaRDHmtxQybnGcH60EUtxS/view> that cuts to Medicaid would devastate caregivers and the people they support.

So where does that leave us? The universal nature of caregiving and its unprecedented visibility give hope that we can continue to make progress, or at least not lose ground. Caregivers, older adults, and people with disabilities are a powerful and growing constituency, with more than 11,000 people turning 65 each day and an increasing population of people with disabilities. As the new Congress and administration are beginning to put forward proposals, it is critical to highlight the impact on caregivers and the people they support. It is equally important to elevate their voices and stories with policy makers.

Given the stakes, I am confident the caregiving community will be powerful and effective advocates. Our collective advocacy has been the key to our success and will be critical to navigating the opportunities and serious challenges ahead. We are determined and well-positioned to make lasting change so that the millions of Americans who need and provide care can get the support they deserve.

The Role of Spirituality in Palliative Care

A Conversation With Tracy A. Balboni, MD, MPH, FAAHPM

By Jo Cavallo

November 25, 2021

National surveys consistently show that spirituality and religion are important components in the lives of most Americans, with more than 90% of adults expressing a belief in God and more than 70% identifying religion as one of the most important influences in their lives.[1] Studies also show that patients with cancer and their family caregivers rely on spirituality and religion to help them cope with the disease and that they want their specific spiritual needs and concerns acknowledged or addressed by their oncology medical team.[1] In addition, the physical and psychosocial health benefits these patients derive from their religious beliefs are significant.

According to research, patients with cancer who have high levels of spiritual well-being report having a better quality of life, lower levels of depression, less anxiety about death, and lower levels of distress. These patients also report finding meaning and a sense of health in their lives.[2]

In recognition that patients with cancer often experience not just physical and psychosocial suffering after a diagnosis, but spiritual suffering as well, in 2016, ASCO and the American Academy of Hospice and Palliative Medicine issued a joint statement defining spiritual and cultural care as one of the nine components of high-quality palliative care in oncology practice.[3] Two years later, ASCO included the integration of spiritual care in its guidelines for palliative care in the global setting.[4]

Assessing the Importance of Religion in Patients' Lives

Providing holistic care that includes addressing the physical, psychosocial, and spiritual needs of patients is central to the clinical practice of **Tracy A. Balboni, MD, MPH, FAAHPM**, Professor, Radiation Oncology at Harvard Medical School; Clinical Director, Supportive and Palliative Oncology Service at Dana-Farber/Brigham and Women's Cancer Center; and Residency Program Director of Harvard Radiation Oncology Program. In recognition of her clinical and research interests in the intersection of oncology, palliative care, and the role of spirituality in life-threatening illnesses, Dr. Balboni received the Walther Cancer Foundation Palliative and Supportive Care in Oncology Endowed Award during the 2021 ASCO Annual Meeting.

In her accompanying lecture, "Historical and Empirical Reflections on Spirituality in Cancer Care," Dr. Balboni said: "Spirituality plays a major role in patient well-being and decision-making." She cited pivotal research showing the impact spirituality and/or religion has on patients with advanced cancer. In one multisite study, scripted interviews were conducted to assess the role and importance of religion or spirituality in the lives of patients facing terminal cancer. The findings showed that most patients, 78%, agreed their religion and/or spirituality had been important in their cancer experience. A total of 74% of the patients reported that their faith helped them cope with the stresses of their illness, and 58% identified spiritual practice, such as, prayer, as being helpful.[5]

In an interview with *The ASCO Post*, Dr. Balboni discussed the importance of spirituality in palliative medicine and in patients' end-of-life decision-making; and how oncologists' sense of purpose and vocation can be spiritually nurturing.

Defining Spirituality

What is your definition of spirituality?

According to the International Consensus Conference, spirituality is defined as a "dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."

> "Our attention to patients' spiritual needs may help them transition to more quality-of-life–focused care.
>
> — *Tracy A. Balboni, MD, MPH, FAAHPM*
>
> *Tweet this quote*

This definition highlights the diversity of ways that individuals may experience their spirituality. It also underscores how spirituality can underlie core values, which may inform choices patients make from survivorship to the end of life.

Coping With Advanced Cancer

What role does spirituality play in palliative medicine, in patients' treatment decision-making, and in end-of-life decision-making?

My colleague Daniel Sulmasy, MD, PhD [Director and Senior Research Scholar of the Kennedy Institute of Ethnics at Georgetown University], well summarized the role that spirituality can play in illness by saying that "illness is a spiritual experience." For most patients, spirituality is important to them, particularly in the context of serious illness and how they experience that illness. And although a person's religion or spirituality can be a source of comfort and a way to cope with advanced cancer, it can also be a source of distress. For example, patients can feel spiritual distress or pain from losses that are experienced because of cancer or other challenging spiritual concerns, such as feeling spiritually abandoned or punished.

Patients can also experience spiritual concerns and conflicts as they approach end-of-life medical decision-making. For example, if a patient believes that God can perform a miracle and cure the patient of cancer, the patient might feel some tension about whether to continue with anticancer treatment. Alternatively, the patient may feel that not pursuing cancer therapy is the equivalent of not upholding the sanctity of life. As

spiritual beliefs, they are core values and sources of meaning that we as caregivers must honor and respect. We can do this in our care—with the help of a spiritual care professional, such as a chaplain—by engaging patients' spiritual beliefs respectfully as they consider their medical decisions.

The goal is to help patients in a person-centered fashion navigate decision-making in a way that honors all they are, from the realities of illness to their core sources of meaning and value.

Seeking Spiritual Support From the Medical Team

Do patients who have a religious belief suffer less than patients without a religious belief system?

Research does suggest that people who rely on spiritual coping in illness tend to preserve a higher quality of life than those without such a framework for managing the stresses of illness. One hypothesis as to why spiritual coping might contribute to better quality of life is that those who have a framework for meaning that is independent of one's physical status may be better able to preserve meaning and value despite the physical stresses of illness.

Some additional compelling research comes from the Coping With Cancer Study of patients with advanced cancer. It shows that terminally ill patients who receive spiritual support from their medical teams are more likely to use hospice care, seek less aggressive treatments, and have a better-quality end of life.[6] These findings suggest that our attention to patients' spiritual needs may help them transition to more quality-of-life–focused care, perhaps in part because we as a team are upholding sources of meaning that are found outside of the realities of illness.

GUEST EDITOR

Jamie H. Von Roenn, MD, FASCO

Addressing the evolving needs of cancer survivors at various stages of their illness and care, *Palliative Care in Oncology* is guest edited by Jamie H. Von Roenn, MD, FASCO. Dr. Von Roenn is ASCO's Vice President of Education, Science, and Professional Development.

Asking Patients About Their Spiritual Needs

Should oncologists ask patients about their spirituality or religion? How well trained are oncologists in terms of spirituality to comfortably discuss the topic with their patients?

Yes, we should ask patients about their spiritual outlook. This can be done with a simple spiritual history as part of a social history. We can ask about other forms of spiritual care patients might want, for example, a visit from a spiritual care professional while they are in the hospital. However, medical training in this area is inadequate. Most medical schools do include competencies around spirituality and training in taking a patient's spiritual history in conjunction with a medical history. However, our research shows that most patients with advanced cancer never receive any type of spiritual care from their oncologists or their oncology nurses, and we think that lack of training is the main barrier.[7]

The role of the oncologist in spiritual care is circumscribed. Spiritual care does not require oncologists to have in-depth conversations with their patients about their spirituality, although at times, such conversations may arise and can be appropriate provided they are entirely patient-centered. Rather the role of the oncologist is in taking a simple spiritual history by asking, for example: "Do you have a faith or spirituality that is important to you?" Such a question, easily included in a patient's social history, can help

oncologists understand the role of spirituality for a patient. Furthermore, such an inquiry signals to patients that they are seen as a whole person and that their spirituality is respected and understood as potentially important in illness.

Or we can just ask what is meaningful to the patient, for example, exercising, going for nature walks, or being with grandchildren. This provides important information about the patient's life and support system, and how treatment might impact the patient's lifestyle and quality of life.

Honoring Patients' Core Values

What should oncologists do if treatment conflicts with a patient's religion or spiritual beliefs?

All the care we provide should be patient-centered to honor patients' core values. Rather than immediately stereotyping a patient who refuses treatment due to a religious objection, we should go deeper and ask the patient to give more details of his or her concern. For example, we can say: "Tell me more about that belief. I want to understand, so I can better support you."

We should be respectful of patients' choices. Perhaps we can have them engage with the hospital chaplain or suggest they talk over the issues with their religious leader. Our goal is to listen to patients and understand as best we can any potential problems and then seek additional input from the medical chaplain, who is trained to engage with patients and help oncologists find a resolution.

Seeking Meaning and Purpose in Physicians' Lives

What role does spirituality play in physicians' health and well-being?

We all have ways of seeking meaning, purpose, and value in our lives and in our work. Many clinicians approach their work with a core "spiritual calling," or a sense that their vocation serves purposes and meanings found within but also transcends the technical realities of cancer.

For me, and I think for many other clinicians, caring for patients holistically, including recognizing their spirituality, helps me to recognize deeper sources of meaning that make work more sustainable and, ultimately, more fully the vocation it is meant to be.

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Minnesota Paid Leave makes time for the moments that matter

Minnesotans take care of one another. Starting in January 2026, Paid Leave will ensure Minnesotans can take the time they need to be there for some of life's most important moments—like welcoming a child, recovering from a serious illness, or caring for a loved one.

Paid Leave coverage

Paid Leave will provide payments and job protection for:

Medical Leave

1-12 weeks

- Someone's own serious health condition

Family Leave

1-12 weeks

- Bonding with a new child
- Caring for a loved one
- Managing military leave
- Certain personal safety issues

Maximum of 20 weeks combined in one year if someone qualifies for both medical and family leave.

Almost all employers and individuals that work in Minnesota will be covered by Paid Leave.

Paid Leave payments

Benefit payments will cover a portion of an individual's usual pay during a qualified leave. Eligibility for payments will be based on earnings in the previous year.

Paid Leave job protection

Paid Leave will ensure that employees are able to return to their job after taking leave. If someone has worked at their job for at least 90 days, their job will be protected when they return from leave.

Paid Leave funding

Paid Leave is a social insurance program. Both employers and employees will contribute premiums to the fund.

Learn more about Paid Leave eligibility, coverage, premiums and more at **info.paidleave.mn.gov**

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