

**FAMILY CAREGIVING FOR PEOPLE WITH CANCER AND OTHER SERIOUS ILLNESSES
A WORKSHOP**

ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

NATIONAL CANCER POLICY FORUM

FORUM ON AGING, DISABILITY AND INDEPENDENCE

**The Keck Center of The National Academies
Washington, D.C.
May 16-17, 2022**

**WORKSHOP AGENDA DAY ONE
Monday May 16, 2022**

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| 8:00 AM | REGISTRATION AND BREAKFAST |
| 8:30 AM | <p>WELCOME TO THE WORKSHOP</p> <p>Peggy Maguire, JD President and Board Chair, Cambia Health Foundation</p> <p>James Tulsky, MD Chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Chief, Division of Palliative Medicine, Department of Medicine, Brigham and Women's Hospital; Co-Director, Harvard Medical School Center for Palliative Care; and Professor of Medicine, Harvard Medical School</p> <p><i>Co-Chairs, Roundtable on Quality Care for People with Serious Illness</i></p> |
| 8:45 AM | <p>OVERVIEW OF THE WORKSHOP</p> <p>Grace Campbell, PhD, MSW, RN Assistant Professor, Duquesne University School of Nursing Director of Quality and System Integration, Family CARE Center Gynecologic Oncology Program, Hillman Cancer Center at UPMC Magee</p> <p>Randall A. Oyer, MD, FACCC Clinical Professor of Medicine, Perelman School of Medicine Executive Medical Director, Ann B. Barshinger Cancer Institute Penn Medicine Lancaster General Health</p> <p><i>Planning Committee Co-Chairs</i></p> |

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| 9:00 AM | <p>SESSION ONE: THE LANDSCAPE OF FAMILY CAREGIVING</p> <p><i>Moderator:</i> <i>Julie Bynum, MD, MPH</i> <i>Margaret Terpenning Professor of Medicine, Division of Geriatric Medicine</i> <i>University of Michigan</i></p> <p>Keynote Speaker Greg Link, MA Director, Office of Supportive and Caregiving Services Administration for Community Living, U.S. Department of Health and Human Services</p> |
| 9:25 AM | <p><i>“Reactor” Panelists:</i></p> <p>Sheria Robinson-Lane, PhD, MSN, MHA, RN Assistant Professor University of Michigan School of Nursing</p> <p>Loretta Christensen, MD, MBA Chief Medical Officer, Indian Health Service (participating remotely)</p> |
| 9:40 AM | MODERATED DISCUSSION/Q&A SESSION |
| 10:15 AM | BREAK |
| 10:30 AM | <p>SESSION TWO: UNDERSTANDING THE NEEDS OF FAMILY CAREGIVERS</p> <p><i>Co-Moderators:</i> <i>Jennifer Moore Ballentine, MA</i> <i>Executive Director</i> <i>CSU Shiley Haynes Institute for Palliative Care</i></p> <p><i>Rebecca Kirch, JD</i> <i>Executive VP, Policy and Programs</i> <i>National Patient Advocate Foundation</i></p> <p><i>Speakers:</i></p> <p>Kimberly D. Acquaviva, PhD, MSW, CSE, FNAP Betty Norman Norris Endowed Professor University of Virginia School of Nursing</p> <p>Cathy J. Bradley, PhD Professor and Associate Dean for Research, Colorado School of Public Health, University of Colorado at Denver Deputy Director, University of Colorado Comprehensive Cancer Center</p> |

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| | <p>Alexandra Drane Co-Founder and CEO ARCHANGELS</p> <p>Wendy G. Lichtenthal, PhD, FT Director, Bereavement Clinic Associate Attending Psychologist Department of Psychiatry and Behavioral Sciences Memorial Sloan Kettering Cancer Center</p> <p>Dannell Shu, BFA, MWS Family Caregiver, Pediatric Palliative Care National Task Force Member, Minnesota Department of Health's Palliative Care Advisory Council</p> |
| 11:35 AM | AUDIENCE Q&A |
| 12:00 PM | Break for LUNCH |
| 1:00 PM | <p>SESSION THREE: PROVIDING EFFECTIVE SUPPORT FOR FAMILY CAREGIVERS</p> <p>Co-Moderators: Randy Jones, PhD, RN, FAAN Professor and Associate Dean, Partner Development and Engagement, University of Virginia School of Nursing Assistant Director of Outreach, Recruitment, and Engagement University of Virginia Comprehensive Cancer Center</p> <p>Clyde W. Oden, Jr., OD, MDiv, MPH, MBA Assistant Director, Alameda County Care Alliance</p> <p>Speaker/Caregiver Dyads:</p> <p>Fayron Epps, PhD, RN, FAAN Assistant Professor NHCGNE Distinguished Educator in Gerontological Nursing Nell Hodgson Woodruff School of Nursing, Emory University Founder, Alter</p> <p>Malcoma Brown-Ekeogu Family Caregiver and Advocate for Frontotemporal Dementia (FTD) care</p> <p>Allison J. Applebaum, PhD Associate Attending Psychologist Director, Caregivers Clinic, Department of Psychiatry and Behavioral Sciences Memorial Sloan Kettering Cancer Center</p> <p>Peter Gee, MPP Family Caregiver Nursing student, NYU School of Nursing (participating remotely)</p> |

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| | <p>Loretta Christensen, MD, MBA Chief Medical Officer, Indian Health Service (participating remotely)</p> <p>Elton Becenti, Jr. (participating remotely) Family Caregiver</p> <p>Janice F. Bell, PhD, MPH, MN, FAAN (participating remotely) Associate Dean for Research, Doctor of Philosophy Program Director Western Health Advantage Endowed Professor and Professor Founding Faculty Member, Family Caregiving Institute Betty Irene Moore School of Nursing, University of California at Davis Lead Evaluator, Alameda County Care Alliance</p> <p>Lyn-Tise Jones, MA (participating remotely) Family Caregiver and Care Navigator</p> <p>Heidi Donovan, PhD, RN Professor of Nursing and Medicine Co-Director, National Rehabilitation Research & Training Center on Family Support, University of Pittsburgh Director, GynOnc Family CARE Center, Magee Womens-Hospital of UPMC</p> <p>Roger Glen Kirwin Family Caregiver</p> |
| 2:40 PM | MODERATED Q & A |
| 3:00 PM | BREAK |
| 3:15 PM | <p>SESSION FOUR: INTEGRATING FAMILY CAREGIVERS INTO THE HEALTH CARE TEAM</p> <p><i>Co-Moderators:</i> <i>Sara Damiano, LCSW, ACHP-SW</i> <i>National Director of Palliative Care, Ascension</i></p> <p><i>Allison J. Applebaum, PhD</i> <i>Memorial Sloan Kettering Cancer Center</i></p> <p>Speakers/Panelists:</p> <p>Jason Karlawish, MD Senior Fellow, Leonard Davis Institute of Health Economics Professor of Medicine, Perelman School of Medicine Co-director, Penn Memory Center University of Pennsylvania</p> |

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| | <p>Courtney Harold Van Houtven, PhD, MSc Research Career Scientist, Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT), Durham Veterans Affairs Health Care System Professor in The Department of Population Health Science Duke University School of Medicine and Duke-Margolis Center for Health Policy</p> <p>Terri Fried, MD Professor of Medicine, Section Chief, Geriatric Medicine Yale University School of Medicine</p> <p>Catherine M. DesRoches, DrPH Associate Professor of Medicine Harvard Medical School Director, OpenNotes Beth Israel Deaconess Medical Center</p> |
| 4:00 PM | MODERATED DISCUSSION |
| 4:30 PM | AUDIENCE Q&A |
| 4:50 PM | Workshop Day One Wrap-Up |
| 5:00 PM | Workshop Day One Adjourns <p style="text-align: center;">RECEPTION IN THE ATRIUM</p> |
| WORKSHOP DAY TWO Tuesday May 17, 2022 | |
| 8:00 AM | REGISTRATION AND BREAKFAST |
| 8:30 AM | <p>Welcome from the Planning Committee Co-Chairs</p> <p><i>Grace Campbell and Randy Oyer</i></p> <ul style="list-style-type: none"> – Brief Review of key themes from Workshop Day One – Overview of Workshop Day Two |
| 8:45 AM | <p>SESSION FIVE: RESEARCH CHALLENGES AND OPPORTUNITIES</p> <p>Co-Moderators: <i>Pamela S. Hinds, PhD, RN, FAAN</i> <i>Executive Director, Department of Nursing Science</i> <i>Professional Practice & Quality Research Integrity Officer, Children's National Hospital</i> <i>Professor of Pediatrics, School of Medicine and Health Sciences</i> <i>George Washington University</i></p> <p><i>Cathy J. Bradley, PhD</i> <i>Professor and Associate Dean for Research,</i> <i>Colorado School of Public Health, University of Colorado at Denver</i> <i>Deputy Director, University of Colorado Comprehensive Cancer Center</i></p> |

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| | <p><i>Speakers:</i></p> <p>Rebekah SM Angove, PhD Vice President, Patient Experience and Program Evaluation Director, Patient Insight Institute, Patient Advocate Foundation</p> <p>Jennifer L. Wolff, PhD Eugene and Mildred Lipitz Professor Director, Roger C. Lipitz Center for Integrated Health Care Department of Health Policy and Management Johns Hopkins Bloomberg School of Public Health</p> <p>Erin E. Kent, PhD, MS Associate Professor, Department of Health Policy and Management UNC Gillings School of Global Public Health Member of the Lineberger Comprehensive Cancer Center Prevention and Control Program</p> <p>Sheria Robinson-Lane, PhD, MSN, MHA, RN Assistant Professor Department of Systems, Populations, and Leadership University of Michigan School of Nursing</p> |
| 9:30 AM | MODERATED DISCUSSION |
| 10:00 AM | AUDIENCE Q&A |
| 10:20 AM | <p>SESSION SIX: POLICY OPPORTUNITIES TO SUPPORT FAMILY CAREGIVERS</p> <p><i>Co-Moderators:</i> <i>Amy Melnick, MPA</i> <i>Executive Director,</i> <i>National Coalition for Hospice and Palliative Care</i></p> <p><i>Rani E. Snyder, MPA</i> <i>Vice President, Programs</i> <i>The John A. Hartford Foundation</i></p> <p><i>Panelists:</i></p> <p>Susan Reinhard, RN, PhD, FAAN Senior Vice President and Director, AARP Public Policy Institute & Chief Strategist, Center to Champion Nursing in America and Family Caregiving Initiatives</p> <p>Devin Plote, PhD Clinical Policy Analyst, Clinical Innovation America's Health Insurance Plans</p> |

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| | <p>Michael Reese-Wittke, MPA Vice President for Advocacy and Research National Alliance for Caregiving</p> <p>Salom Teshale, PhD Policy Associate, Behavioral Health, Aging and Disability National Academy for State Health Policy</p> |
| 11:20 AM | AUDIENCE Q AND A |
| 11:40 AM | <p>Workshop Wrap-up Grace Campbell and Randall Oyer <i>Planning Committee Co-Chairs</i></p> |
| 11:45 AM | <p>Closing Remarks Abena Apau Buckley, MBA <i>Family Caregiver</i> <i>Farm Production and Conservation</i> <i>US Department of Agriculture</i></p> <p>Dannell Shu, BFA, MWS <i>Family Caregiver</i> <i>Pediatric Palliative Care National Task Force</i> <i>Member, Minnesota Department of Health's Palliative Care Advisory Council</i></p> |
| 12:00 PM | Workshop Adjourns |