

# NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

National Institutes of Health  
Bethesda, MD  
October 16–17, 2017

## DAY ONE: OCTOBER 16, 2017

7:00 a.m.–8:00 a.m.      **REGISTRATION**

8:00 a.m.–8:30 a.m.      **WELCOME AND INTRODUCTORY REMARKS**

**Summit Co-Chairs:** Laura N. Gitlin, PhD, Johns Hopkins University  
Katie Maslow, MSW, The Gerontological Society of America

### **Sponsor Remarks**

Advancing Research Toward Care and Support Solutions

Harry Johns, Alzheimer's Association

The Imperative of Diverse Voices and Collaborative Decision Making

Ian Kremer, JD, LEAD Coalition (Leaders Engaged on Alzheimer's Disease)

Setting Care Goals for 2025

George Vradenburg, UsAgainstAlzheimer's

8:30 a.m.–9:00 a.m.      **PLENARY LECTURES: Context for the Summit**

View from the Advisory Council on Alzheimer's Research, Care, and Services

Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine

Biomedical and Care Research in Dementia: Interdependent and Complementary

Maria C. Carrillo, PhD, Alzheimer's Association

9:00 a.m.–10:00 a.m.      **PLENARY LECTURES: Demographic Framework**

Demographics of Dementia and Dementia Caregiving: Key Changes in the Decades Ahead

Ken Langa, MD, PhD, University of Michigan

Deconstructing Race, Ethnicity, and Culture for ADRD Research

Jennifer Manly, PhD, Columbia University

Implications of Diversity in Dementia Care, Services, and Supports

Maria Aranda, PhD, MSW, MPA, LCSW, University of Southern California

10:00 a.m.–10:15 a.m.      **BREAK**

**10:15 a.m.–12:30 p.m. SESSION I: Research on Care Needs and Supportive Approaches for Persons with Dementia**

**Co-Chairs:** Richard H. Fortinsky, PhD, University of Connecticut School of Medicine  
Ann Kolanowski, PhD, RN, FGSA, FAAN, Colleges of Nursing and Medicine,  
Pennsylvania State University

**Speakers**

**Causality Matters: Preventing and Mitigating Behavioral and Psychological Symptoms of Dementia**

Helen Kales, MD, PPA, University of Michigan

**Maintaining and Supporting Function in Persons with Dementia**

Barbara Resnick, PhD, RN, CRNP, FAAN, FAANP, School of Nursing, University of Maryland

**Slowing Cognitive Decline and Supporting Resilience in Patients with Dementia**

Davangere P. Devanand, MD, Columbia University Medical Center

**Home Is Where the Future Is: BrightFocus Foundation Consensus Panel on Dementia Care**

Constantine Lyketsos, MD, MHS, DFAPA, FAPM, FACNP, Johns Hopkins Medicine

**Dementia Care in Residential Long-Term Care**

Sheryl Zimmerman, PhD, University of North Carolina at Chapel Hill

**Technologies for Assessment and Interventions to Improve and Accelerate Dementia Care Research**

Jeffrey Kaye, MD, Oregon Health & Science University

**Brief Reports and Commentaries**

**Living Well with Dementia**

Melanie (Lonni) Schicker, EdD, MHSA, RN, Persons Living with Dementia Stakeholder Group

**Researching Rhythms of Daily Life: The Role of Sleep and Daily Activity in Entraining Circadian Patterns**

Nancy A. Hodgson, PhD, RN, FAAN, University of Pennsylvania School of Nursing

**Physical and Social Environments for Care and Services: Research Recommendations for the Design of Care Settings**

Margaret Calkins, PhD, EDAC, Mayer-Rothschild Foundation

**Living Alone with Dementia: Identification, Unmet Needs, and Safety Concerns**

Elizabeth Gould, MSW, National Alzheimer's and Dementia Resource Center,  
RTI International

**Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities**

Tamar Heller, PhD, University of Illinois at Chicago

**Moderated Audience Discussion**

**12:30 p.m.–1:30 p.m. LUNCH**

1:30 p.m.–3:30 p.m.

## **SESSION II: Research on Supportive Approaches for Family and Other Caregivers**

**Co-Chairs:** Linda Teri, PhD, University of Washington  
Lisa Fredman, PhD, Boston University School of Public Health

### **Speakers**

**Supporting Family Caregivers Effectively: Lessons Learned from Research**

Linda Nichols, PhD, Memphis Veterans Affairs Medical Center

**Evolving Knowledge About the Health Effects of Caregiving to Persons with Dementia and Other Conditions**

Lisa Fredman, PhD, Boston University School of Public Health

**Dyadic Intervention: From Early Stage to End of Life**

Carol J. Whitlatch, PhD, Benjamin Rose Institute on Aging

**The Use of Technology in the Support of Family Caregivers**

Sara Czaja, PhD, University of Miami

**Innovating the Next Generation of Dementia and Alzheimer's Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers**

Vincent Mor, PhD, Brown University

### **Brief Reports and Commentaries**

**Personal Perspectives on Family Caregiving**

Sowande Tichawonna, Family Caregiver Stakeholder Group

**Dementia Family Caregiving: Recommendations from a Conference to Advance Interventions in Diverse Populations**

Oanh Meyer, PhD, MAS, University of California, Davis, School of Medicine

**Equity: A Powerful Force in the Future of Sexual and Gender Minority Dementia Caregiving**

Karen Fredriksen Goldsen, PhD, University of Washington

**Dementia Caregiving in the U.S. Research Recommendations**

Gail Gibson Hunt, National Alliance for Caregiving

**Family Caregiving's Impact on Women**

Mary E. Worstell, MPH, U.S. Department of Health and Human Services, Office of the Assistant Secretary for Health

### **Moderated Audience Discussion**

3:30 p.m.–5:00 p.m.

### **SESSION III: Involving Persons with Dementia and Caregivers as Members of the Research Team**

**Co-Chairs:** Mark Snowden, MD, MPH, University of Washington  
Lee Jennings, MD, MSHS, University of Oklahoma

#### **Speakers**

##### **Principles and Practices for Engagement in Research**

Lori Frank, PhD, Patient-Centered Outcomes Research Institute (PCORI)

##### **Challenges and Solutions for Involving Persons with Dementia and Dementia Family Caregivers as Members of the Research Team**

Jason Karlawish, MD, University of Pennsylvania, Penn Memory Center

##### **European Perspectives and Experience in Involving Persons with Dementia and Dementia Family Caregivers as Members of the Research Team**

James Pickett, PhD, Alzheimer's Society (UK)

#### **Brief Reports and Commentaries**

##### **Person with Dementia Perspective on Participating as a Member of the Research Team**

Teresa Webb, RN, Persons Living with Dementia Stakeholder Group

##### **The Who, What, Why, When, and Where of Care Partners in Research**

Sharon Hall, Family Caregiver Stakeholder Group

#### **Moderated Audience Discussion**

## **DAY TWO: OCTOBER 17, 2017**

7:00 a.m.–7:55 a.m.

### **REGISTRATION**

7:55 a.m.–8:00 a.m.

### **INTRODUCTION TO DAY**

**Summit Co-Chairs:** Laura N. Gitlin, PhD, Johns Hopkins University  
Katie Maslow, MSW, The Gerontological Society of America

8:00 a.m.–8:30 a.m.

### **PLENARY SESSION: Nomenclature: Words Matter**

#### **The Terminology Issues**

Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine

#### **Effect of Stigma on Access to Care and Services**

Angela Taylor, Lewy Body Dementia Association

#### **Perspectives of a Family Affected by Dementia**

Edward K. Kaplan, PhD, Professor Emeritus, Brandeis University; Persons Living with Dementia Stakeholder Group

Janna Kaplan, MSc, Brandeis University; Family Caregiver Stakeholder Group

8:30 a.m.–9:45 a.m.

## **SESSION IV: Involving Persons with Dementia as Study Participants**

**Co-Chairs:** Darby Morhardt, PhD, LCSW, Northwestern University  
David M. Bass, PhD, Benjamin Rose Institute on Aging

### **Speakers**

**Clinical Heterogeneity of Dementia and Impact on Research Participation**  
Sandra Weintraub, PhD, Northwestern University

**Work with Us! We Want to Help: Perspectives of a Person with Dementia on Involvement as a Study Participant**

Cynthia Huling Hummel, PhD, BS, MDiv, DMin, Persons Living with Dementia Stakeholder Group

**Role of Research in Examining and Understanding the Illness Experience of Individuals with Dementia**

Katherine S. Judge, PhD, Cleveland State University

**Measuring Disease Impact on People Living with Dementia: PCORI Pre-Summit Summary**

Darby Morhardt, PhD, LCSW, Northwestern University, and Lisa Gwyther, MSW, LCSW, Duke University

### **Moderated Audience Discussion**

9:45 a.m.–12:30 p.m.

## **SESSION V: Research on Models of Care for Persons Living with Dementia and Their Families Across the Disease Trajectory**

**Co-Chairs:** Vincent Mor, PhD, Brown University  
David B. Reuben, MD, University of California, Los Angeles

### **Speakers**

#### ***Dementia-Specific Models of Care***

**Components of a Comprehensive Care Model for Dementia**  
David M. Bass, PhD, Benjamin Rose Institute on Aging

**Health System-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities**

Zaldy S. Tan, MD, MPH, University of California, Los Angeles

**Community-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities**

Quincy Miles Samus, PhD, MS, Johns Hopkins School of Medicine

#### ***General Models of Care that Include Persons with Dementia***

**Successful VA Innovations in Geriatric Care**  
Thomas E. Edes, MD, MS, U.S. Department of Veterans Affairs

**Dementia Care Management within the Federal Financial Alignment Demonstration**  
Debra L. Cherry, PhD, Alzheimer's Greater Los Angeles

**Consumer-Directed Care Models**  
Julie Robison, PhD, University of Connecticut

### Service Provider and Payer Reactor Panel

Shari M. Ling, MD, Centers for Medicare and Medicaid Services  
Steve Waring, DVM, PhD, Essentia Institute of Rural Health  
Nora Super, MPA, National Association of Area Agencies on Aging

### ***Facilitators of Models of Care for Persons Living with Dementia and Their Families***

#### **Workforce Size, Composition, Retention, and Competence**

Gregg Warshaw, MD, University of North Carolina at Chapel Hill

#### **Quality Measures**

Gary Epstein-Lubow, MD, Brown University/Hebrew SeniorLife  
Louise Phillips, MD, Persons Living with Dementia Stakeholder Group, with off-site contribution from Brenda Nicholson, MD, Persons Living with Dementia Stakeholder Group

#### **Scaling Up: Research to Promote Diffusion of Successful Models**

David B. Reuben, MD, University of California, Los Angeles

### **Moderated Audience Discussion**

12:30 p.m.–1:30 p.m.

### **LUNCH**

1:30 p.m.–4:45 p.m.

### **SESSION VI: Thinking Outside the Box**

**Co-Chairs:** Christopher Callahan, MD, Indiana University School of Medicine  
Alan B. Stevens, PhD, Baylor Scott & White Health

### **PLENARY LECTURES: Thinking Outside the Box**

#### **Moving Forward Faster to Provide Care Together**

Christopher Callahan, MD, Indiana University School of Medicine

#### **Retail and the Consumer Lens: An Outside Perspective**

Raha Alavi, Nielsen Retail Services

#### **Translation and Implementation of Effective Care, Services, and Supports**

#### **Keeping Research Relevant: Moving from RCT to Practice**

Linda Teri, PhD, University of Washington

#### **Balancing Treatment Fidelity with Feasibility and Acceptance by End Users**

Mary Mittelman, DPH, New York University

#### **Evidence-Based Programs: Mapping Out the Future**

Leisa R. Easom, PhD, RN, Rosalynn Carter Institute for Caregiving

#### **Integrating Evidence-Based Dementia Care Programs into Existing Service and Reimbursement Systems**

Richard H. Fortinsky, PhD, University of Connecticut School of Medicine

### ***Innovative Research Methods and Outcomes***

#### **Research Methods for Dementia Care and Services**

Brian Mittman, PhD, Kaiser Permanente; U.S. Department of Veterans Affairs

#### **Stakeholder Perspectives on Research Outcomes that Matter**

Sarah Lenz Lock, JD, AARP

#### **New Directions in Measurement for Psychosocial Research on Dementia Care and Services: Report from Two Pre-Summit Meetings**

Sam Fazio, PhD, Alzheimer's Association

#### **Understanding What Matters Most to Inform Care and Services Research**

Debra Lappin, JD, Faegre Baker Daniels Consulting

### ***New Directions from Different Vantage Points***

#### **Moderator**

Laura N. Gitlin, PhD, Johns Hopkins University

#### **Discussants**

Mark Snowden, MD, MPH, University of Washington

Alan B. Stevens, PhD, Baylor Scott & White Health

Joseph E. Gaugler, PhD, University of Minnesota

Alice Bonner, PhD, RN, FAAN, Massachusetts Executive Office of Elder Affairs

Amy M. Kilbourne, PhD, MPH, Veterans Health Administration

Lisa Onken, PhD, National Institute on Aging

#### **Moderated Audience Discussion**

4:45 p.m.–5:00 p.m.

#### **WRAP UP**

#### **Speakers**

Laura N. Gitlin, PhD, and Katie Maslow, MSW, Summit Co-Chairs

Greg O'Brien, Persons Living with Dementia Stakeholder Group

Venoreen Browne-Boatswain, MEd, Family Caregiver Stakeholder Group