



Family Caregiver Recommendations

Dementia Care Virtual Summit Meeting

July 2020

Prepared by:
Family Caregiver Stakeholder Group

Additional information can be found at the Summit website (<https://www.nia.nih.gov/2020-dementia-care-summit>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers

2020 Dementia Care Virtual Summit Meeting: Family Stakeholder Group Research Recommendations

1. Research should be conducted on strategies to reach and enhance public, professional, and family awareness of the impact of dementia at all ages and stages of family life, particularly in rural locations and communities of color with disparate access to published and digital information. Emphasis needs to be placed on reducing misunderstanding of the disease and its negative stigma.
2. Research aims, goals, and outcomes should actively engage participation of diverse and under-represented family caregivers (age, relationship to and diagnosis; e.g. IDD/Downs/younger onset) and stage of person living with dementia, racial, ethnic, cultural, socio-economic, LGBTQ, and living situation status. This research should identify characteristics of family caregivers to be measured in large representative real-world studies to determine those most likely to benefit from specific programs, interventions, services, and supports.
3. Research should be conducted on how best to prepare, train, reward, and certify medical and social service professionals to work effectively and collaboratively with family caregivers as they manage complex vulnerabilities and risks to their financial, social, emotional and physical health over prolonged diagnostic challenges (including multi-morbidities, Frontotemporal Degeneration [FTD]) or prolonged care from diagnosis through bereavement.
4. Research should be conducted to identify and disseminate best practices for the development of professional navigators and/or dementia care specialists in the context of integrated medical and community-based systems to increase access to quality, affordable home, community-based, and residential services over the dementia trajectory.
5. Research should be conducted to develop, test, and disseminate innovative delivery systems (technologies, platforms, apps, clearinghouse) for timely, relevant, disease-specific vetted services and supports offered by trained providers for all families in disparate contexts of care.
6. Research should be conducted to identify effective approaches to educate families and health professionals to better manage common current co-existing multi-morbidities or lifelong disabilities in the context of dementia and in diverse care contexts.

7. Research should be conducted to develop and test information, approaches, and access strategies to help family caregivers with nutritional, functional, and early palliative and hospice care for a person with advanced dementia regardless of age or disabilities at home and in residential settings.
8. Research should be conducted to identify, test, and develop strategies to reduce negative financial, emotional, social and physical effects of caring on family caregivers. Best practices should be identified in preventive and coping measures for specific caregiver health vulnerabilities when caring at home for someone with younger onset FTD or Down's/Alzheimer's, sleep disruptions, challenging behavioral symptoms, and prominent safety risks or when caring for multiple family members over time.
9. Research should be conducted to address the social isolation; loneliness; and financial, legal, and emotional vulnerabilities of spouses and partners. These spouse/partner vulnerabilities may be distinct from risks facing working sole and/or long-distance adult child or sibling caregivers, who may be coping with significant tolls on other personal relationships, professional status, future financial stability, and mental health related to time spent caring.
10. Research should be conducted on current and proposed policies addressing common issues with shared family health decisions; employee family leave; and financial, health, and safety barriers for burdened family caregivers with strong preferences, but limited capacities, for home care, or for families who lack quality affordable alternatives to care at home.

Appendix A: List of Family Caregiver Stakeholder Group Members

Co-Chairs

Lisa Gwyther	Durham, North Carolina
Ann Cheslaw	Santa Monica, California

Members

Jacquie Alexander-Sykes	Los Angeles, California
Chuck Anastasia	Bristol, Rhode Island
Karen Appert	Winston-Salem, North Carolina
Venoreen Browne-Boatswain	Plymouth, Minnesota
Liliana Rodriguez Cracraft	Houston, Texas
Richard Gamez	Houston, Texas
Adele Gorelick	Bethesda, Maryland
Ron Hendler	Mariottsville, Maryland
Mary Hogan	Eliot, Maine
Janna Kaplan	Boston, Massachusetts
Carol O'Malia	Dallas, Pennsylvania
Sowande Tichawonna	Washington, D.C.
Lynda Wagner	Bismarck, North Dakota
Sonia Waidelich	Bloomsburg, Pennsylvania
Eileen Weber	Los Angeles, California