

DEMENTIA CAREGIVING IN THE U.S.



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Dementia Caregiving in the U.S.

Research Recommendations

October 2017

The following recommendations draw from findings in the *Dementia Caregiving in the U.S.* (February 2017) report¹ which analyzes the experiences of providing unpaid care in the United States to a relative or friend diagnosed with Alzheimer's disease, dementia, or other mental confusion, with the goals of both understanding the experiences of people caring for someone with dementia and identifying approaches to enhance and support this unique caregiving experience.

The report analyses are from the nationally representative study *Caregiving in the U.S. 2015* and examine caregivers who indicate that their care recipient had Alzheimer's disease, dementia, or some other type of mental confusion as either a primary or secondary reason for providing care. The highlighted findings below describe the experiences of these caregivers (n=372, referred to hereafter as *dementia caregivers*) and compares their experiences with those of caregivers who provided care to someone without dementia (n=963, referred to hereafter as *non-dementia caregivers*). The report also analyzed subgroups of caregivers within dementia caregivers to better understand variations in experiences of dementia caregiving.

Alignment with the National Plan to Address Alzheimer's Disease and Related Dementia

The National Alzheimer's Project Act (NAPA) (Public Law 111-375) requires the U.S. Department of Health and Human Services (HHS) to create and maintain a National Plan to "overcome Alzheimer's disease" and related dementias. Supported by the work of the Advisory Council on Research, Care, and Services (Advisory Council), this National Plan is updated each year to reflect new science and innovation in the field.

The research recommendations articulated below align with several goals of the National Plan as described in the 2017 update.² The National Plan recognizes that

¹ National Alliance for Caregiving and the Alzheimer's Association, *Dementia Caregiving in the U.S.* (February 2017), available at http://www.caregiving.org/wp-content/uploads/2014/01/Dementia-Caregiving-in-the-US_February-2017.pdf.

² See <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2017-update>.

“while research on AD/ADRD has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the diseases.” Because of this, family members and unpaid caregivers provide extensive care to people living with dementia. The National Plan identifies that caregivers need services and supports to provide care and to offset the “toll of caregiving” for caregivers and their families.

Supporting caregivers aligns with Goal 3 of the National Plan to expand supports for people with dementia and their families. As the plan describes:

Families and other unpaid caregivers play a central role in caring for people with AD/ADRD and may need supports beyond the care provided in settings such as doctors' offices, hospitals, and nursing homes. Supporting people with AD/ADRD and their families and caregivers includes providing access to tools that they need and helping to plan for future needs with the goal of maintaining safety and dignity. Under this goal, the Federal Government and partners will undertake strategies and actions that will support people with the disease and their families and caregivers.

Where applicable, the research recommendations below include the areas of the National Plan that align with the research findings and suggested future areas of work.

Research Recommendations

Key Findings from <i>Dementia Caregiving</i>	Future Research Areas	Alignment with National Plan
<p>The average person receiving care (the person with Alzheimer’s disease or another form of dementia) is 77.2 years old, significantly older than other care recipients who are supported by a family caregiver, and more than a third of care recipients are 85 or older (27%). A quarter of dementia caregivers over age 75 report worse health due to caregiving.</p>	<p>Examine ways to increase access to geriatric and dementia-specific training for dementia caregivers.</p> <p>Analyze the needs of “the oldest old,” including support for dementia caregivers and the unique care needs of those with dementia over age 75.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p>

Key Findings from <i>Dementia Caregiving</i>	Future Research Areas	Alignment with National Plan
<p>State Medicaid programs have shifted long-term care services from institutional care to home and community-based services to reduce unnecessary costs and to meet the growing demand for these services. With regard to dementia care, almost half of dementia care recipients live in their own home (40%), and of those recipients, many live alone (47%). A third of dementia caregivers are co-resident with the person with dementia (33%). Co-resident caregivers often experience higher strain and burden due to caregiving.</p>	<p>Understand the dynamic between the caregiver and home care providers in supporting a safe home environment for the person with dementia.</p> <p>Examine whether home care providers can provide training and respite to the dementia caregiver that delays the institutionalization of the person with dementia.</p>	<p>Strategy 3.C: Assist families in planning for future care needs.</p> <p>Strategy 3.D: Maintain the dignity, safety, and rights of people with ADRD.</p> <p>Strategy 3.E: Assess and address the housing needs of people with ADRD.</p>
<p>Dementia caregivers are nearly twice as likely to say that their health has gotten worse due to their caregiving responsibilities. More than one in three dementia caregivers say their health has declined (35%), versus just one in five non-dementia caregivers.</p>	<p>Develop a comprehensive dementia caregiver assessment to determine the health, willingness, and ability of the dementia caregiver to provide care.</p> <p>Identify resources that can help dementia caregivers engage in self-care.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p> <p>Strategy 3.D: Maintain the dignity, safety, and rights of people with ADRD.</p>

Key Findings from <i>Dementia Caregiving</i>	Future Research Areas	Alignment with National Plan
<p>Employed dementia caregivers work an average of 34.9 hours per week while caregiving, and more than half (57%) work full-time. Two in three employed caregivers report that they had to make workplace accommodations in some way (statistically significantly higher than the 59% of non-dementia caregivers). Fifteen percent either gave up work entirely or retired early to provide care.</p>	<p>Identify and evaluate “low-cost, no cost” workplace accommodations (such as flexible workplace environments and paid leave) that can be adapted to meet the needs of working dementia caregivers to protect their financial security.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p>
<p>Dementia caregivers want greater support from healthcare professionals. Less than half of dementia caregivers (44%) report having a doctor, nurse, or social worker <i>ever</i> ask them what they need to care for their loved one. Moreover, only a quarter (24%) have <i>ever</i> been asked about their own self-care needs.</p>	<p>Identify and evaluate technologies that can simplify care planning for the family caregiver, the person with dementia, and the healthcare provider.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p> <p>Strategy 3.C: Assist families in planning for future care needs.</p>

Key Findings from <i>Dementia Caregiving</i>	Future Research Areas	Alignment with National Plan
<p>Many dementia caregivers want to be kept more involved in their loved one’s medical care. More than half would find it helpful to require health providers to include their name on their care recipient’s chart (56%).</p>	<p>Conduct research on shared decision-making to assess whether it plays a role in care planning between caregivers and providers as well as potential ways to increased shared decision-making between these groups.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p> <p>Strategy 3.D: Maintain the dignity, safety, and rights of people with ADRD.</p>
<p>One out of four (27%) dementia caregivers has never made use of respite care but wants to do so. This indicates that there is a need among some dementia caregivers for easily accessible respite services.</p>	<p>Examine ways to promote greater access and awareness of respite care, as well as identify effective characteristics of respite care.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p> <p>Strategy 3.D: Maintain the dignity, safety, and rights of people with ADRD.</p>

Key Findings from <i>Dementia Caregiving</i>	Future Research Areas	Alignment with National Plan
<p>When many dementia caregivers need resources to assist them with caregiving, they cannot access these needed resources. In fact, 28% of dementia caregivers encounter difficulties in finding affordable services in their communities.</p>	<p>Examine ways to expand caregiver access to long-term services and supports. Explore potential support models for caregivers including options for individual and family counseling, caregiver support groups, and a call-in phone line offering immediate assistance to dementia caregivers.</p>	<p>Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being.</p> <p>Strategy 3.C: Assist families in planning for future care needs.</p>

For More Information

These recommendations result from the findings in the *Dementia Caregiving in the U.S.* report and are intended as a starting point for discussion. For more information on supporting caregivers of people living with dementia, we recommend these resources:

Alzheimer’s Association: Alzheimer’s and Dementia Caregiver Center
www.alz.org/care/

National Alliance for Caregiving Research: Alzheimer’s and Related Dementias
www.caregiving.org/research/condition-specific/

National Plan to Address Alzheimer’s Disease: 2017 Update
<https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2017-update>

AARP: From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia
www.aarp.org/content/dam/aarp/ppi/2017/08/from-research-to-standard-practice.pdf

National Institute on Aging: Alzheimer’s Disease and Related Dementias: Caregiving
<https://www.nia.nih.gov/health/alzheimers/caregiving>

ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.

ABOUT THE ALZHEIMER'S ASSOCIATION

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Learn more at www.alz.org.

