STATEMENT FOR THE RECORD
SUBMITTED TO THE

Advisory Council on
Alzheimer's Research, Care, and Services
U.S. Department of Health and Human Services

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AARP appreciates the opportunity to comment as the Advisory Council prepares to make 2014 recommendations to the Secretary of Health and Human Services (HHS) on the National Plan to Address Alzheimer's Disease (National Plan). AARP's mission is to enhance the quality of life for all as we age. Living independently, connected to family, friends and community is key to a high quality of life. As we age, a decline in cognitive health is not only one of people's greatest fears, but it is also one of the greatest threats to living independently and a high quality of life.

As with all family caregivers and the loved ones they are helping, tangible steps can be taken to improve the quality of care, quality of outcomes, and quality of life for people living with dementia and their family caregivers. As this country moves forward with the National Plan goal of preventing and effectively treating Alzheimer's by 2025, we also need to move forward with more effective care for those already affected by dementia, including better care coordination and planning, better access to affordable care, and support for family caregivers who take care of their loved ones.

A. <u>Translate evidence-based, person and family-centered care into widespread practice.</u>

It is important to expand person and family-centered care models broadly to reach the tens of millions of people and their families who could benefit from them. We know that person and family-centered models of dementia care that emphasize continuity of care and coordinate across settings and providers can also improve outcomes. Thanks to academic researchers across the country and the support from federal agencies who are represented on the Advisory Council such as the National Institutes of Health, the Administration for Community Living, the Centers for Medicare & Medicaid Services, and the Department of Veterans Affairs, we have developed an evidence-base from which we can implement better care.[1] In some cases, in addition to improving individual outcomes, we can even deter or delay expensive, disruptive, unwanted hospitalization and institutionalization.[2] Both domestically and internationally, models of care exist which demonstrate interventions that preserve abilities, improve behaviors, and reduce caregiver burden. These models show that we can do more to help those with a diagnosis of dementia – and find ways to do it in responsible, cost-effective ways.[3]

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[1] Christopher M. Callahan, Greg A. Sachs, Michael A. LaMantia, Kathleen T. Unroe, Greg Arling, and Malaz A. Boustani, "The Care Span: Redesigning Systems of Care for Older Adults with Alzheimer's Disease," *HEALTH AFFAIRS*, 33:4 (2014) 626-628.

[2] Zaldy S. Tan, Lee Jennings, and David Reuben, "Coordinated Care Management for Dementia in a Large Academic Health System," *HEALTH AFFAIRS*, 33:4 (2014) 620.

[3] June Andrews, "Designs on Dementia, A UK-Based International Center of Expertise Improves the Lives of People with Dementia in Innovative and Practical Ways," *AARP International: The Journal*, January 2014.

Despite the evidence that we can improve outcomes for people with dementia, these models of care are unfortunately neither widely known nor widely adopted. All too often, people either go untreated, or even after diagnosis, think there is nothing that can be done. It is important to educate people with dementia and their family caregivers that medical, social and behavioral interventions can help even while we struggle to find a cure for the future.[4]

That is why AARP urges the Council to redouble their efforts around goals 2 and 3 of the plan:
Goal 2: To enhance care quality and efficiency and
Goal 3: Expand supports for people with Alzheimer's disease and their families.

More broadly, individuals and their family caregivers should be made aware of interventions that can help them.

B. <u>Apply evidence-based quality of care across all settings – for those living at home receiving care through primary care settings, as well as in residential and institutional settings.</u>

Individuals should receive quality care no matter where they live. As the Advisory Council considers how to achieve the goal of enhanced quality and efficiency of care for those with dementia, it is critical to think about the care provided for those with dementia living in different types of settings. People often live with dementia for long periods of time – and dementia manifests itself over a continuum of time and abilities. Therefore, quality care needs to adapt over a continuum as well.

AARP is striving to make it easier for older people to live with independence and remain in their homes and communities for as long as they can, surrounded by family and friends. People with dementia are often happier and have more control in their own familiar home, and with the right help and support, they too can continue to live independently.[5]

While we want people to have the option of living in their homes as long as possible, for some people, particularly those who face advanced stages of dementia, living in a residential setting or nursing home may be the best option for them. Clearly these people still want and deserve to live life on their terms, with dignity and respect, and need high quality care that is affordable and sustainable. Our emphasis on promoting independent living applies to people

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[4] David B. Reuben, Leslie C. Evertson, Neil S. Wenger, Katherine Serrano, Joshua Chodosh, Linda Ercoli, and Zaldy S. Tan, "The University of California at Los Angeles Alzheimer's and Dementia Care Program for Comprehensive, Coordinated, Patient-Centered Care: Preliminary Data," *J Am Geriatr Soc* 61:2214-2218, 2013. December 2013-Vol. 61, No. 12.

[5] Alzheimer's Society, Living alone" available at

www.alzheimers.org.uk/site/scripts/download_info.php?file ID=1017, accessed April 15, 2014.

living in nursing homes and assisted living facilities as well as in home or other smaller community settings.

C. Recognize that quality of care also must include family caregiver support.

In 2009, about 42 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time. They provided unpaid care valued at $450 billion that year, more than total Medicaid spending in 2009 and more than twice the total for paid services and supports, according to AARP's Public Policy Institute.[6] The Alzheimer's Association estimates that more than 15 million of those caregivers are providing care for someone with Alzheimer's disease or other dementia.[7]

While this concept is important in family caregiving broadly, best practices of care for those with dementia recognize caregiver well-being is essential to maintaining the well-being and abilities of the individual as well.[8] It has been clearly established that counseling and support for spousal caregivers of those with dementia benefit the individual, family caregiver and society. Individuals whose family caregivers received the counseling and support interventions designed by the New York University Caregiver Intervention Study compared to usual care experienced a 28.3% reduction in the rate of nursing home placement.[9] A 2012 report released by AARP's Public Policy Institute and the United Hospital Fund also found that almost half of family caregivers perform medical/nursing tasks for care recipients, such as managing multiple medications and helping with assistive devices for mobility.[10] Families generally do not receive training and other assistance to help them provide care. Such training and supports also benefit the person receiving the assistance.

We need to help the millions of family caregivers navigate the confusing care systems to provide assistance for their loved ones and otherwise support them in their caregiving roles. Family caregivers should be given an assessment of their needs and then receive help based on the assessment, especially when a care

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[6] L. Feinberg, S. Reinhard, A. Houser & R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* 1,3 (AARP PPI, 2011), available at http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html.

[7] Alzheimer's Association, *2014 Alzheimer's Disease Facts and Figures, Alzheimer's and Dementia*, Vol 10, Issue 2.

[8] Geriatric Mental Health Foundation, "Caring for the Alzheimer's Disease Patient, How You Can Provide the Best Care and Maintain Your Own Well-being." Available at www.gmhfonline.org/gmhf/consumer/factsheets/caring_alzheimer_disease.html accessed April 15, 2014.

[9] Mary S. Mittleman, William E. Haley, Olivio J. Clay and David L. Roth, "Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease." NEUROLOGY 2006, 67:1592-1599.

[10] S. Reinhard, C. Levine & S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* 1 (AARP PPI and United Hospital Fund, 2012), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.

or discharge plan depends on a family caregiver voluntarily providing services to an individual. Such assistance should include information, training, counseling, links to community resources, help locating services, respite care, or other supports. In September, a federally appointed Commission on Long-Term Care released a report with important bipartisan recommendations to help build a better system to support individuals and their family caregivers nationwide.[11] Importantly, the Commission called for a national strategy to address the needs of family caregivers. The Commission specifically recommended assessing family caregivers and their needs in the care planning process, including family caregivers in patients' health records and as members of care teams, ensuring family caregivers have access to relevant information technology and, importantly, encouraging family caregiver interventions, including respite, training, and other supportive services. We need to provide the support and tools to all family caregivers so that both the recipient and provider of care can sustain themselves.

D. Conclusion

AARP is dedicated to improving the quality of care to all individuals who need long-term services and supports (LTSS) and supporting creative, innovative mechanisms by which that care can be personalized, delivered, evaluated and financed. We know that older adults with end stage dementia are some of the most complicated and expensive individuals with LTSS needs. They often are living with multiple chronic conditions – and if we can improve the quality of care for those with dementia, we can use those lessons to improve the care for all people with LTSS needs. Focusing on concrete steps to deliver on goals 2 and 3 of the plan could help make significant strides to assist all older adults and their families.

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[11] Commission on Long-Term Care, *Report to the Congress* 5 (September 30, 2013) *available at http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Commission-on-Long-Term-Care-Final-Report-9-26-13.pdf.*