Written Testimony
Senate Special Committee on Aging

A Public Health Approach to Alzheimer's Disease

Statement of

Lisa C. McGuire, Ph.D.

Lead, Alzheimer's Disease and Healthy Aging Program
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention
Department of Health and Human Services

For Release upon Delivery
Expected at 2:30 pm
June 19, 2018

Chairman Collins, Ranking Member Casey and members of the committee, thank you for the opportunity to share information on the public health approach to Alzheimer’s disease and related dementias. My name is Lisa McGuire and I lead the Alzheimer’s Disease and Healthy Aging Program at the Centers for Disease Control and Prevention (CDC), within the Department of Health and Human Services (HHS).

Alzheimer’s disease places a significant emotional and financial burden on people with the disease, their families and caregivers, and the health care system. Unlike other leading causes of death, there is currently no known cure or definitive prevention for Alzheimer’s disease. The growing burden of this disease has increased the visibility of Alzheimer’s disease and related dementias at national, state, and local levels. Through the Healthy Brain Initiative, the CDC. continues efforts to advance cognitive health in the public health arena.

Background

Dementia is a form of cognitive decline that seriously affects a person’s ability to carry out daily activities. The most common form of dementia among older adults is Alzheimer’s disease, which initially affects the parts of the brain that control thought, memory, and language. Alzheimer’s is a devastating, progressive, and ultimately fatal disease that begins with mild memory loss and can lead to the loss of the ability to carry on a conversation and respond to the environment. People with Alzheimer’s gradually lose the ability to care for themselves and to remain independent.

As people age, their risk of cognitive decline, including Alzheimer’s disease and other dementias, increases. The growing number of older adults in the U.S. population has already placed unprecedented demands on aging services and the public health and health care systems. By 2030, 1 in 5 Americans, or 72.7 million, will be aged 65 years or older, and by 2050 the number of adults aged 65 years or older in the United States is projected to reach 83.7 million.[1]

An estimated 5.7 million Americans of all ages are living with Alzheimer’s dementia in 2018.[2] This number includes an estimated 5.5 million people aged 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.[2] By 2050, the total number is projected to rise to 14 million people.[3]

Risk Reduction

We do not yet fully understand what causes Alzheimer’s disease. Age is an important risk factor. Researchers are actively investigating the role of genetics and increased risk of developing Alzheimer’s disease. Researchers are finding evidence that some of the risk factors for heart disease and stroke, such as high blood pressure and high cholesterol, may increase the risk of Alzheimer’s disease. There is also growing evidence that physical, mental, and social activities may reduce the risk of developing the disease. A 2015 Institute of Medicine (now known as the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) report provides evidence-based recommendations to promote brain health for individuals, families, communities, health care providers and systems, financial organizations, community groups, and public health agencies.[4] HHS developed an online Brain Health Resource that offers current, evidence-based information and resources to facilitate conversations with older people and their families about brain health.[5]

In 2017, a National Academies of Sciences, Engineering, and Medicine expert committee evaluated a National Institute of Aging-funded report by the Agency for Healthcare Research and Quality's Evidence-based Practice Centers Program. It concluded that with respect to prevention of Alzheimer's disease and cognitive decline, cognitive training, blood pressure management for those with hypertension, and increased physical activity are supported by "encouraging although inconclusive evidence," and recommended pursuing additional research in these and related areas.[6]

Burden

Not only are more people living with Alzheimer's disease, but Alzheimer's disease-related death rates are also increasing. Alzheimer's disease is the sixth leading cause of death in the United States, accounting for 4.1percent of all deaths in 2014. It is the fifth leading cause of death among adults aged 65 years or older.[7] As there has been more success in reducing rates of deaths due to heart disease and cancer, more adults are living longer and, as a result, their risk for developing Alzheimer's disease increases as they age. Alzheimer's is the only top ten cause of death in America that currently cannot be prevented, cured, or even slowed.

Alzheimer's disease-related deaths have increased over the past 16 years in every race, sex, and ethnicity category, and will most likely continue to increase as the population continues to age.[8] Alzheimer's deaths significantly increased in 41 states and the District of Columbia from 1999 to 2014. Overall, the age-adjusted Alzheimer's death rate per 100,000 population increased from 16.5

(or 44,536 deaths) in 1999 to 25.4 (or 93,541 deaths) in 2014, an increase of 55%. In addition, studies have suggested that the Alzheimer's deaths reported on death certificates might be underestimates of the actual number of Alzheimer's deaths in the United States.[9]

Caregiving

Family members and friends provide most of the care for people with Alzheimer's disease and related dementias who live in the community. While some aspects of caregiving may be rewarding, the health of those caring for persons with Alzheimer's disease or related dementias is often negatively impacted. These unpaid, informal caregivers — who are mostly family members or friends – often report higher levels of anxiety and depression and have poorer health outcomes than their peers who do not provide such care.[10] Caregivers themselves may have chronic health conditions, and providing care to others may interfere with their own self-care, as they give their attention to others and delay their own needs.[11]

The percentage of people with Alzheimer's disease who died at home increased from 13.9 percent in 1999 to 24.9 percent in 2014.[7] As the number of older Americans, Alzheimer's deaths, and persons with Alzheimer's dying at home all increase, so will the number of caregivers needed to provide care.

Older adults with Alzheimer's and related dementias are more likely than other older adults to have multiple chronic conditions. Among Medicare fee-for-service beneficiaries with Alzheimer's disease and other dementias, 95 percent had at least one other chronic medical condition.[12]Alzheimer's complicates the management of these other conditions, resulting in increased hospitalizations and costs.[2] For example, Alzheimer's and related dementias can negatively affect one's ability to:

- Manage medication
- Remember doctor's appointments
- Recognize and articulate the onset of new physical or emotional symptoms
- Seek assistance/care in the face of changes.

Because of the progressive nature of decline with Alzheimer's disease, the need for care also changes over time.[13]

These unique complications in turn contribute to caregiver burden, spiraling health care costs, and economic hardship for people and their families. In 2017, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid assistance, which has an estimated economic value of $232.1 billion.[2]

Health Care Costs

Alzheimer's and related dementia care also place a tremendous burden on the national health care system. Alzheimer's disease is the most expensive disease in America, as total payments in 2018 for all people with Alzheimer's or other dementias are estimated at $277 billion, with Medicare and Medicaid expected to cover $186 billion of those payments.[2] Total annual payments for health care, long-term care, and hospice care for people with Alzheimer's or other dementias are projected to increase to more than $1.1 trillion in 2050.[2] Currently, one in five Medicare dollars is spent on the care of people with Alzheimer's. In 2050, it is projected to be one in every three dollars.[2]

CDC Healthy Brain Initiative

With congressional appropriations that began in 2005, CDC established the Alzheimer’s disease-specific segment of our Healthy Aging Program and launched our Healthy Brain Initiative. Through this initiative and with continued congressional appropriations, CDC has been involved with and provided leadership in a number of national efforts. The Healthy Brain Initiative addresses cognitive health from a public health perspective to ensure that CDC informs state and local health departments about the importance of cognitive health.

In 2007, CDC partnered with the Alzheimer’s Association to create the first in a series of road maps to integrate cognitive health and functioning into the routine practice of public health: *The National Public Health Road Map to Maintaining Cognitive Health.* The first Road Map proposed a set of 44 recommendations or actions. This landmark document served as both a call-to-action and a guide for a coordinated approach to moving cognitive health into the national public health arena. The development of the Road Map was guided by a Steering Committee with representatives from a variety of organizations and agencies, including CDC, the Alzheimer’s Association, National Institute on Aging, Administration on Aging, AARP, and other experts from across the nation.

Congress passed the National Alzheimer’s Project Act (NAPA) in 2011 in recognition of the escalating public health, social, and economic consequences associated with Alzheimer's disease. NAPA created an important opportunity for federal agencies to review and coordinate their efforts related to Alzheimer’s disease and related dementias. Since its passage, CDC has served as an active member of the Advisory Council on Alzheimer’s Research, Care, and Services, which reports to the U.S. Secretary of Health and Human Services. *The National Plan to Address Alzheimer's Disease* (National Plan) was issued in 2012 by HHS, as mandated by NAPA. The National Plan is updated annually and seeks to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's disease and related dementias, as well as increase support for people with Alzheimer's disease and related dementias and their caregivers.

Building on the National Plan, CDC and partners released a second road map entitled *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* (Road Map) in 2013. The second Road Map lays out 35 actions the public health community can do to support brain health and caregivers. Over 200 organizations at the national, state, and local levels contributed to the development of this Road Map.

CDC currently funds the Alzheimer's Association and The Balm in Gilead, to accomplish the Healthy Brain Initiative Road Map's 35 action items. The Alzheimer's Association tracks cognitive decline and caregiving (using data from CDC's Behavioral Risk Factor Surveillance System optional modules), helps state public health agencies develop and revise Alzheimer's plans, and educates constituent groups about aspects of cognitive health and caregiving. The Balm in Gilead, an organization that primarily works with African American faith-based organizations, trains health professionals who are affiliated with African American health care organizations, such as the National Black Nurses Association and the National Medical Association, to recognize the signs and symptoms of Alzheimer's and raises awareness of the disease through activities in faith-based communities.

A third Road Map, planned for release later in 2018, will outline how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. In developing this Road Map, a Leadership Committee consisting of members across many sectors met over a six-month period to examine progress to-date and identify leading public health issues for the next five years. The Leadership Committee identified actions from the previous Road Map that had not been fully accomplished and issues that would require continued effort in the coming years.

Twenty-five specific actions will be proposed in four traditional domains of public health: 1) educate and empower, 2) develop policies and mobilize partnerships, 3) assure a competent workforce, and 4) monitor and evaluate. The action items speak to critical issues of disease risk identification and risk reduction, diagnosis, education and training, caregivers, and evidence on impact of the disease.

The Road Map series promotes partnerships and ensures critical linkages at the national, state, and community levels, which is essential to the success of the National Plan. As of April 2018, 48 states and territories have published Alzheimer's disease plans and a few cities and counties have created regional plans. While these states have plans and are poised to take action, many lack resources and expertise to implement their plans and action items stemming from the Road Map series. There are a number of states that are tackling this looming public health crisis, however, and may serve as examples for other states.

State Examples

Recent work from the Utah Department of Health and the Colorado Department of Public Health and the Environment illustrate the lasting contributions that can be made when states have access to expertise and are able to implement their action items and state plans.

Two action items in the second Road Map are improving health care providers' ability to recognize early signs of dementia, including Alzheimer's disease, and educating healthcare providers about validated cognitive assessment tools.[14] Utah contracted with HealthInsight to improve early detection of cognitive impairment in Utah. HealthInsight interviewed providers about their experiences and processes in conducting cognitive assessments during the Medicare Annual Wellness Visit. The resulting report, *Cognitive Assessments during Medicare Annual Wellness Visits,* was sent to all Utah primary care physicians, along with a list of resources for people with cognitive impairment. It also included a recommendation from the Utah Department of Health's executive director for routine cognitive assessment during the Medicare Annual Wellness Visit using both a primary and follow-up assessment tool.

The Colorado Department of Public Health and the Environment partnered with the Alzheimer's Association Colorado Chapter to deliver its *Approaching Alzheimer's: First Responder Training* program. Emergency Medical Service providers receive many calls to assist people with Alzheimer's and other dementias, yet often lack the preparation for the unique physical, behavioral, and communication challenges related to dementia. Colorado marketed the availability of the free, in-person training through its internal networks and all 11 of Colorado's Regional Emergency and Trauma Advisory Councils. The training helps first responders serve people with Alzheimer's in emergencies.

CDC has an established public health network and the ability to work with states to implement disease prevention and health promotion programs, including state plans and Road Map action items. Examples such as these from Utah and Colorado demonstrate the many ways that CDC, states, and national organizations work together to achieve more than working alone.

CDC’s Data Collection

CDC has a unique surveillance capacity to monitor the health status of older Americans and those living with Alzheimer’s disease and other dementias.

CDC utilizes its state-based Behavioral Risk Factor Surveillance System (BRFSS), the only system of its kind in the United States, to gather baseline information on self-reported subjective cognitive decline (a precursor to Alzheimer’s disease), as well as caregiving. CDC works with partners and states to gather information on the prevalence of subjective cognitive decline and caregiving among adults, through BRFSS surveys. BRFSS remains the only source of public health data at the state, territorial, and local levels for most states in these topic areas.

The Subjective Cognitive Decline Module assesses and monitors self-reported cognitive decline. The Caregiver Module collects information about the health, quality of life, and behaviors of caregivers, including caregivers of persons with dementia, to better understand their activities and needs. Both of these modules are optional for states to implement with CDC support. CDC was able to provide support to 33 states, the District of Columbia, and Puerto Rico to add BRFSS questions about subjective cognitive decline to their surveys in 2015; and 16 additional states to add the questions in 2016. CDC was able to provide support to 24 states to add questions about caregiving in 2015; and 14 additional states, the District of Columbia, and Puerto Rico to add caregiving questions in 2016. States and jurisdictions use this information to develop state plans, increase awareness about the needs of these populations, and guide elder justice and emergency preparedness efforts for older adults.

Those looking for more general data on the health status of older adults in the United States can find this information using CDC’s Healthy Aging Data Portal, which provides free access to a range of national, regional, and state data on older adults. Users can examine data on key indicators of health and well-being of older Americans, such as tobacco and alcohol use, screenings and vaccinations, and mental and cognitive health. Portal users may retrieve CDC data by indicator or geographic area, and then download datasets, develop reports, and create customizable maps, charts, and graphics for all participating states, regions, or by individual state in which data were collected. The Portal provides a snapshot of the health of older adults in their states in order to prioritize and evaluate public health interventions.

CDC also supported expansion of the National Health and Nutrition Examination Survey (NHANES) to include cognitive data. NHANES is a nationally representative sample of about 5,000 persons that over-samples persons aged 60 and older, African Americans, and Hispanics. For the first time, in the 2011-12 and 2013-14 NHANES cycles, cognition was included in both the interview questions (2 questions about perception of memory status) and in the mobile exam center (3 validated and standardized performance measures of cognitive functioning). Results from these survey questions are expected soon.

As part of the Healthy Brain Initiative, in 2010, CDC also was invited to lead a workgroup to develop national objectives related to dementias, including Alzheimer’s disease. CDC co-chaired this effort with the National Institute on Aging and worked with the large set of stakeholders. As a result, there are two objectives related to Alzheimer’s disease and other dementias in Healthy People 2020. The first objective shows the proportion of older adults aged 65 and older with a diagnosis of dementia, who are aware of their diagnosis. The second objective tracks preventable hospitalizations for persons with diagnosed dementias over the age of 65. The Healthy Brain Initiative worked with researchers to develop baseline measures and monitor these measures over the 10-year span to track progress over time.

Conclusion

Spurred by Congressional recognition of Alzheimer’s as a public health issue and the growing need to help patients and their families, Alzheimer’s disease and related dementias are now prominent parts of our nation’s health care discussions. However, much work remains. While there is no cure at this time, much can be done to improve the health and wellbeing of those with Alzheimer’s disease and related dementias. Many people with Alzheimer’s and their caregivers are unaware of tools, resources, supports, and services available to them. Better dissemination of this vital information for people with Alzheimer’s and their caregivers will improve disease management. The Healthy Brain Initiative and Road Map series will continue to provide states and communities with information about Alzheimer’s and other dementias in order to support their residents. Further action in the areas of epidemiology, data collection, and wide-scale promotion of evidence-based interventions can significantly enhance our understanding of the

Alzheimer’s disease crisis as well as have a tremendous impact on the lives of those people living with Alzheimer’s disease and their caregivers.

---

[1] U.S. Census Bureau. An aging nation: the older population in the United States, population estimates and projections. Washington, DC; 2014 May. www.census.gov/prod/2014pubs/p25-1140.pdf

[2] Alzheimer’s Association. 2018 Alzheimer’s disease facts and figures. Alzheimers Dement 2018;14(3):367-429. Access at https://www.alz.org/documents_custom/2018-facts-and-figures.pdf

[3] Hebert LE, Weuve J, Scherr PA, Evans DL. Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*. 2013;80:1778-83.

[4] Institute of Medicine. Cognitive Aging: Progress in Understanding and Opportunities for Action. Washington, DC: National Academies Press; 2015.)

[5] https://www.nia.nih.gov/health/brain-health-resource

[6] National Academies of Sciences, Engineering, and Medicine. Preventing Cognitive Decline and Dementia: A Way Forward. Washington, DC: National Academies Press; 2017

[7] Heron M. Deaths: Leading causes for 2015. National Vital Statistics Reports; vol 66 no 5. Hyattsville, MD: National Center for Health Statistics. 2017.

[8] (Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft JB. Deaths from Alzheimer’s Disease — United States, 1999–2014. MMWR Morb Mortal Wkly Rep 2017;66:521–526. https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm

[9] James BD, Leurgans SE, Hebert LE, Scherr PA, Yaffe K, Bennett DA. Contribution of Alzheimer disease to mortality in the United States. Neurology 2014;82:1045–50

[10] Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. JAMA. 2014;311(10):1052-1060.

[11] Roth DL, Fredman L, Haley WE. Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies. The Gerontologist. 2015;55(2):309-319.

[12] Center for Medicare and Medicaid Services. Chronic conditions among Medicare beneficiaries: 2015. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Chartbook_Chrts.html

[13] Phelan et al. A Systematic Review of Intervention Studies to Prevent Hospitalizations of Community-dwelling Older Adults with Dementia. Medical Care. 2015;53(2), 207)

[14] Alzheimer’s Association and Centers for Disease Control and Prevention. The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018: Chicago, IL: Alzheimer’s Association; 2013. https://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf