Healthy People 2020

Proposed Topic Area:
Alzheimer’s Disease and Dementia

Alzheimer’s disease is the sixth leading cause of death in the United States. Alzheimer’s and other dementias result in substantial morbidity for those affected, high use and costs of health care and long-term care services, and negative emotional and health outcomes for family caregivers. Moreover, many middle-aged and older Americans fear these conditions as much or more than other serious health conditions, such as cancer and stroke.

Despite these facts, among the 556 objectives in the “Proposed Healthy People 2020 Objectives” draft for public comment, there is not a single proposed objective that specifically addresses Alzheimer’s disease or dementia. In fact, the words “Alzheimer’s disease” and “dementia” do not appear in the 261-page draft for public comment.

The Alzheimer’s Association requests that the Secretary of Health and Human Services’ Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020 and the Federal Interagency Workgroup on Healthy People 2020 add a topic area and objectives to address Alzheimer’s disease and dementia in Healthy People 2020.

Alzheimer’s Disease is the only one of the ten leading causes of death in the United States that does not have a designated topic area in the “Proposed Healthy People 2020 Objectives” draft for public comment.

The latest CDC/NCHS data (preliminary data for 2007) show that Alzheimer’s disease is the sixth leading cause of death in the United States. Since 2000, the same ten diseases and conditions have constituted the top ten causes of death in the United States. Each of the top ten causes of death, except Alzheimer’s disease, has a designated topic area in the “Proposed Healthy People 2020 Objectives.” This is true even though Alzheimer’s disease is the only disease in the top ten that moved up in position since 2000, from number 8 to number 6.

Since 2000, deaths from Alzheimer’s disease have increased 51 percent (from 49,558 in 2000 to 74,944 in 2007). During that time, the number of deaths from three of the other top ten causes of death decreased: heart disease (down 15%); stroke (down 20%); influenza and pneumonia (down 19%). The number of deaths from the other six of the top ten causes of death increased from 2000 to 2007, but by considerably smaller proportions than Alzheimer’s disease: cancer (up 1%); chronic lower respiratory diseases (up 6%); accidents (up 20%); diabetes (up 2%); kidney disease (up 24%); and septicemia (up 12%).

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Alzheimer’s disease and other dementias result in substantial morbidity as well as high use and costs of health care and long-term care services.

In addition to mortality, Alzheimer’s disease and other dementias result in substantial morbidity, high use of health care and long-term care services, and high costs for all payors. An analysis of data from the 2004 Medicare Current Beneficiary Survey found that Medicare beneficiaries age 65 and older with Alzheimer’s and other dementias were 3.1 times more likely than other Medicare beneficiaries in the same age group to be hospitalized.³ People with these conditions constitute half of all nursing home residents and one-third of all older users of Medicaid-funded home and community-based long term care services.⁴ In 2004, total average per person payments from all sources, including Medicare and Medicaid, for health care and long-term care services for people age 65 and older with Alzheimer’s and other dementias were three times higher than for other older people ($33,007 vs. $10,603).

Older people who have Alzheimer’s or another dementia plus other serious medical conditions (such as heart disease, cancer, stroke, chronic obstructive pulmonary disease, or diabetes) have higher morbidity and use and costs of health care and long-term care services than people with the same other medical conditions but no Alzheimer’s or dementia. In 2004, for example, people age 65 and older with Alzheimer’s or another dementia plus diabetes had 64 percent more hospitalizations per 1,000 people than those with diabetes but no Alzheimer’s or other dementia. Their hospital stays were almost twice as long (6 days vs. 3.2 days), and total average per person Medicare payments for their care were 59 percent higher ($20,655 vs. $12,797).⁵

The prevalence of Alzheimer’s disease and other dementias will increase dramatically in coming decades.

The incidence and prevalence of Alzheimer’s disease and many other diseases and conditions that cause dementia increase with age. Thus, the number of people affected by these conditions will increase rapidly as the number of older Americans grows in coming decades. The number of people age 65 and older with Alzheimer’s disease is expected to increase by 12 percent from 5.1 million in 2010 to 5.7 million in 2020, and by 50 percent, to 7.7 million in 2030.⁶ About 14 million of the 78 million baby boomers alive today can expect to develop dementia in their remaining lifetime, including about 10 million who can expect to develop Alzheimer’s disease.⁴

³ Alzheimer’s Association, Characteristics, Costs, and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, contract report prepared for the Alzheimer’s Association by J.Bynum, Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research, Lebanon, NH, January 2009.


⁵ Alzheimer’s Association, Characteristics, Costs, and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries, contract report prepared for the Alzheimer’s Association by J.Bynum, Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research, Lebanon, NH, January 2009.

Alzheimer’s disease is one of the single, greatest fears of Americans as they age.

Survey data show middle-aged and older Americans fear getting Alzheimer’s disease. A Gallup poll conducted in 2003, found that 42 percent of Americans age 50 and older said they were worried about getting Alzheimer’s disease. A Harris Interactive poll conducted in 2006, found that Alzheimer’s disease was the second most feared disease in America, behind cancer, for people age 18 and older. Among adults aged 55 and older, it was the most feared disease. Twenty percent of survey respondents said they were most afraid of getting Alzheimer’s disease, compared with 14% who named cancer, and 13 percent who named stroke.

Family caregivers of people with Alzheimer’s disease and other dementias experience high levels of stress and depression as well as negative health and financial effects associated with caregiving.

In 2008, an estimated 9.9 million family members and friends in the United States provided 8.5 billion hours of unpaid care for people with Alzheimer’s and other dementias, a contribution to the nation valued at $94 billion. Caring for a person with Alzheimer’s or other dementia is often difficult, and 40 percent of family and other unpaid caregivers report high levels of emotional stress. These caregivers are more likely than non-caregivers to report that their health is fair or poor, and research shows that they are more likely than non-caregivers to have high levels of stress hormones, reduced immune function, slow wound healing, new hypertension, and new heart disease. Many family and other unpaid caregivers have to quit work, reduce their work hours, turn down promotions, or take time off because of caregiving responsibilities. As a result, they lose job-related income and benefits, including employer-provided health insurance.

Inclusion of a topic area and objectives for Alzheimer’s disease and dementia in Healthy People 2020 will provide a critical foundation for new initiatives to address this growing public health issue.

Inclusion of a topic area and objectives for Alzheimer’s disease and dementia in Healthy People 2020 will constitute explicit recognition by the federal government of current national data and peer-reviewed research findings indicating that these conditions are a major cause of mortality, morbidity, and health and long-term care service use and costs, as well as a major cause of distress for Americans. By addressing Alzheimer’s disease and dementia in this manner within Healthy People 2020, the Department of Health and Human Services will call attention to the many steps that can be taken to improve recognition, diagnosis and care for people with these conditions, reduce symptom severity, support family caregivers, and encourage “healthy brain” behaviors that are increasingly being shown to reduce risk for the conditions.

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Healthy People 2020

Possible Objectives for Alzheimer’s Disease and Dementia

Surveillance

1. Objective: Increase the proportion of states that have public health surveillance questions to measure cognitive impairment and the impact of cognitive impairment, Alzheimer’s disease and dementia on individuals and households.

   Data Source: State BRFSS questionnaires, CDC

Detection of Alzheimer’s Disease and Dementia

2. Objective: Increase the proportion of people with memory impairment who have a diagnosis of Alzheimer’s disease or other dementia

   Data Source: Medicare Current Beneficiary Survey (MCBS), CMS

Ongoing Care and Treatment

3. Objective: Decrease the proportion of people with diagnosed Alzheimer’s disease or dementia who have difficulty obtaining care (could include a break-out by race-ethnicity to measure disparities)

   Data Source: Medicare Current Beneficiary Survey (MCBS), Centers for Medicare and Medicaid Services

4. Objective: Increase the proportion of people with diagnosed Alzheimer’s disease or dementia who are satisfied with their access to their doctor (could include a break-out by race-ethnicity to measure disparities)

   Data Source: Medicare Current Beneficiary Survey (MCBS), Centers for Medicare and Medicaid Services
5. **Objective:** Increase the proportion of people with diagnosed Alzheimer’s disease or dementia who are satisfied with the information they receive from their doctor (could include a break-out by race-ethnicity to measure disparities)

**Data Source:** Medicare Current Beneficiary Survey (MCBS), Centers for Medicare and Medicaid Services

6. **Objective:** Increase the proportion of persons with diagnosed Alzheimer’s disease or dementia and diabetes who report (or their proxy reports) that the person’s blood sugar is well controlled all of the time or most of the time, and that the person (or their proxy) has received training on how to manage the diabetes.

**Data Source:** Medicare Current Beneficiary Survey (MCBS), Centers for Medicare and Medicaid Services and Medicare Part B claims

7. **Objective:** Increase the proportion of persons with diagnosed Alzheimer’s disease or dementia and one or more other serious medical conditions (including heart disease, congestive heart failure, hypertension, pulmonary disease, and cancer) who receive treatment for both conditions (could include a break-out by race-ethnicity to measure disparities)

**Data Source:** Medicare Current Beneficiary Survey (MCBS), Centers for Medicare and Medicaid Services and Medicare Part B claims

**Physical Activity**

8. **Objective:** Increase the proportion of older adults with memory loss and confusion who engage in light, moderate, or vigorous leisure-time physical activities.

**Data Source:** National Health Interview Survey, CDC, NCHS

**Social and Emotional Support**

9. **Objective:** Increase the proportion of older adults with memory loss and confusion reporting sufficient emotional support

**Data Source:** National Health Interview Survey, CDC, NCHS
Unnecessary Hospitalizations

10. **Objective:** Reduce hospitalization rates for ambulatory sensitive conditions in people with diagnosed Alzheimer’s disease and dementia.

   **Data Source:** Medicare Chronic Condition Warehouse, CMS

Mental Health

11. **Objective:** Increase the number of States, territories, and the District of Columbia with an operational mental health plan that addresses specialized mental health services for people with Alzheimer’s disease and dementia

   **Data Source:** State Mental Health Agency Profiling System, National association of State Mental Health Program Directors

Developmental Objectives

Awareness and Reduction of Risk for Alzheimer’s Disease and Dementia

**Objective (developmental):** Increase by 75 percent awareness and knowledge among at risk populations and the general public about the relationship of cognitive impairment, Alzheimer’s disease and dementia to cardiovascular health, level of physical activity and other brain protective behaviors.

**Objective (developmental):** Increase the number of community-based organizations (including local health departments, tribal health services, nongovernmental organizations, State agencies) providing population-based primary prevention services in the following areas: Add a bullet saying: “risk factors for cognitive impairment, Alzheimer’s disease and dementia.

Patient and Caregiver Information and Counseling about Alzheimer’s Disease and Dementia

**Objective (developmental):** Increase the proportion of persons with diagnosed Alzheimer’s disease and dementia who receive formal Alzheimer’s and dementia information

**Objective (developmental):** Increase the proportion of people with Alzheimer’s and dementia and their family caregivers who receive information and counseling about health-risk behavior areas, including driving, medication management, firearms in the home, and falls
Ongoing care and treatment

Objective (developmental): Increase the proportion of people with diagnosed Alzheimer's disease and dementia who receive dementia care and treatment consistent with current standards (followed by a list of standards)

Emergency Department Visits

Objective (developmental): Reduce Alzheimer's- and dementia-related hospital emergency department visits

Objective (developmental): Reduce emergency department visits caused by preventable adverse events in people with Alzheimer’s disease and dementia who are not able to manage their own medications

Counseling and Services for People with Down’s Syndrome and Alzheimer’s Disease

Objective (developmental): Increase appropriate counseling and services for people with Down’s syndrome and Alzheimer’s disease.

Data Source: MCBS has question about Mental Retardation

Long-term Care Services and Supports

Objective (developmental): Reduce the proportion of noninstitutionalized people with Alzheimer’s disease and dementia who have an unmet need for long-term care services and supports

Family Caregiver Support

Objective (developmental): Reduce the proportion of unpaid caregivers of people with Alzheimer’s disease and dementia who report an unmet need for caregiver support services

Ongoing Physical Activity and Social, Recreational and Community Activities

Objective: Increase the proportion of people with Alzheimer’s and dementia who participate in social, recreational, community and civic activities to the degree that they wish

Mental Health

Objective (developmental): Reduce the number of people with diagnosed Alzheimer's disease and dementia who have serious unmanaged psychiatric and behavioral symptoms