Alzheimer's Disease and Other Dementias: Trends, Risk Factors, and Impacts



Dementias are a group of brain disorders marked by a decline in memory, language, problem-solving, and other cognitive skills that is severe enough to interfere with a person's ability to perform normal everyday tasks. Alzheimer's disease is the most common cause of dementia^{1,2} but many people, especially in older age groups exhibit "mixed dementia," or dementia from multiple causes.³⁻⁷ In this document, we combine Alzheimer's disease with other dementias (which we call "Alzheimer's/dementia" as shorthand), based on the literature and due to similar public health impact and similar needs in care. In those places that we cite information on Alzheimer's disease alone, we do so because this was the only data available to us.

One of the risk factors for Alzheimer's is having mild cognitive impairment (MCI).^{8,9} MCI is thought to impact fifteen to twenty percent of those 65 years and older, and eight out of ten people who are diagnosed with MCI go on to develop Alzheimer's disease within seven years.^{10,11} MCI symptoms are somewhere between normal memory challenges associated with aging and Alzheimer's disease, which impacts a person's day-to-day ability to function.¹² Signs of MCI include memory loss (such as forgetting im-

portant information that would have been recalled easily in the past like appointments, conversations, or recent events) and impaired thinking (such as impaired ability to make sound decisions or to judge the time or sequence of steps needed to complete a complex task).13 It takes a comprehensive assessment to diagnose MCI because memory changes can be attributed to many different causes.14 It is important that those experiencing cognitive impairment seek help as soon as possible for diagnosis and appropriate care. Early diagnosis can provide medical benefits, such as introduction to medications and to other interventions that could improve and prolong cognitive function. Early diagnosis could also provide a patient with extra motivation to make behavioral change that could help improve his or her brain health. Additionally, early detection could prompt a patient to enroll in a clinical trial. Early diagnosis may also open doors to training, education and support programs for individuals and family members, and may provide motivation to plan for the future.15

Alzheimer's is a progressive disease. Some signs of mild Alzheimer's/dementia include confusion about familiar tasks and places, impaired judgement, poor decision mak-



ing, taking longer than normal to do familiar tasks such as paying bills or playing cards, and difficulty keeping track of a purse or wallet more often than before. Some signs of moderate Alzheimer's/dementia include increased confusion, loss of short-term memory (remembering things that just happened or were just said), shortened attention span, problems with language such as finding correct words (especially descriptive words such as nouns), getting lost in one's own neighborhood, great difficulty in planning and preparing meals, and making repetitive statements. ^{16,17} Alzheimer's disease, in its most advanced stages, leaves a person dependent, with a loss of long-term memory, a loss of language, weight loss, and the impairment of crucial functions such as walking and swallowing. ¹⁸



Although there is currently no cure for Alzheimer's, there has been tremendous growth in research on early detection in the last ten years, and researchers believe that early intervention offers the best chance of slowing and stopping Alzheimer's .19 There has also been increased understanding of behavior and lifestyle factors for prevention and management of the disease. Active management of Alzheimer's/dementia in all stages of the disease has been shown to improve the quality of life for those living with Alzheimer's/dementia and their caregivers. Active management includes appropriate use of all treatment options, effective management of coexisting conditions, care coordination among health care professionals and lay caregivers, participation in activities and/or adult day care, and supportive services and support groups.²⁰ In terms of pharmacological treatment, although none of the treatments available today slows or stops the underlying damage and death of neurons that causes Alzheimer's symptoms, there have been six medications FDA approved so

far to temporarily improve symptoms by increasing neurotransmitters in the brain. These medications vary in effectiveness for different people. ²¹ Non-pharmacologic therapies are aimed at maintaining or improving cognitive function, performance of daily living activities, and quality of life. They are also aimed at managing behavioral symptoms like depression, apathy, wandering, sleep disturbances, agitation, and aggression. These therapies include art therapy, activity-based therapy, and memory training. ²² Exercise, gardening, word games, music, and cooking show promise, however compared with pharmacological treatment, few non-pharmacological treatments have been tested in large randomized controlled studies .

Advancing age is a major risk factor for Alzheimer's disease.²³ Of the 5.7 million people in the United States with Alzheimer's in 2018,²⁴ 96% were 65 years and older and most of these were 75 years and older.²⁵ Whereas one in ten people 65 years and older have Alzheimer's disease,^{26,27} about one in three people 85 years and older have Alzheimer's disease.²⁸

Due to longer life expectancies and a growing elderly baby boomer population, the number and percentage of people above 85 years is increasing, and so will the number of people with Alzheimer's/dementia. In the absence of medical breakthroughs, the number of people in the United States 65 years and older with Alzheimer's alone is expected to rise from 5.7 million to 13.8 million by 2050.^{29,30}

Almost two-thirds of Americans with Alzheimer's disease are women.^{31,32} This is thought to be largely due to women living to older ages than men.³³⁻³⁵ A greater percentage of women are 85 years and over compared to men, and in turn among those 71 years and over it is estimated that 16 percent of women have Alzheimer's/dementia compared with 11 percent of men.^{36,37}

In the United States, the highest number of cases of Alzheimer's are for whites (due to the structure of the population). However, older African Americans and Latinos have a higher risk of having Alzheimer's than older whites (two times and 1.5 times that of whites, respectively).³⁸⁻⁴² The pri-

Among the older population,
African Americans have twice the risk of whites for
Alzheimer's

mary causes for these racial/ethnic differences are thought to be variations in co-morbid health conditions (e.g. diabetes) and social determinants of health (e.g. education) rather than genetics.⁴³

About 1% of those with Alzheimer's have 'autosomal dominant Alzheimer's disease (ADAD),' also called 'familial Alzheimer's disease,' which is due to having one of several rare genes.44 It is believed that anyone who inherits one of these genes will get Alzheimer's, and these genes often affect people in their 40s and 50s.45 Aside from those with ADAD, Alzheimer's is a chronic disease that develops as a result of multiple risk factors. In addition to older age, 46,47 some of the risk factors for Alzheimer's disease include having a family history of Alzheimer's disease48-51 and carrying certain 'risk genes' (genes that increase the likelihood of developing Alzheimer's but do not guarantee that Alzheimer's will develop, such as the apolipoprotein E (APOE)-e4 gene).^{52,53} A number of modifiable risk factors have also been found to be associated with Alzheimer's/dementia, including heart disease, stroke, diabetes, high blood pressure, high cholesterol, obesity, Parkinson's disease, head injury, smoking, mild cognitive impairment, exposure to certain pesticides or other toxins, physical inactivity, and lower education.⁵⁴⁻⁵⁶

The societal burden of Alzheimer's/dementia is huge. Alz-

Deaths due to Alzheimer's and other dementias are often underestimated heimer's is the sixth-leading cause of death in the United States.⁵⁷ In fact, Alzheimer's deaths may be underestimated, which will be discussed in the next paragraph. The long duration of illness before death (a person 65 years and over with Alzheimer's lives on average four to eight

years after diagnosis of Alzheimer's, yet some live as long as twenty years after diagnosis) has a large public health impact: on average, 40% of the total number of years a person is living with Alzheimer's/dementia is spent in its most severe stage.⁵⁸ Alzheimer's is a leading cause of disability and poor health. Looking at disability-adjusted life years (DALYs), Alzheimer's rose from the 25th most burdensome disease in 1990 to the 12th most burdensome disease in 2015.⁵⁹ Older people with Alzheimer's/ dementia also have more hospitalizations, more skilled

nursing facility stays, and more home health care visits than other older people.⁶⁰

Identifying the true number of people who die from Alzheimer's disease is difficult. In 2013, 84,767 people in the United States had Alzheimer's disease listed as the underlying cause of death on their death certificates, according to the Centers for Disease Control and Prevention.⁶¹



However, by some estimates, the number of deaths due to Alzheimer's disease is about seven times this number.⁶² The higher estimates include people who may not have had Alzheimer's disease coded on their death certificates as the *final cause*, but who died of an Alzheimer's-*related* condition (like pneumonia for example).⁶³⁻⁶⁵ Furthermore, this does not take into account the underreporting of Alzheimer's/dementia caused by omission of an Alzheimer's/dementia diagnosis anywhere on the death certificate.

Adults 65 years and older with Alzheimer's/dementia have twice as many hospitalizations per year as older people without Alzheimer's/dementia.66 These hospitalizations are most commonly caused by syncope and falls, ischemic heart disease, GI disease, pneumonia, and delirium.67 An estimated 25% of these hospitalizations are preventable (hospitalizations that could have been avoided given better access and/or quality of primary and preventative care).68 Recognizing this, Healthy People 2020 includes the objective to reduce the proportion of preventable hospitalizations in those with Alzheimer's/dementia. The symptoms of Alzheimer's/dementia, which include memory loss and impaired judgement, can make it difficult for those affected to manage their own health care, to recognize when their health is deteriorating, and to manage other chronic conditions.⁶⁹ Thus, hospitalizations for those with Alzheimer's/dementia are often due to complications of comorbid conditions due to cognitive impairments rather than due to the cognitive impairments themselves. To In addition, those with other chronic diseases such as coronary heart disease and diabetes, who also have Alzheimer's/dementia, have higher use and costs of health care services than people who do not have Alzheimer's/dementia as a co-occurring condition. Although there are a limited number of studies on how to directly reduce hospitalizations for those with Alzheimer's/dementia, improved primary care and disease management for those living in the community with Alzheimer's/dementias may help address the problem.

Cost of health care and long-term care of Alzheimer's and other dementias in the U.S.:
\$277 billion

In the United States, the total cost in 2018 for all individuals with Alzheimer's/dementia, including health care and long -term care costs, were estimated at \$277 billion.⁷³ Approximately sixty-seven percent of these costs were covered by Medicare and Medi-

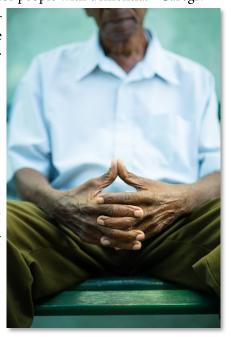
caid, 22% by out-of-pocket payments, and 11% by other sources.⁷⁴ Among patients on Medicare, those with Alzheimer's/dementia had three and a half times greater annual per-person health care and long-term care costs than other patients in the same age group without Alzheimer's/dementia (\$48,028 per year for those with Alzheimer's/dementia compared with \$13,705 per year for those without Alzheimer's/dementia).^{75,76} Among those with both Medicare and Medicaid, average Medicaid payments per person for beneficiaries with Alzheimer's/dementia were 19 times as great as average Medicaid payments for those without Alzheimer's/dementia.⁷⁷

Out-of-pocket costs for insurance premiums, deductibles, copayments, and services not covered by Medicare, Medicaid, or other insurance are also very high for those with Alzheimer's/dementia. The average amount of out-of-pocket expenses for those with Alzheimer's/dementia is \$10,589 per year in health care and long-term care services, compared to \$2,291 per year on average for those in the same age group without Alzheimer's/dementia.⁷⁸ Furthermore, the average out-of-pocket costs for Alzheimer's/dementia patients in a nursing home or assisted living facility is almost six times the average cost of those

with Alzheimer's/dementia living in the community.⁷⁹ As their disease progresses, many people with Alzheimer's/dementia require more care (both paid and unpaid). Paid care includes such facilities as adult day care centers, assisted living facilities, and nursing homes. The average cost of these services is high (assisted living \$43,200 per year; nursing home care \$80,300 to \$91,250 per year)⁸⁰ and Medicaid is the only public program that covers the long nursing home stays that most people with Alzheimer's/dementia require in the late stages of their illnesses. For those not on Medicaid, this can cause a quick depletion of savings and assets that leaves the patient and his or her family financially depleted.⁸¹

The majority (83%) of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. According to the Alzheimer's Association's 2018 Alzheimer's Disease Facts and Figures report, in 2017 in the United States, caregivers of people with Alzheimer's/dementia provided an estimated 18.4 billion hours of unpaid assistance, a contribution valued at \$232.1 billion.⁸² Family caregivers often lack the information or resources necessary to manage the complex medication regimens for people with dementia.⁸³ Caregiv-

ers of people with Alzheimer's/dementia are more likely than other caregivers to aid with self-care, mobility, and health or medical care, but half of these caregivers report having no experience with medical or nursing tasks.84 Caregiving for someone with Alzheimer's/dementia is shown to have negative impacts on caregivers' mental and physical health, em-



ployment, and financial well-being, and may even increase their risk of death. 85

Paid caregivers such as nurse aides, nursing assistants, home health aides and personal home care aides have difficult jobs and thus a high turnover rate, and many do not receive the training necessary to provide quality care. 86,87 There is also a large shortage of geriatricians (estimated one half of that needed in the United States). 88

In conclusion, Alzheimer's and other dementias are chronic conditions that have a large personal, family, and societal burden in addition to high out-of-pocket costs and high costs to public programs. This burden is expected to increase significantly in the coming decades, with the grow-

ing elderly population. Alzheimer's and other dementias are multifactorial diseases, some of whose risk factors can be modified. In order to maintain and improve quality of life for those with Alzheimer's/dementia and their caregivers, it is important to actively manage Alzheimer's/dementia and to promote change at the community, clinical, and policy levels.

Recommendations at the community and clinic levels ⁸⁹	Recommendations for policymakers ⁸⁹
Provide more resources and trainings to caregivers.	Create an Alzheimer's and related disorders commission in line with the Health and Human Services Agency and the California State Plan.
Promote awareness and educate the public.	Help those with Alzheimer's/dementia by producing a statewide coordinated and collaborative plan among public and private agencies and other stakeholders.
Raise awareness among health professionals about the need for early detection.	Advocate for additional funding for basic research on Alzheimer's disease and other dementias.
Promote standard post-diagnostic care among clinicians.	Advocate for efforts to find effective treatments.
	Enact a national policy agenda of strategies to improve financial support and create workforce reform for caregivers.
	Advocate for a fully funded system of care to support people living with Alzheimer's/dementia, their families, and their caregivers.

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