alzheimer's association

Alzheimer's Disease Facts and Figures in California

Current Status and Future Projections

2008
588,208 families in California
living with Alzheimer's disease

2015
678,446 families in California
living with Alzheimer's disease

2030
1,100,000 families in California
living with Alzheimer's disease

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Alzheimer's Disease Facts and Figures in California:

Current Status and Future Projections

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Executive Summary

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Over the next 20 years, the impact of Alzheimer's disease on the State of California will increase dramatically. The leading edge of the baby boomer generation turned 62 this year. This enormous demographic bulge has defined its times in the past and the graying of the boomers can soon define California's future. Individuals are also living longer, resulting in a growing population of older adults. Since the primary risk factor for Alzheimer's disease is older age, we can expect a substantial increase in the numbers of people who will be living with the disease.

This report was drawn from a variety of data sources. It details the broad and significant implications that this increased prevalence of Alzheimer's disease and related conditions will have on California's businesses, public programs, and affected families.

Prevalence of Alzheimer's Disease in California

Between now and 2030 there will be a doubling in the number of Californians living with Alzheimer's disease. This dramatic increase will affect all race and ethnic groups as well as all regions of the state. The data reveal that:

- Currently, there are 588,208 Californians 55 and over living with Alzheimer's disease; one-tenth of the nation's Alzheimer's patients reside in this state.
- By 2030, this number will nearly double in California; growing to over 1.1 million.
- Due to a rapidly aging population, the number of California's Latinos and Asians living with Alzheimer's disease will triple by 2030.
- The number of African-Americans living with Alzheimer's disease will double in this timeframe.

Lifetime Risk for Alzheimer's in California

Among California's baby boomers aged 55 and over:

- One in eight will develop Alzheimer's Disease
- One in six will develop a dementia

Deaths from Alzheimer's Disease in California

- Alzheimer's disease is now the sixth leading cause of death in California.
- Compared to other leading causes of death in California, Alzheimer's disease showed the greatest increase (58.3% from 2000–2004)

Caregiving for People with Alzheimer's Disease in California

There are 1.1 million Californians caring for people living with Alzheimer's disease and other dementias, about 11% of our nation's caregivers. While caregiving has its satisfactions, for many, the burden of care is substantial.

In every case, Alzheimer's disease results in a progressive decline in one's ability to care for oneself, ultimately leaving the individual dependent on others for help with basic activities of living. As a result, caring for a person with Alzheimer's is often very difficult and poses physical, emotional, and economic challenges. This is particularly true because, contrary to common belief, most care is delivered at home by families.

Traditionally, most caregivers have been the wives or adult daughters of the individual with dementia. With more women participating in the workforce, there has been a decrease in the number of women available to fill these caregiving roles. In addition, family members are increasingly likely to live far apart from one another. These changes have significant implications for families, businesses and society at large. Who will care for our aged?

- Caregiving negatively impacts the individual's ability to work outside the home. Disproportionately high percentages of these caregivers report being forced to miss work (21%), reduce their work hours (8%), quit their jobs (11%) or change jobs due to caregiving demands (4%).
- California caregivers provide 952 million hours of unpaid care per year with an economic value of slightly more than $10 billion dollars.

- Families provide almost three-quarters of the value of informal (unpaid) and formal care for individuals living with Alzheimer's disease in the community and in facilities - $72.7 billion out of an estimated total cost of $104 billion.
- Informal care services, those typically provided for by family members, will double between now and 2030—increasing in value from $37.2 billion to $72.7 billion in unpaid care.

Compared to other family caregivers, those who care for people with severe memory problems are more likely to: experience financial hardship, report health difficulties, experience emotional stress (depression or anxiety), and suffer from sleep disturbance.

Cost of Caregiving in California

While the burden of care falls primarily on families, the rapid growth in the prevalence of Alzheimer's will also impact California's healthcare costs, causing them to rise significantly. In particular, Alzheimer's disease and other dementias are a major contributor to Medi-Cal costs.

- The cost to the Medi-Cal program for an individual with Alzheimer's disease or a related dementia is 2.5 times greater than the cost for an individual not having a diagnosis of dementia.
- Most of the Medi-Cal cost difference is accounted for by nursing home expenditures, which are almost three times greater for individuals with Alzheimer's disease or other dementias compared to other patients.
- Long-term care costs in California are increasing more rapidly than in the rest of the nation, 44 % from 2004 to 2008, as compared to a nationwide cost increase of 17%.
- Other formal care services, including traditional medical and social services, are expected to double in cost between now and 2030 – increasing from $16 billion to $31.3 billion.

California businesses will also be significantly impacted by the growth in the number of individuals living with Alzheimer's disease. Among employed caregivers, 71% work full-time and 29% are part-time employees. Because many caregivers miss work, reduce their work hours, or change jobs, California's employers experience an estimated $1.4 billion in lost productivity annually from full-time employed caregivers alone.

Recommendations

Recommendations

The impact of Alzheimer's disease is already being felt across all sectors of society but the numbers tell us that the worst is yet to come. This report offers a number of recommendations that would help California better meet the growing demand for support and services that meaningfully address the needs of individuals with Alzheimer's disease and related dementias and their families. The order in which the following recommendations are presented does not reflect their order of importance. Each of these recommendations is an essential component to building an effective system of support and care for individuals and families living with Alzheimer's. All references to Alzheimer's also refer to the related dementias.

1 Build an integrated and comprehensive health and long term care service network for those living with Alzheimer's funded from both the private and public sectors.

People living with Alzheimer's disease have medical and social needs that must both be addressed if the individual is to maintain the highest quality of life possible throughout the course of the disease. Given the high cost of caring for these individuals as well as the limited availability of state and federal funding, it is imperative that both the public and private sectors be engaged to develop a comprehensive network of services. Such a network would extend from diagnosis to end-of-life care and include the following:

- Implementation of evidence-based guidelines and provider training in all health care settings to facilitate:
    - Earlier detection of patients with the warning signs of possible Alzheimer's,
    - Increased access to accurate and complete diagnosis,
    - Comprehensive Dementia Care Management for integration of the medical and social support components of the patient and family caregiver's needs, and
    - Improved linkage of patients and their families to appropriate community-based services and supports.
- Expanded availability of affordable home and community-based services that meet the needs of individuals across the spectrum of the disease- from individuals under the age of 65 diagnosed with early-onset Alzheimer's to the more traditional client in the mid and late stages of the disease.
- Support for individuals as they transition between settings such as their home, the hospital and residential or nursing home care.
- Appropriate end of life care.

2 Develop and implement robust family caregiver policies and a network of publicly and privately funded services.

The trend to community-based care must include a thoughtful and comprehensive policy for family caregivers that would include:

- Assessment of the caregiver in addition to the individual diagnosed with Alzheimer's disease,
- Increased availability of respite care,
- Inclusion of the family caregiver in developing a family and patient care plan,
- Increased availability of caregiver education on issues such as managing challenging behaviors, and
- Development of financial incentives, such as tax credits, that would support families in their efforts to keep their loved one at home.

3 Support the development of a geriatrically trained workforce prepared to handle the unique needs of the growing population of older adults.

- The U.S. will experience an imminent shortage of formal care providers, and it is estimated that 200,000 new direct-care workers will need to be recruited each year to meet future demand among the 78 million baby boomers as they age. To achieve this growth, these workers must be adequately reimbursed, trained and supervised.
- While California did implement a rate increase for nursing homes specifically to improve pay rates as well as staffing training on a variety of topics, there has been limited oversight to ensure that facilities are complying with these requirements. So it is not enough to call for the development of public policies and educational and provider practices that help to elevate these jobs to recog-

nized, valued professions. The State must combine these requirements with adequate oversight.

- Less than 1% of California physicians have geriatric training and this percentage is declining. Policymakers at the federal, state and local levels must work together to provide financial incentives for geriatric training, such as tuition relief, to encourage individuals to pursue careers in geriatrics. The state can also provide leadership on this issue by including geriatric training requirements in medical school curriculums as well as licensing exams.

- Public employees such as Adult Protective Service workers, Police and Emergency Medical Technicians often come into contact with individuals with dementia at a time of extreme crisis. Unfortunately, all too often the special needs of these individuals are not well understood and the results can be tragic. Training on the management of people with Alzheimer's would greatly improve the ability of these first responders to take appropriate action and thereby ensure the health and safety of these individuals.

4 Encourage the private sector to implement supportive services and policies for caregivers.

The business community also has a role to play in implementing caregiver friendly programs and policies that respond to caregivers' needs to take time off from work to attend to the needs of the care recipient. By proactively implementing and making available eldercare resources, costs to California businesses can be better controlled. Eldercare resources may include: flextime; telecommuting and job-sharing; programs that provide respite care; adult day services and caregiver support groups; information, referral and educational programs; and employee and/or employer funded long-term care insurance.

5 Improve access to care for diverse racial and ethnic groups.

The Alzheimer's Association has developed a number of successful models for serving diverse communities that address barriers such as language differences; cultural values and beliefs about dementia and the role of the caregiver; limited income, health insurance, and education. The Association's work has clearly demonstrated that these communities will access services if they are delivered in a way that is culturally relevant; as such, tese models should be more broadly implemented.

6 Improve access to diagnostic and supportive services for rural communities.

- Improve the availability of transportation services that cross over county lines and are "dementia friendly," and

- Increase availability of both caregiver and professional education to build local capacity to deliver dementia-capable services.

7 Develop policies and programs that address the unique needs of people under age 65 who are diagnosed with Alzheimer's disease.

As diagnosis and early detection of Alzheimer's disease improves, more people will be diagnosed under the age of 65 and at earlier stages of the disease. Many of these individuals find themselves unable to access services in the community or pay for health care because they do not meet the age-based eligibility requirements of many publicly-funded programs. Even in cases where their age is not a barrier, the programs may not be designed to meet their unique needs. In addition, many of these individuals have the added burden of needing to continue to provide for their families, which may include caring for children as well as aging parents. To enhance care and support for these individuals, the public and private sectors must work together to:

- Remove age-related barriers that reduce access to the network of community-based services and assisted living communities that provide services to older adults, and
- Improve employer-based understanding of the unique needs of individuals diagnosed with Alzheimer's and the need for disability services and supports.

8 Implement a public health approach to disease identification, surveillance, and prevention.

Health planning for people with Alzheimer's and other dementia disorders is seriously hampered by the lack of California data. Adding questions to existing statewide health surveys, e.g. the Behavioral Risk Factor Surveillance System (BRFSS) and the California Health Interview Survey (CHIS), is a possible avenue for collecting this data. The availability of such data would provide important guidance to cities, counties and the state in setting priorities for the enhancement of existing services as well as identifying the need for new policies and programs.

9 Invest more funding in research.

Accelerating state research funding will hasten the day when people will be able to delay the debilitating symptoms of Alzheimer's. A delay of just 5 years could cut prevalence rates in half. Such a decline in the number of people diagnosed with dementia would significantly reduce the cost of the Medi-Cal program.

10 Expedite development of a State Alzheimer's Disease Plan.

Not since 1987 has California conducted a thorough review of policies and practices related to families living with Alzheimer's and related dementias. The number of Americans living with Alzheimer's has more than doubled since 1980, and 95% of what we know about the disease has been discoverd in the last twenty years. California must prepare for the impending epidemic of Californians living with dementia by bringing together a broad array of stakeholders to develop recommendations for effective strategies and systems for ensuring appropriate program and policy changes are made to meaningfully support individuals with Alzheimer's and their families.

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Section I

Alzheimer's Disease in California

Introduction[A]

Alzheimer's disease is the most common form of dementia. Dementia is a clinical syndrome of loss or decline in memory and other thinking abilities. It is caused by various diseases and conditions that affect the brain. These conditions result in damage to brain cells and lead to distinct symptom patterns and distinguishing brain abnormalities. Alzheimer's disease accounts for 70% of all causes of dementia, and vascular disease is the second most common cause, accounting for 17% of all dementing disorders. More detailed information about Alzheimer's disease and other dementias can be found in Appendix A at the end of this report.

A Adapted with permission from: 2008 Alzheimer's Disease Facts and Figures, Chicago, IL: Alzheimer's Association, 2008.

Prevalence[B,C]

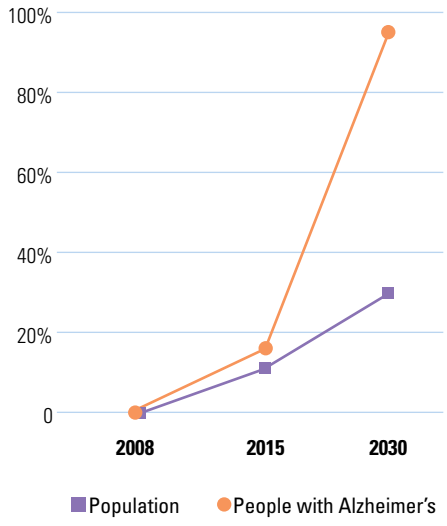
As California's population increases in the future, the number of older persons will grow dramatically as the baby boomers, those born between 1946-1964, reach age 65. The first wave of baby boomers turns 65 in 2011. The largest growth in people living with Alzheimer's disease will occur between the years 2015 and 2030, as a greater percentage of the baby boomers age.

Factors that are likely to increase the number of people with Alzheimer's disease in the future include this growth in the state's older population—especially the population age 80 and over—and reduced mortality from other causes. If California residents experience an increase in average years of education or have healthier lifestyles in the future, we may see a slower increase in the total number of people with Alzheimer's disease because higher population educational levels or people engaging in healthy behaviors are associated with decreased risk of developing the disease. However, due to advances in medicine and medical technology, the number of individuals living into their 80s and 90s is also expected to grow, as will the number of people with Alzheimer's disease.

B Information from several sources is used to describe the prevalence of Alzheimer's disease within the State of California. The numbers of people living with Alzheimer's disease from different studies varies, depending on how each study was conducted.

C Prevalence information discussed in this section primarily refers to estimates of Californians 55+ who will develop Alzheimer's disease. Appendix B contains prevalence estimates for Californians 65+ who will develop Alzheimer's disease.

Figure 1: Percent Increase in the Population of California and in Californians with Alzheimer's Disease: 2008, 2015, 2030



Source: State of California, Department of Finance Race/Ethnic, Population with Age Sex Detail, 2000–2050. Sacramento, CA, July 2007, accessible at http://www.dof.ca.gov/html/DEMOGRAP/Data/RaceEthnic/Population-00-50/RaceData_2000-2050.php. See Appendix F for methodology used to estimate California Alzheimer's disease prevalence.

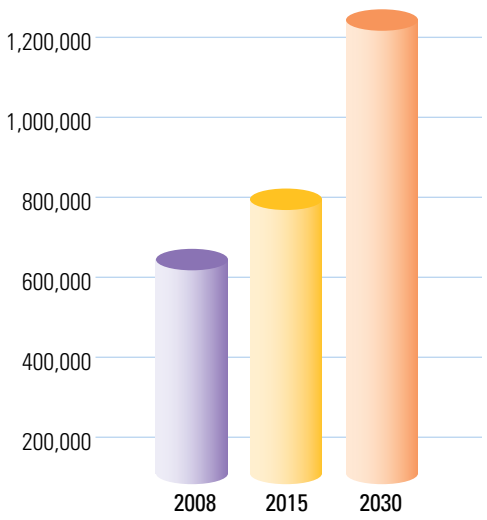
Figure 1 highlights the growth in the number of people with Alzheimer's disease compared to overall growth of the population of California. Relative to the 2008 population, by 2030 the population of the state will increase by 28%, whereas people with Alzheimer's disease will increase by 95%. In other words, by 2030, the number of people living with Alzheimer's disease in California will nearly double, compared to an overall population growth of less than one-third.

By 2030, the number of people living with Alzheimer's disease in California will nearly double.

As shown in ***Figure 2***, the expected increase in people with Alzheimer's disease will grow exponentially between 2008, 2015 and 2030. The percentage of Californians 55 years of age and over with Alzheimer's disease is projected to increase by 15% between 2008 to 2015, from 588,208 to 678,446. Between 2015 and 2030, the percent of individuals 55 years of age and over living with Alzheimer's disease is projected to increase by 69%, from 678,446 to 1,149,560. In summary, between 2008 and 2030 the number of Californians 55 years of age and older who are projected to acquire Alzheimer's disease will almost double. A similar projection from 2008-2030 is anticipated for individuals 65 years and older (see Appendix B, Table B6).

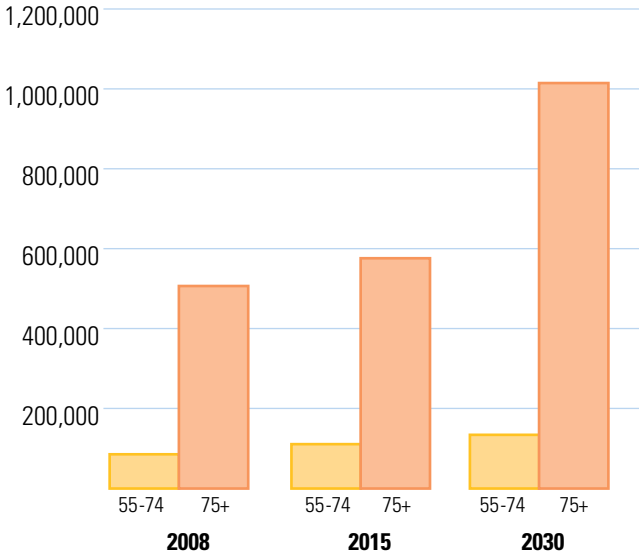
D Appendix B lists the Alzheimer's disease frequency changes from 2008-2030 for California counties and shows dramatic differences in increases across all counties, ranging from 54 percent to 212 percent.

Figure 2: Estimated Number of People 55+ with Alzheimer's Disease; 2008, 2015, 2030



As displayed in ***Figure 3***, the majority of people with Alzheimer's disease are 75 years of age and older. In 2008, this age group constitutes 85% of the total number of people over the age of 55 years who have this disease By 2030, approximately twice as many persons 75 years of age and older will have Alzheimer's disease, amounting to over one million persons. However, growth in the number of people living with Alzheimer's disease is not limited to older adults, as we also project considerable increases in the number of individuals with Alzheimer's disease between the ages of 55-74. Currently, there are 76,420 persons within this age group who have Alzheimer's disease. By 2030 this number will almost double to 139,532 people. [D]

Figure 3: Age Distribution of Californians with Alzheimer's Disease; 2008, 2015, 2030



Estimated Number of People with Alzheimer's Disease in Select California Counties; 2008, 2015, 2030

The number of older people differs greatly across California's counties. Consequently, the number and proportion of people in each county with Alzheimer's disease varies significantly. As shown in ***Table 1***, by 2030 the number of people living with Alzheimer's disease in thirteen of California's fifteen largest counties, those with a population of 700,000 or more, will see close to a doubling or more.

Underreporting and obtaining a diagnosis at a later stage of Alzheimer's disease often occurs among people of color.

Alzheimer's Disease Among California's Ethnic and Culturally Diverse Population

California is among the most ethnically and culturally diverse states in the U. S. It dominated the Census 2000 diversity score rankings with nine counties in the top 20 (Alameda, Los Angeles, San Francisco, Solano, Santa Clara, San Joaquin, San Mateo, San Bernardino, Fresno), two of which were in the top 10 (Alameda and Los Angeles).[1] As such, it is important to examine how current and future population trends among the state's diverse population will change the face of Alzheimer's disease in the next three decades.

Though there is some evidence of genetic differences and environmental risk factors for Alzheimer's disease among ethnically diverse groups, more studies are needed to confirm these variations.[2] Additionally, cultural biases in cognitive testing and inadequate translation of diagnostic tools may influence the identification

Table 1: Number and Percent Change in People 55+ with Alzheimer's Disease in California Counties with a Population of 700,000 or More; 2008, 2015, 2030

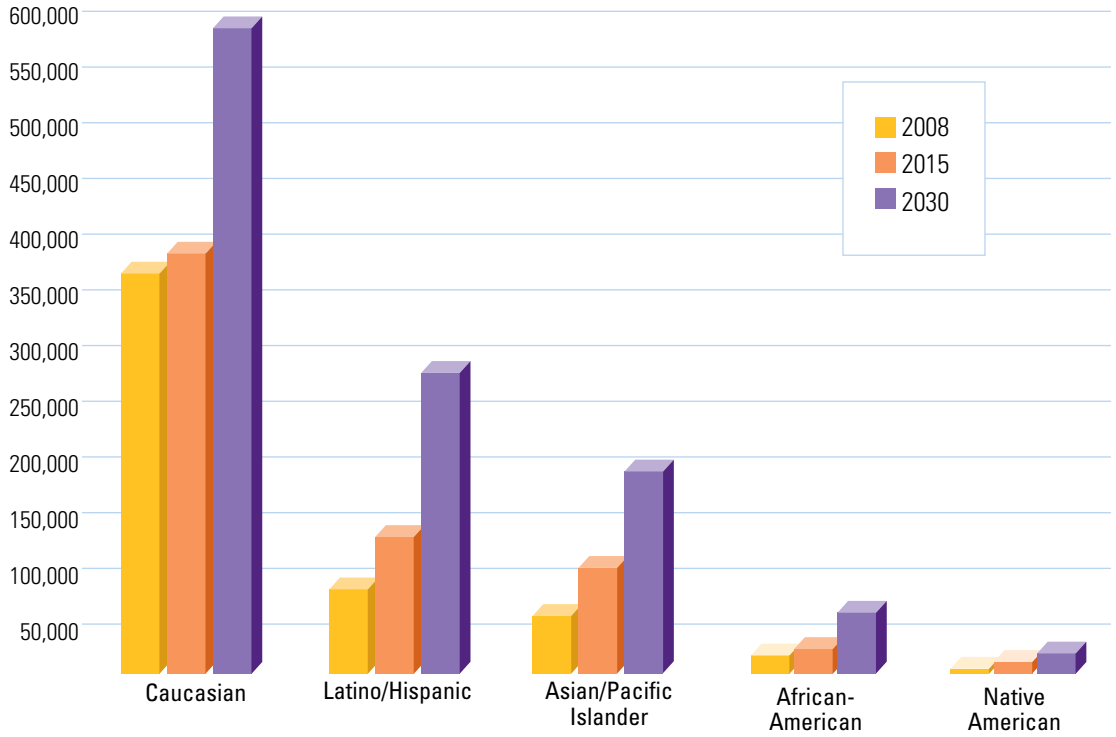
	2008	2015	2030	% increase 2008-2015	% increase 2015-2030	% increase 2008-2030
Los Angeles	155,575	177,000	289,280	14	63	86
San Diego	49,530	54,490	92,804	10	70	87
Orange	46,263	54,109	92,150	17	70	99
Riverside	31,992	37,025	60,116	16	62	88
Santa Clara	27,658	32,988	58,569	19	78	112
Alameda	23,748	26,847	47,438	13	77	100
San Bernardino	23,680	29,922	56,591	26	89	139
Sacramento	22,006	25,692	44,181	17	72	101
Contra Costa	17,511	20,435	36,895	17	81	111
San Francisco	17,438	19,206	26,868	10	40	54
San Mateo	13,684	14,610	23,298	7	59	70
Ventura	12,541	14,819	26,301	18	77	110
Fresno	12,249	14,216	24,808	16	75	103
San Joaquin	9,796	11,840	20,514	21	73	109
Kern	9,197	11,418	20,614	24	81	124

Source: Based on California Department of Finance data for 2008.

of dementia in ethnically diverse populations. Coupled with the lack of bilingual professionals in this field nationwide, testing and diagnosis of non-English, monolingual-speaking elders is especially challenging.

While significant progress has been made in developing culturally sensitive tools, they have not been standardized or normed across diverse populations, nor are they being widely used outside of academic or specialized research settings. As a consequence, underreporting and obtaining a diagnosis at a later stage of Alzheimer's disease often occurs among people of color. This not only limits our understanding of the impact of Alzheimer's disease within the racially and culturally diverse communities of the state but can directly impact the individual living with Alzheimer's disease, since the effectiveness of medications, psychological or social interventions depends upon early intervention. ***Figure 4*** displays the current and projected number of people who have, and will develop, Alzheimer's disease in the future among Caucasian/non-Latino, Latino/Hispanic, African-American, Asian/Pacific Islander, American Indian, and multiracial population groups.

Figure 4: Estimated Number of Californians 55+ with Alzheimer's Disease by Race/Ethnicity; 2008, 2015, 2030



Caucasians

In California, 66% of older persons with Alzheimer's disease are Caucasian/non-Latino. This population sub-group will experience the largest absolute growth in the number of people living with Alzheimer's disease between 2008-2030 due to the aging of the predominantly Caucasian baby boomers. However, the proportional increase relative to the entire Caucasian/non-Latino population will not be as steep compared to California's other ethnic sub-populations, primarily due to lower fertility rates among the baby boomers. Other related reasons for this include, but are not limited to, lower risks associated with developing Alzheimer's disease because of higher educational levels, associated health factors (e.g., lower rates of diabetes and vascular disease than other population sub-groups), and generally better access to, and use of, health services among this population.

Latinos/Hispanics

In California, Latinos/Hispanics are the second largest population group and are fast becoming the state's majority ethnic group. Similar to national trends, in California the number of Latinos/Hispanics living with Alzheimer's disease will triple between 2008 and 2030. We currently estimate that 92,242 Latinos/Hispanics have Alzheimer's disease and by 2030 276,821 Latinos/Hispanics will be living with Alzheimer's disease in this state.

While research is only beginning to uncover the impact of Alzheimer's disease among Latinos, what we have learned to date suggests that this population may be at greater risk of developing Alzheimer's disease and dementia than other ethnic or cultural groups due to the following:[3]

- Age is the most significant risk factor for developing Alzheimer's disease. The prevalence doubles every 5 years beyond the age of 65, and reaches 47% for people 85 years of age and older. It is projected that the average life expectancy of Latinos/Hispanics will increase to age 87 by 2050, surpassing all other ethnic groups in the United States.
- Education appears to have some protective effect against Alzheimer's disease. Latinos/Hispanics have the lowest education levels of any group in the U.S. Currently, one in ten Latino/Hispanic elders has no formal education, and over one-half have eight years or less of formal education.
- A growing body of evidence indicates that vascular disease risk factors—including diabetes—may also be risk factors for Alzheimer's disease and stroke-related dementia. Latinos/ Hispanics have high rates of each of these risk factors.4 The high incidence of diabetes—64% higher than Caucasian/non-Latino Americans—is a matter of particular concern.

Latinos/Hispanics living with Alzheimer's disease will triple between 2008 and 2030.

African-Americans living with Alzheimer's disease will double by 2030.

Asian/Pacific Islanders living with Alzheimer's disease will triple between 2008 and 2030.

- There is a substantial body of evidence, reinforced by clinical experience, that Latinos/Hispanics with dementia are low users of formal health care services. For example, among adults with diabetes, high blood pressure, or heart disease —all potential risk factors for dementia —Latinos/Hispanics are less likely to receive services to help monitor and control those conditions. They are less likely than non-Latinos/Hispanics to see a physician and much less likely to use services provided by other health professionals—both of which may increase the risk of dementia. Furthermore, by not accessing health-care services, there may be delays in the identification and diagnosis of dementia. Like pharmacologic interventions, non-pharmacologic approaches are most beneficial at the earlier stages of the disease.

African-Americans

In California, the number of African-Americans living with Alzheimer's disease will double by the year 2030, with an estimated increase from 26,521 to 52,369 people. These may be underestimates because screening and assessment tools and the design of clinical trials do not address the unique presentation of Alzheimer's disease in African-Americans.5 Ethnic and cultural bias in current screening and assessment tools is well documented. As a result, African-Americans who are evaluated have a much higher rate of false-positive results. At the same time, there is substantial evidence of under-reporting of dementia among this population. Like their Latino/Hispanic counterparts, African-Americans tend to be diagnosed at a later stage of Alzheimer's disease—limiting the effectiveness of interventions that are generally more beneficial in the early stages of the disease. In addition, African-Americans are seriously under-represented in current clinical trials of potential treatments for Alzheimer's disease, particularly in trials conducted by drug companies. This has occurred even though evidence of genetic differences and response to drugs varies significantly by race and ethnicity. [5]

Age is a key risk factor for Alzheimer's disease in all racial and ethnic groups.[5] However, additional risk factors may influence the dramatic increase in Alzheimer's disease in African-Americans:

- There is a greater familial risk of Alzheimer's in African-Americans where the cumulative risk of dementia among first-degree relatives of persons with Alzheimer's disease is 43.7%.[5]
- Genetic and environmental factors may work differently to cause Alzheimer's disease in African-Americans. Genetic risk factors seem different in African-Americans and Caucasian/non-Latino Americans. APOE genotype alone does not explain the increased frequency of Alzheimer's disease in older African-Americans. For spouses (who share environmental but not genetic backgrounds), the cumulative risk was 18.4%. These findings of familial risk, reported in January 2002, are based on family histories of the largest number of African-American families ever studied for Alzheimer's disease.[5]
- Persons with a history of either high blood pressure or high cholesterol levels—both relatively common among African Americans—are twice as likely to get Alzheimer's disease. Those with both risk factors are four times as likely to become demented.[5]
- Sixty-five percent of African-American Medicare beneficiaries have hypertension, compared to 51% of Caucasian/non-Latino beneficiaries. They are also at higher risk of stroke and vascular dementia than Caucasian/non-Latino Americans.[5]
- African-Americans have a 60% higher risk of type 2 diabetes, a condition that contributes directly to vascular disease, which is a risk factor for developing Alzheimer's disease.[5]
- Years of education seems to be a particularly important factor in explaining why African-Americans are more likely than Caucasian/non-Latino Americans to have Alzheimer's disease and dementia. Some researchers point out that quality of education and socioeconomic factors that affect access to education are probably also important in understanding why African-Americans are more likely to have Alzheimer's disease and dementia.[5]

Asian/Pacific Islanders

Asian/Pacific Islanders are another group that is experiencing significant population growth in California and will have a corresponding increase in the number of individuals living with Alzheimer's disease. However, far from being a homogeneous group, Asian/Pacific Islanders encompass immigrants and their descendants from a large number of countries with widely varying histories, cultures, traditions, and languages.

Alzheimer's disease in this group will almost triple between 2008–2030, increasing from approximately 72,075 to 194,266. This may also be an underestimate, since studies suggest that Asian/Pacific Islander Americans may not report symptoms of dementia to medical professionals unless family caregivers require medical assistance with behavioral issues.[6] Also, as with other ethnic groups of elders in general and Asian/Pacific Islanders in particular, they are unlikely to receive a diagnosis of Alzheimer's disease until the disease has progressed to the later stages, when combined bio-psycho-social interventions are less beneficial. While this community has a keen awareness of Alzheimer's disease, beliefs regarding the disorder may be influenced at least as strongly by folk wisdom and cultural beliefs.[6]

Some of the risk factors for Alzheimer's disease within this community include: genetic risk factors and hypertension. A study within San Francisco's Asian community found that 69 percent of adults suffered from hypertension, compared to 29 percent nationwide.[7] This study also found that compared to the U.S. population, a lower percentage of the Asian adults took medications to treat their hypertension. Cultural and language barriers, low health literacy, economic difficulties, limited health access, lack of health insurance, and related reasons were considered to be major factors contributing to the low frequency of antihypertensive medication use and control. Also, as with the general population, the incidence of diabetes is growing within the Asian/Pacific Islander community.[8,9,10]

Between 2000 and 2004, African-Americans and Asian/Pacific Islanders showed the greatest increase in reported deaths due to Alzheimer's disease.

Lifetime Risk of Alzheimer's Disease and Dementia

The "lifetime risk" of a disease or condition is the likelihood that a person will develop the disease or condition at any time in his or her life. Currently, there is no information to calculate risk from birth for Alzheimer's disease or dementia. National estimates of lifetime risk indicate that one in six women and one in ten men who live to be at least age 55 will develop Alzheimer's disease in their remaining lifetime. Higher proportions, one in five women and one in seven men who reach age 55, will develop some type of dementia, including Alzheimer's disease. The risk of developing Alzheimer's disease and dementia is higher for women than men because women live longer, on average, than men. As deaths from other causes decrease in the future, the average lifespan for the U. S. population will increase, thus increasing the lifetime risk of Alzheimer's disease and other dementias. Even without that increase, about 10 million of the 78 million baby boomers in the U. S. who are alive today can expect to develop Alzheimer's disease. About 14 million baby boomers who are alive today can expect to develop some form of dementia, including Alzheimer's disease.[2]

These figures for remaining lifetime risk are conservative because the study on which they are based, the Framingham Heart Study, used a relatively high threshold for including an individual as a person with dementia. The study criteria required that the individual must have dementia specified as at least moderate and that the dementia symptoms must have been present for at least six months. Thus, people who had very early or mild dementia and individuals with moderate dementia of less than six months' duration were not counted as having dementia. If these people had been counted as having dementia, the figures for remaining lifetime risk would be higher.[2]

True lifetime risk for baby boomers will also be greater because the number of deaths due to heart disease, cancer and stroke (the three leading causes of death) is decreasing, while the number of deaths due to Alzheimer's disease is increasing (refer to the next section of this report, Mortality, for additional discussion of Alzheimer's disease and other leading causes of death). As a result, people will be living longer, increasing their probability of developing Alzheimer's disease and other dementias.

Lifetime Risk and California's Baby Boomer Population

The baby boomers are people living in the U. S. now who were born from 1946 through 1964. In 2008, the oldest baby boomers, people born in 1946, are 62. The youngest baby boomers, people who were born in 1964, are 44.

The remaining lifetime risks of Alzheimer's disease and dementia apply to baby boomers who are already age 55 or over. The remaining lifetime risks of Alzheimer's disease and other dementias also apply to baby boomers who are under age 55, assuming that they live to be at least age 55.[2]

California's baby boomer population now includes over 9 million people, of whom over 3 million are ages 55–62 and approximately 6 million are ages 44–54. Applying the national proportions to California's population, it is estimated that 1.2 million of California baby boomers can expect to develop Alzheimer's disease in their remaining lifetime. Similarly, about 1.6 million can expect to develop dementia, including Alzheimer's disease. The lifetime risk for developing Alzheimer's disease for a California baby boomer who lives to be 55 is one in eight. The lifetime risk is one in six for developing dementia, including Alzheimer's disease, for people who live to be 55 (see Appendix C for county-specific rates).

Mortality[E]

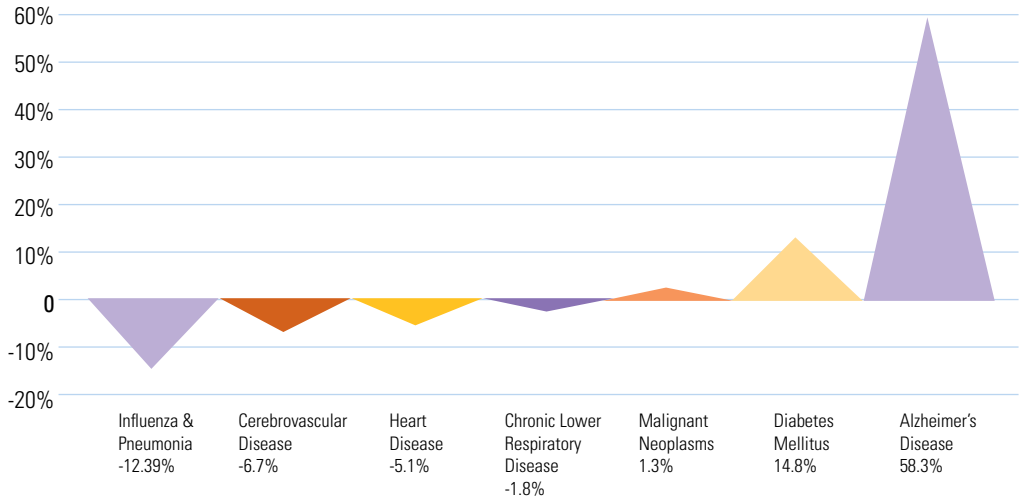
Alzheimer's disease remained the seventh leading cause of death in the United States in 2005. However, in California Alzheimer's disease moved from the eighth leading cause of death in 2004 to sixth in 2005 as the number of deaths increased from 6,962 to 7,694 people.

As shown in ***Figure 5*** and ***Table 2***, comparing Alzheimer's disease to other leading causes of death in California between 2000 and 2004, Alzheimer's disease showed the greatest increase (58.3%). The only other illnesses to show an increase in deaths during this time period were those associated with malignant neoplasms (cancers) and diabetes mellitus. The other leading causes of death—heart disease, cerebrovascular disease, chronic lower respiratory disease, and influenza and pneumonia—actually show declines. As medical treatments and other interventions become more effective in preventing, curing, or better managing chronic illnesses and people live longer, they are at greater risk of developing Alzheimer's disease. Thus, in the future the deaths due to this disease may continue to increase relative to other illnesses. Also, a likely factor contributing to the increased number of reported Alzheimer's disease deaths is more accurate protocols for its diagnosis.

In California, Alzheimer's disease moved from the eighth leading cause of death in 2004 to sixth in 2005.

Even though deaths attributed to Alzheimer's disease are increasing, the number does not fully capture the disease's public health impact. Numerous studies have suggested that death certificates substantially under-report Alzheimer's disease as a cause of death for people living in the community because most individuals with Alzheimer's disease are age 65 and older and tend to have other serious coexisting medical conditions such as heart disease or stroke. Given these multiple medical issues, physicians may tend to attribute death primarily to one of these other conditions even when Alzheimer's disease is present. In the large percentage of cases where the medical record fails to reflect an Alzheimer's disease diagnosis, the certifying physician may not even be aware that the individual had the disease.[2]

Figure 5: Percentage Change in Leading Causes of Death in California; 2000 to 2004



Source: California Department of Public Health, Center for Health Statistics, *Deaths and Age-Adjusted Death Rates for Leading Causes of Death by Sex, California, 2000-2004.*

E In 2008 the California Office of Health Information and Research (OHIR) published a report on Alzheimer's Disease Deaths California for 2005.[11] Alzheimer's disease data were extracted from vital statistics records with deaths attributed to Alzheimer's disease as defined by the International Classification of Diseases, Tenth Revision (ICD-10) code G30 in accordance with the National Center for Health Statistics (NCHS). The OHIR report calculated age-specific death rates. Age-specific death rates are the number of deaths per 100,000 people in a specific age group, and are used along with standard population proportions to develop a weighted average rate. The weighted average rate is referred to as an age-adjusted death rate and removes the effect of different age structures of the populations whose rates are being compared. Age-adjusted death rates therefore provide the preferred method for comparing different race/ethnic groups, sexes, and geographic areas, and for measuring death rates over time. Unless otherwise noted, all death rates in this report are age-adjusted. When possible, information from the OHIR report is used in this section. However, there are additional issues that this report highlights that were not addressed in the OHIR report. In these instances, 2004 Death Record information from the California Department of Public Health was used to augment the OHIR findings.

Table 2: Number of Deaths and Percent Change in Leading Causes of Death in California: 2000 to 2004

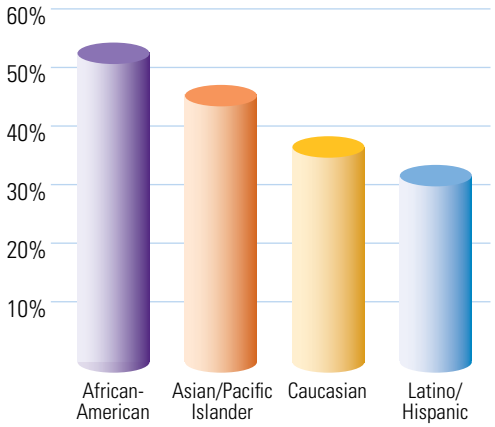
	2000	2004	% change
Heart Disease	68,533	65,002	-5.1
Malignant Neoplasms	53,005	53,708	1.3
Cerebrovascular Disease	18,090	16,884	-6.7
Chronic Lower Respiratory Disease	12,754	12,519	-1.8
Influenza & Pneumonia	8,355	7,331	-12.3
Diabetes Mellitus	6,203	7,119	14.8
Alzheimer's Disease	4,398	6,962	58.3

Source: California Department of Public Health, Center for Health Statistics, *Deaths and Age-Adjusted Death Rates for Leading Causes of Death by Sex, California, 2000-2004.*

Alzheimer's Disease Mortality Among California's Ethnic and Culturally Diverse Population

Information from 2004 indicates that the vast majority of deaths due to Alzheimer's disease (94%) occur in individuals 75 years of age and older. Most of these deaths occurred within the Caucasian/non-Latino population. However, given California's aging population and the projected increase in the number of African-Americans, Latinos/Hispanics, and Asian/Pacific Islanders living with Alzheimer's disease over the next 22 years, deaths due to Alzheimer's disease within these groups will increase. As displayed in ***Figure 6***, between 2000 and 2004 African-Americans and Asian/Pacific Islanders showed the greatest increase in reported deaths due to Alzheimer's disease.

Figure 6: Percent Change in Deaths Due to Alzheimer's Disease by Race/Ethnicity; 2000 to 2004 (crude death rates)[F]



Source: California Department of Public Health, Center for Health Statistics, *Deaths and Age-Adjusted Death Rates for Leading Causes of Death by Sex, California, 2000-2004.*

F A crude death rate is defined as the number of cause-specific events (e.g. deaths, disease cases, individuals at risk) over a specified period of time (e.g. a year) divided by the total population. Crude death rates are sometimes expressed as annual rates per 100,000 population and may be calculated for males, females, or some other subset of the population.

In 2005, California's Alzheimer's disease death rate was 23.4 deaths per 100,000 people, higher than the U. S. rate of 22.9 deaths. Caucasian/non-Latinos had the highest reliable death rate (27.8), followed by African Americans (27.3), Latinos/Hispanics (13.0), and Asians/Pacific Islanders (8.0). Differences among the groups were significant, except for the African American and Caucasian/non-Latino rate comparisons.

The lower death rates for the Latino/Hispanic and Asian/Pacific Islander populations might be due to under-reporting.[11] Within both of these groups, Alzheimer's disease is diagnosed later in the course of the disease due to access to care issues or not reporting dementia symptoms to medical professionals unless assistance is needed with behavioral issues (see section Prevalence of Alzheimer's Disease Among California's Ethnic and Culturally Diverse Population).

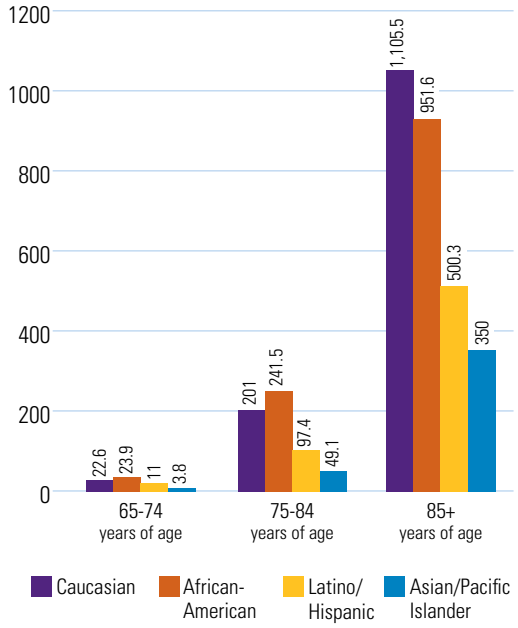
As shown in ***Figure 7***, in 2005 African-Americans had the highest death rate in the 65 to 74 and 75 to 84 age groups, while Caucasian/non-Latinos had the highest rate in the 85 and older age group. Asian/Pacific Islanders had the lowest rates in the 75 to 84 and 85 and older groups,

but the rate was unreliable in the 65 to 74 age group. The generally low death rate within this latter group is probably due to under-reporting of Alzheimer's disease on death certificates due to its either being diagnosed later in the course of the disease, not reporting dementia symptoms to medical professionals unless needing assistance with behavioral issues, or health provider under-reporting.

As displayed in ***Figure 8***, Alzheimer's disease death rates for California residents for the past five years increased by 39.3 percent from 16.8 deaths per 100,000 in 2001 to 23.4 deaths in 2005. All population sub-groups showed significant increases in rates over this time period. African-Americans had the largest increase in death rates (69.6 percent), followed by Latinos/Hispanics (64.6%), Asians (63.3%), and Caucasian/non-Latinos (41.1%). The reasons for increased death rates due to Alzheimer's disease might be due to fewer people dying from other illnesses such as heart disease and the fact that individuals are living longer, as increased age is the most significant risk factor for developing the disease.

Figure 7: Alzheimer's Disease 2005 Death Rates by Race/Ethnicity and Age Group

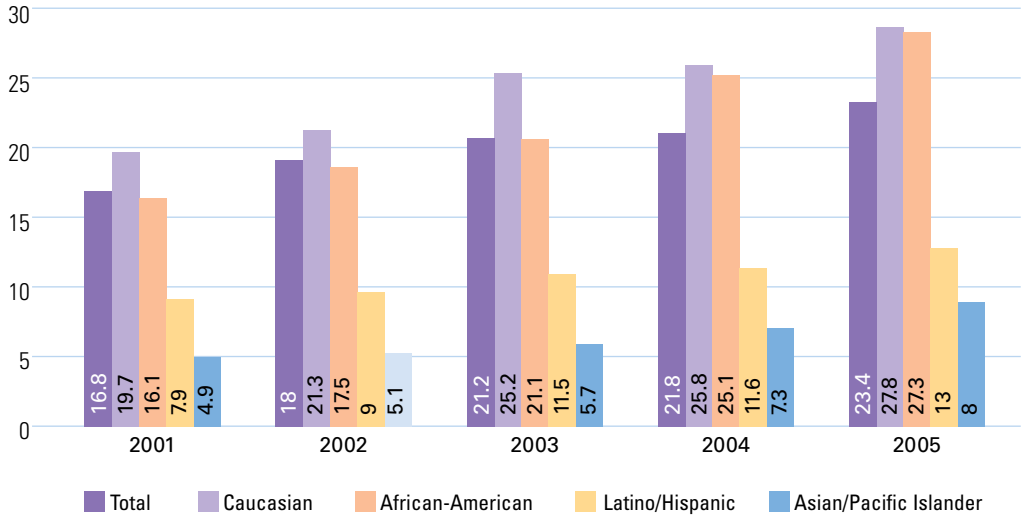
Death Rates Per 100,000



Source: Jew-Lochman, S. (2008). *Alzheimer's disease Deaths California, 2005.* California Department of Public Health, Office of Health Information and Research.

Figure 8: Alzheimer's Disease Death Rates by Race/Ethnicity; 2001-2005

Age-Adjusted Death Rates Per 100,000



Source: Jew-Lochman, S. (2008). *Alzheimer's disease Deaths California, 2005.* California Department of Public Health, Office of Health Information and Research.

Alzheimer's Disease Mortality in California Counties

As displayed in ***Table 3***, Los Angeles, San Diego, and Orange counties have the highest number of deaths due to Alzheimer's disease, given their large numbers of older adults. Complete California county information for Alzheimer's disease deaths from 2003 to 2005 can be found in Appendix D.[G] The county Alzheimer's disease death rates were calculated using 2004 mid-year population denominators and are presented as rates per 100,000 population.

There are likely to be many reasons that contribute to the variability in death rates between counties in California. One influence might be the differences in the racial/ethnic composition of the counties. Eight of the counties listed in Table 3 are considered to be in the top 20 for racial/ethnic diversity, based on the United States 2000 census (Alameda-2nd, Los Angeles-9th, San Francisco-11th, Santa Clara-13th, San Mateo-18th, San Bernadino-19th and Fresno-20th).[1] Some of the wide range in death rates among the counties may be due to different risk factors associated with Alzheimer's disease such as level of education, health status, and access to health care. As noted earlier, there is also likely to be variability among counties in the reporting of Alzheimer's disease as a cause of death. ***Figure 9*** shows a thematic map of the Alzheimer's disease death rates for all California counties.[11] Appendix D lists the death rates by county.

Table 3: California Counties with the Greatest Number of Alzheimer's Disease Deaths in 2005

	2003-2005 Deaths (Average)	Percent of Total Population	2004 Population	Rate per 100,000 Population [H]
CALIFORNIA	7,080.3	100.0	36,525,947	22.1
Los Angeles*	1,391.7	19.7	10,152,410	16.3
San Diego*	1,068.0	15.1	3,031,055	38.6
Orange	564.7	8.0	3,038,670	22.2
Riverside*	474.3	6.7	1,845,185	28.6
Santa Clara	311.0	4.4	1,747,295	20.8
San Bernardino*	299.3	4.2	1,922,467	26.1
Sacramento	283.0	4.0	1,357,367	24.5
Contra Costa	229.7	3.2	1,014,992	23.9
Alameda*	212.3	3.0	1,497,316	15.8
San Mateo	156.0	2.2	720,229	18.9
Fresno	153.0	2.2	874,745	23.4
Sonoma*	150.0	2.1	477,419	27.5
Kern*	140.3	2.0	744,489	31.4
Ventura	136.0	1.9	808,735	20.0
San Francisco*	134.3	1.9	793,564	13.3

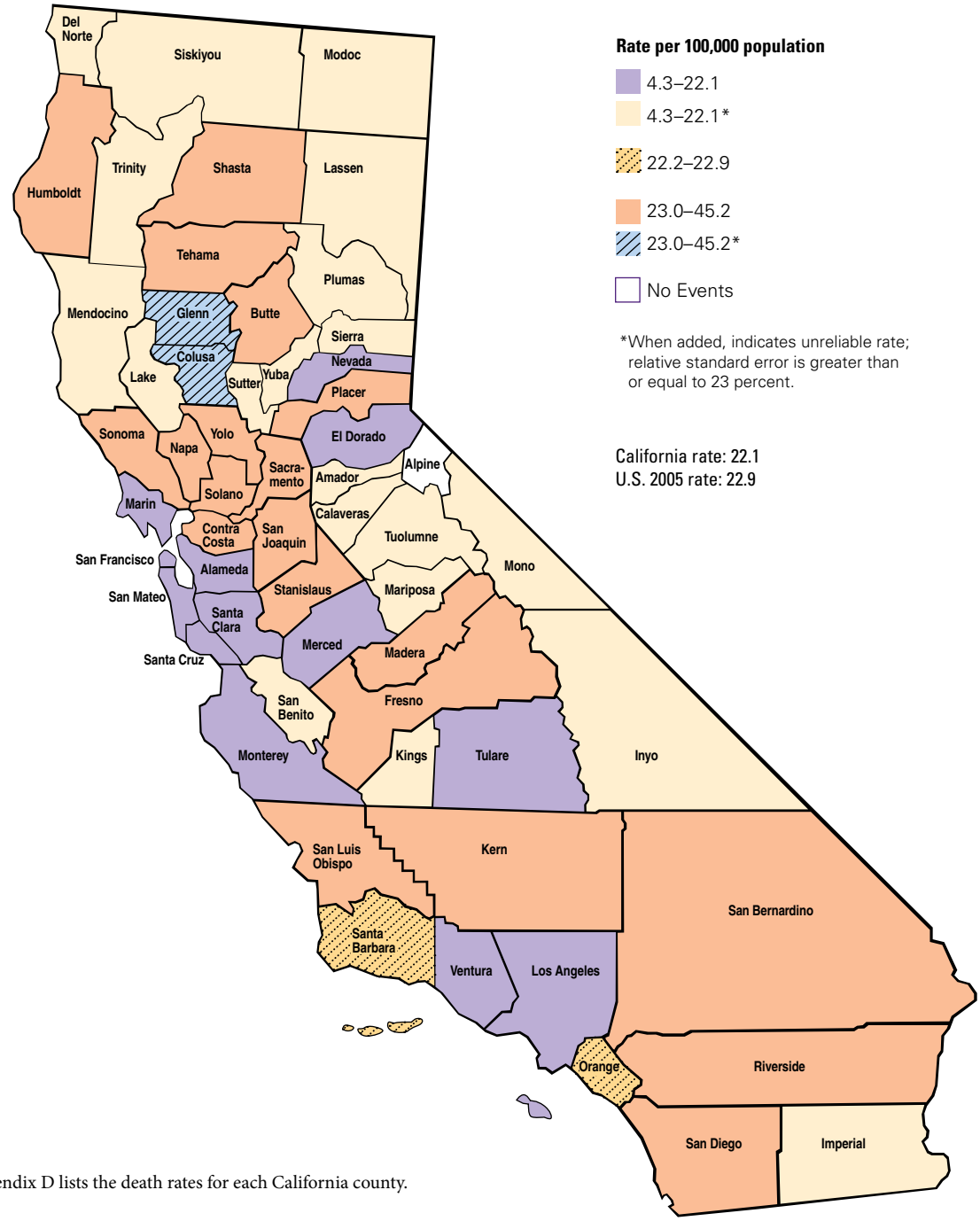
* County age-adjusted rate is significantly different from the state age-adjusted rate.

Source: Jew-Lochman, S. (2008). *Alzheimer's disease Deaths California, 2005.* California Department of Public Health, Office of Health Information and Research.

G Appendix D includes age-adjusted and crude death rates for each California county.

H Age-specific death rates are the number of deaths per 100,000 people in a specific age group, and are used along with standard population proportions to develop a weighted average rate. The weighted average rate is referred to as an age-adjusted death rate and removes the effect of different age structures of the populations whose rates are being compared. Age-adjusted death rates therefore provide the preferred method for comparing different race/ethnic groups, sexes, and geographic areas, and for measuring death rates over time.

Figure 9: Average Alzheimer's Disease Death Rates For All California Counties: 2003-2005 [I]



I Appendix D lists the death rates for each California county.

Source: Jew-Lochman, S. (2008). *Alzheimer's disease Deaths California, 2005*. California Department of Public Health, Office of Health Information and Research.

Section II

Caregiving for People with Alzheimer's Disease and Other Dementias

Who are the Caregivers?

An Alzheimer's caregiver is anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help due to having Alzheimer's disease. Examples include a husband who must help his wife to dress and bath; a wife who takes over bill paying and other chores that her husband can no longer complete; a daughter who brings one of her parents to live in her home because the parent is no longer safe living alone. Caregivers of people with other dementias also face these challenges.

Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends, and neighbors who provide care. These individuals can be primary or secondary caregivers, provide full- or part-time care, and can live with the person being cared for or live separately. Formal caregivers—sometimes called professional caregivers—are care providers associated with a health care or social service system, or hired independent providers.

Nationally, almost 10 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia.[2] These unpaid caregivers are primarily family members, but also include friends and neighbors. Many people living with Alzheimer's disease and other dementias will have more than one unpaid caregiver. For example, people who live with their primary caregiver and receive help from another relative, friend, or neighbor. In addition, family caregivers are often managing other serious medical condition, such as diabetes or congestive heart failure, in themselves and/or in the person living with Alzheimer's disease.

Caring for a person with Alzheimer's disease or another dementia is often very difficult and poses physical, emotional and economic challenges for the family. However, it does not mean that there will no longer be times of joy, shared laughter, and companionship. Alzheimer's disease develops gradually, which means that there is time to plan ahead, time to adjust to the diagnosis, and time to enjoy being with each other.

About 1.1 million Californians provide unpaid care for a person with Alzheimer's disease or dementia.

Who are California's Caregivers?

About 1.1 million Californians[J] provide unpaid care for a persion with Alzheimer's disease or dementia. While specific information on these individuals is not available, there is information describing caregivers for care recipients who are older than 50 years of age. These California caregiver characteristics are similar to national studies that have provided information about caregivers of people living with Alzheimer's disease.

California caregivers caring for individuals 50 years or older have an average age of 51 years, which is slightly older than caregivers nationally. Women tend to shoulder the vast majority of caregiving—75% are women, 60% are married, and 31% have children under the age of 18 living at home (as compared with 41% nationally). Sixty-one percent are Caucasian/non-Latino, 25% are Latino/Hispanic, six percent African American, and five percent Asian/Pacific Islander. Most caregivers were born in the U.S. (86%), but a notable number (6%) report Mexico as their country of origin. About half of California's caregivers are employed—71% full-time and 29% part-time. Three-fourths of caregivers (74%) evaluate their health as good, very good, or excellent, with 26% indicating their health is fair or poor; 28% report health or emotional problems.[12]

The Alzheimer's Association in California and the Caregiver Resource Centers (CRCs) are two non-profit organizations that provide a single point of entry for support services for caregivers throughout the state. Appendix H and Appendix I provide a list of Alzheimer's Association and Caregiver Resource Centers in California.

J The number of caregivers of people living with Alzheimer's disease in California is gathered from a number of sources that use varying methodologies to arrive at an estimate of caregivers. The Alzheimer's Association Alzheimer's Disease Facts and Figures, 2008 report estimates that there are 1.1 million California caregivers caring for individuals living with Alzheimer's disease or related dementia.[2]

The Alzheimer's Association in California has five chapters and 20 service offices to meet the needs of family caregivers and the growing number of people living with Alzheimer's disease or a related dementia. The Association provides disease education, support, family care consultations, information and referral, support groups and a wanderer's identification program called Medic Alert+Safe Return. The Alzheimer's Association serves 105,201 caregivers and families each year but lacks resources to fully meet their needs.

California also has a statewide network of 11 Caregiver Resource Centers (CRCs), operating under the California Department of Mental Health, that provide support services to help family and informal caregivers continue their care and avoid premature institutionalization of their loved ones. Data from California's CRCs indicate that the average caregiver served by the program is a 59-year-old woman who has been caring for her father or husband with Alzheimer's disease for three to four years. Nearly half are 60 or older—those who are at highest risk of health problems themselves. Most are women (77%), most often an adult child of the care receiver (47%). Thirty-five percent are spouses, and nine percent have another (non-family) relationship with the care receiver. Most caregivers served by the CRC system are likely to live with the care receiver (71%).[13]

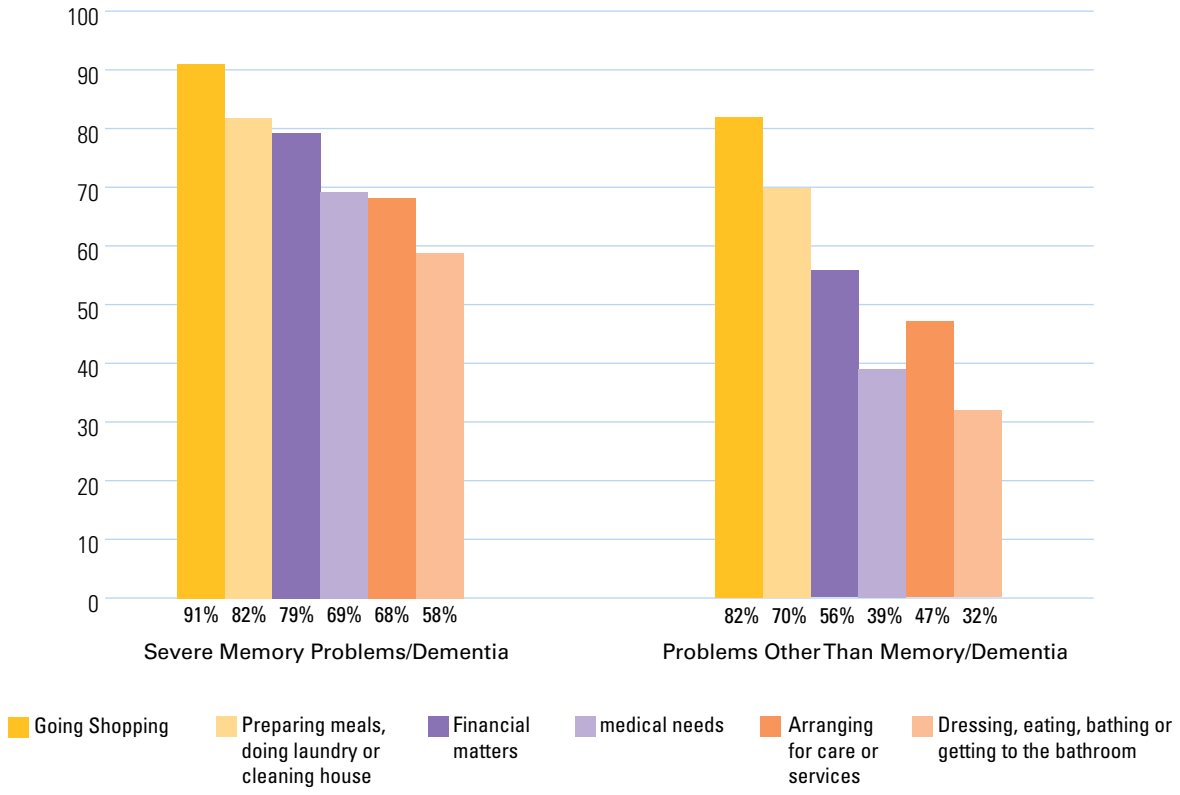
What are the Characteristics of Care Recipients?

Fewer care recipients with memory problems/dementia live alone in their own home or apartment than do care recipients without these problems (27% vs. 37%). Approximately one-third of both groups reside with a caregiver. However, caregivers of people with severe memory problems/dementia spend an average of 53.7 hours per week providing help, as opposed to 34.1 hours spent by caregivers of people without memory problems/dementia.[12]

As displayed in ***Figure 10***, people living with Alzheimer's disease need more help with personal care tasks known as Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (e.g., transportation, shopping, managing finances and cooking) compared to physically impaired individuals.[12] Care recipients with memory problems or dementia require significantly more assistance with IADLs than care recipients with problems other than memory/dementia.[14]

Some family and other unpaid caregivers who live with a person who has Alzheimer's disease or another dementia provide supervision and help 24 hours a day, seven days a week, getting up with the person at night and assisting with all daily activities. Such around-the-clock care is needed when a person cannot be left alone because of risk of wandering, getting lost, and other unsafe activities. These additional needs result in caregivers of people with Alzheimer's disease and other dementias providing more hours of help,

Figure 10: Differences in Care Recipient Needs for Individuals with Severe Memory Problems/ Dementia Compared to Individuals with Problems Other Than Memory/Dementia



Source: Scharlach, A., Sirotnik, B., Bockman, S., Neiman, M., Ruiz, C., & Dal Santo, T. (2003). *A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers*. Center for the Advanced Study of Aging Services, University of California, Berkeley.

on average, than caregivers for physically impaired individuals. Not surprisingly, given these additional needs, the costs of caring for an individual living with Alzheimer's disease in the community in the U. S. are approximately 31% more than caring for a person with a serious physical ailment.[14]

The average number of hours of unpaid care provided for people with Alzheimer's disease and other dementias increases as the person's disease progresses.[15] The number of hours of unpaid care is also greater, on average, for people with coexisting medical conditions in addition to Alzheimer's disease or another dementia.[16]

Long-Distance Caregivers

National estimates indicate that 10% of the 9.8 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias live more than two hours from the person for whom they provide care, and another four percent live one to two hours from the person.[2] Depending on the definition of "long-distance caregiving," living more than two hours or between one and two hours from the person receiving care, and applying these estimates to the 1.1 million unpaid Alzheimer's disease caregivers in California, an estimated 110,307 to 154,430 caregivers of people with Alzheimer's disease and other dementias are "long-distance caregivers."

Caregivers of people with severe memory problems/ dementia spend an average of 53.7 hours per week providing help.

Duration of Caregiving

Because Alzheimer's disease and other dementias usually progress slowly, most caregivers spend many years in the caregiving role. At least 25% of California family and other unpaid caregivers have been providing care for six years or more to someone age 50 or older, and 75% have been providing care for five years or less. California caregivers as a whole typically spend 14 hours a week (median) and get about 10 hours of help weekly from other unpaid family members, friends or volunteers (median, with average not available).[12]

The national figures of family and other unpaid caregivers for people with Alzheimer's disease who have been providing help for five years or longer is 32%, and 39% have been providing care for one to four years. In contrast, 27% of caregivers of other older people have been providing help for five years or longer, and 32% have been providing care for one to four years.[2]

Both state and national figures highlight the greater amount of time caregivers spend caring for people living with dementia or Alzheimer's disease compared to other older individuals without dementia.

Impacts of Caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. Although memory loss is the best-known symptom, this disease can also cause loss of judgment, orientation, ability to understand and communicate effectively and, frequently, changes in personality and behavior. Individuals require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security.

Emotional Well-Being

While it is not uncommon to hear about the "burden" of caregiving, the vast majority of caregivers do not find caregiving as burdensome as some might believe. Many report that the caregiving experience has enriched their lives in various ways such as feeling that they are contributing to the family, feeling as if they are setting an example for the children in the family, feeling as if caregiving has brought the family closer together, and feeling good about being able to help.[12]

Most family and other unpaid caregivers are proud of the help they provide, and some manage caregiving tasks with little difficulty. However, there is substantial evidence that caregiving can exact a toll on emotional health and cause stress and depression, especially for caregivers of people living with Alzheimer's disease. On a scale of one to five, with five being "very emotionally stressful" and one being "not at all stressful," 41 percent of Alzheimer's caregivers rate their situation as a four or five, compared to 31 percent of other caregivers. Caregiving is rated as a physical strain, a four or five on a similar scale, for 22% of Alzheimer's caregivers while non-Alzheimer's caregivers are less likely to rate their situation as a four or five (13%).[17] About one-third of family caregivers of people with Alzheimer's disease and other dementias have symptoms of depression.[18]

In the Caregiver Resource Center system, assessments of caregivers show:[13]

- High caregiver burden (54%)—an average score of 18 on the Adapted Zarit Interview, a standardized tool measuring caregiver burden (scores may range from 0 to 48, with higher scores showing higher burden and a score above 16 indicating "high burden").
- Many are depressed—almost half (45%) appear to have mild to moderate depression, with a score of 16 or higher on the Center for Epidemiologic Studies Depression scale (CES-D), a standardized tool to measure depression.
- Most (63.4%) report experiencing anxiety or depression in the past 12 months.
- Most report themselves to be in excellent (13.4%) or good (52.6%) health.
- But, almost a third (29.4%) say their health is worse than it was six months ago.

As shown in ***Table 4***, more caregivers of people with cognitive impairment felt the negative impacts of emotional stress, sleep interruption, physical strain, and financial hardship; and fewer enjoyed excellent or very good health than caregivers of people with other types of problems.[12]

Table 4: Impact on Caregivers of Individuals with Severe Memory Problems/Dementia Compared to Caregivers of Individuals with Problems Other Than Memory/Dementia

	Person receiving care has:	
Impact on Caregiver	Severe Memory Problems/ Dementia	Problems Other Than Memory/ Dementia
Emotionally stressful	44%	26%
sleep interrupted	32%	22%
Physical strain	24%	13%
Financial hardship	19%	11%
Excellent or very good health	36%	44%

Source: Scharlach, A., Sirotnik, B., Bockman, S., Neiman, M., Ruiz, C., & Dal Santo, T. (2003). *A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers.* Center for the Advanced Study of Aging Services, University of California, Berkeley.

Health

There are a significant number of caregivers for whom the stresses and strains of caregiving negatively impact their health. While almost 75% of California caregivers describe their health as excellent or good, 25% consider their health fair or poor. These proportions do not differ significantly among non-Alzheimer's caregivers.[12] National estimates are similar, with nearly three quarters of Alzheimer's disease and other caregivers reporting that caring for their relative has had no effect on their own health. However, 18% of Alzheimer's disease caregivers perceive a link between caregiving responsibilities and a decline in their own health compared to 12% of non-Alzheimer's caregivers.[17]

Income and Financial Security

Many caregivers of people with Alzheimer's disease and other dementias have to quit work, reduce their work hours, or take time off because of caregiving responsibilities. Significantly more California caregivers who provide care to someone age 50 or over with memory problems or dementia changed their work schedules (reduced the number of work hours) than did those not dealing with this condition.[12] In the two weeks before the survey, 21% of employed caregivers had missed work—from arriving late or leaving early to taking three or more days off. One half of these employees missed at least 16 hours of work during this two-week period.[12]

Family and other unpaid caregivers who turn down promotions, reduce their work hours, and quit work, lose job-related income and benefits including employer contributions to their own retirement savings. In addition, people with Alzheimer's disease and other dementias use substantial amounts of paid care.[19] Some of this care is covered by public programs and private insurance, but the person and family must pay out-of-pocket for much of the care.[2]

Table 5: Income of Caregivers Caring for an Individual 50 Years of Age and Older

2001 Household Income	Percentage	Grouped
Under $10,000	9%	25%
$10,000–$20,000	16%	
$20,001–$30,000	13%	26%
< $30,000 (unspecified)*	2%	
$30,001–$39,999	11%	
$40,000–$50,000	12%	49%
$50,001–$80,000	17%	
Over $80,000	17%	
> $30,000 (unspecified)*	3%	

* Respondents were asked whether their annual income was above or below $30,000, then asked to specify their income more precisely. While most answered the more specific question, a small percentage responded only to the first question.

Source: Scharlach, A., Sirotnik, B., Bockman, S., Neiman, M., Ruiz, C., & Dal Santo, T. (2003). *A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers.* Center for the Advanced Study of Aging Services, University of California, Berkeley.

The costs of caring for an individual with Alzheimer's disease are approximately 31% more than caring for a person with a serious physical ailment.

About one-half of California's caregivers caring for an individual 50 years of age or older are employed outside the home. Among employed caregivers, 71% are full-time and 29% are part-time employees.[12] Of non-employed caregivers, about half (49%) said they were retired and 8% were taking a leave of absence. Asked how caregiving activities affected their job status, 13% reported reducing work hours, 4% had changed jobs, and 6% reported other job impacts. As shown in ***Table 5***, at least one-fourth of California's caregivers have very low annual house-

hold incomes—$20,000 or less.[12] A large proportion of caregivers live in lower-middle-income households, with annual incomes between $20,000 and $40,000.

Data from California's eleven Caregiver Resource Centers (CRCs) indicate that more than one-half (56%) of the care recipients have a degenerative illness, primarily Alzheimer's disease (31%).[13] Among the caregivers served by the CRCs who are under the age of 65, a similar picture emerges in that about one-half are employed, with about 31% of them full-time employees and 18% part-time.[13] When all caregivers were asked whether their employment status had changed due to caregiving activities, 8% said they had reduced work hours, 11% quit their job, and 16% reported other types of job impacts.[20] As ***Table 6*** displays, the CRC system tends to serve a less affluent population, with only 31% of respondents reporting income above $40,000 a year (compared to 49% of caregivers in the state as a whole).[20]

Caregivers' lives change forever when their loved ones fall ill. With enormous dedication, families are providing care at home for as long as they can, as an alternative to the institutionalization of the person they care for. The CRCs provide an invaluable resource to caregivers. However, the need for the type of services provided by the CRCs greatly exceeds their current capabilities. At the end of 2006-07 fiscal year, 5,697 family caregivers were on respite waiting lists at CRCs in California. The average client wait-time for CRC respite assistance was 24 months, representing a decrease from the previous year of about two months.[13]

Table 6: Income of Caregivers Served by the Caregiver Resource Centers

2001 Household Income	Percentage	Grouped
Under $9,000	5%	26%
$9,000–$11,999	4%	
$12,000–$19,999	17%	
$20,000–$39,999	43%	43%
$40,000–$59,999	17%	31%
$60,000–$79,999	8%	
$80,000–$99,999	3%	
$100,000 or above	3%	

Source: *Family Caregiver Alliance Fact Sheet: California Caregivers: A Profile.* (2007), accessible at http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1961).

Section III

Costs of Caring for People with Alzheimer's Disease in California

Cost and Provision of Care for People with Alzheimer's Disease

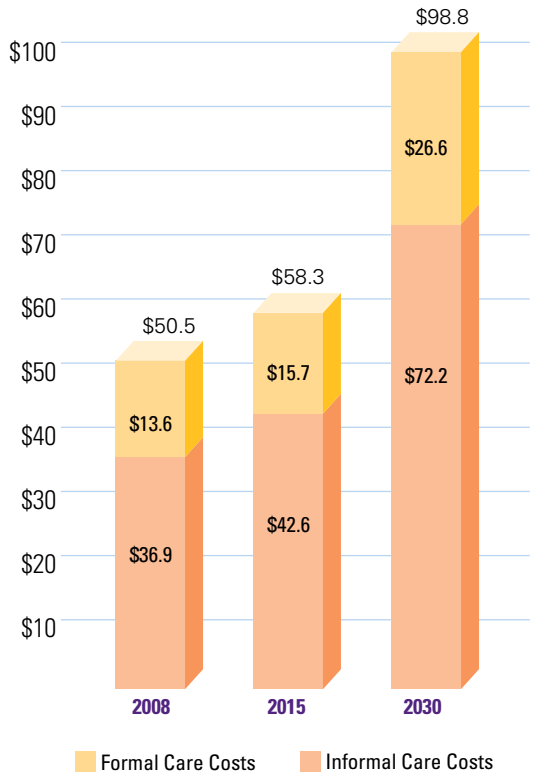
Informal and Formal Care Costs

As discussed in the previous section, families largely shoulder the responsibility of care for both community-resident and institutionalized individuals with Alzheimer's disease through the delivery of informal (unpaid) care. Informal care services refer to assistance rendered outside of the traditional medical and social service markets and for which providers are not reimbursed —they are usually provided by family members. Formal services refer to those rendered for a price in the traditional medical and social service marketplace.

The value of informal care is enormous, and its replacement by formal service providers would be extremely costly. Estimates of the economic value of informal caregiving provide a way to quantify this enormous societal contribution by answering the question: "If informal caregivers were not available, what would it cost to substitute formal services for the care provided?" To answer this question, estimates of the informal costs of caring for individuals with Alzheimer's disease who live in the community or reside in institutions were updated, based on original data provided by Dorothy Rice and colleagues using 2007 dollars and revised Alzheimer's disease prevalence estimates.[21]

Figure 11: Formal and Informal Community Care Costs for People with Alzheimer's Disease 55 and Older; 2008, 2015, 2030

Costs in Billions of Dollars



These estimates represent the total social costs of caring for people living with Alzheimer's disease in California for the years 2008, 2015, and 2030. We use the term "social costs" to emphasize the fact that we include both the unpaid value of informal caregivers' labor in addition to out-of-pocket expenditures by families for formal services. Both of these costs are associated with caregiving to address the needs of a person having Alzheimer's disease.

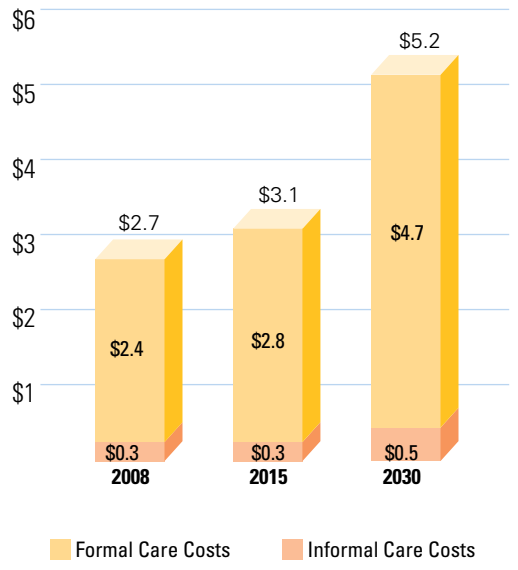
If informal caregivers were not available, what would it cost to substitute formal services for the care provided?

In thinking about the economic value (or cost) of informal care and the cost of formal care, it is prudent to keep in mind that a reduction in costs in one type of care will reflect an increase in costs in the other type of care. So, for example, if we reduce formal care costs, we increase informal care costs, and vice versa. This is because the care needs of people living with Alzheimer's disease will remain, regardless of which long-term care sector (i.e., informal or formal) provides the assistance. Since the value of informal care is imputed, it therefore represents a social cost rather than an actual out-of-pocket expenditure for the care of people with Alzheimer's disease.

As displayed in ***Figures 11 and 12***, between 2008 and 2030 it is estimated that the total cost of caring for community-resident (Figure 11) and institutionalized (Figure 12) individuals 55 years and older living with Alzheimer's disease in California will increase from $53.2 billion to $104 billion. This near doubling in cost parallels the doubling in the number of people 55 years of age and older who will be living with Alzheimer's disease, largely due to the aging of the baby boomers. Family members' labor will contribute almost three-quarters of the total cost of care for community-resident and institutionalized individuals living with Alzheimer's disease.

Figure 12 Formal and Informal Institutional Care Costs for People with Alzheimer's Disease 55 and Older; 2008, 2015, 2030

Costs in Billions of Dollars



In the next 20 years, the total costs of caring for people with Alzheimer's disease in California who live in the community are estimated to increase 49%, from $50.5 billion in 2008 to $98.8 billion in 2030. A similar increase will occur for individuals living in institutions, such as skilled nursing facilities, from $2.7 billion in 2008 to $5.2 billion in 2030. However, compared to community-resident individuals, the majority of costs for institutionalized individuals with Alzheimer's disease are due to skilled nursing facility expenditures.

Given the projected increases in the number of Californians living with Alzheimer's disease, the economic impact of the disease in the future will be substantial in terms of formal costs alone. Since a high proportion of costs for institutional care are borne by the federal and state governments, the costs to taxpayers will be high. The impact on families will be even more dramatic, since the majority of care for individuals is provided for through informal sources, typically the family. The informal and formal costs are estimated to double between now and 2030. Informal care costs, currently estimated to be $37 billion, will exceed $72 billion by 2030. Formal care costs are estimated to increase from $16 billion (2008) to more than $31 billion (2030).

As would be expected, there is a higher total cost of caring for people with severe Alzheimer's disease. The relative increased cost of informal care for individuals with Alzheimer's disease living in the community with severe cognitive impairment compared to those having mild or moderate impairment is 12%; whereas the cost increase for providing formal care services is significantly greater, a more than doubling of estimated costs for caring for a person with severe Alzheimer's disease compared to someone with mild or moderate impairments (see Appendix E).

Although informal care costs represent an imputed value rather than an actual dollar expenditure, if unpaid caregivers were not available, caregiving services would probably be purchased from paid providers, or else people living with Alzheimer's disease now cared for in the community would be placed in institutions such as skilled nursing facilities. Smaller family size, coupled with the increasing labor force participation of those who provide most of the care—women— will result in fewer available informal caregivers for people with Alzheimer's disease in the future. Therefore, more of these imputed costs may become actual expenditures.

Costs to the Medi-Cal Program

People living with Alzheimer's disease and related dementias are high users of health care and long-term care services, and all people who have these conditions will eventually need end-of-life care unless they die suddenly of another cause. Medi-Cal pays for skilled nursing facility and other long-term care services in the community, and high use of these services by people living with dementia translates into high costs for Medi-Cal.

The care of people with Alzheimer's disease and other dementias is a significant contributor to Medi-Cal costs. Lack of community-based services may increase hospitalization rates and may contribute to people being placed into nursing homes earlier than necessary, thereby driving up Medi-Cal costs. In addition to nursing home care, other services are often needed when caring for people living with Alzheimer's disease, such as psychiatric visits, adult day health care, home health, hospice, psychological services, durable medical equipment, lab and x-ray, and ambulance services.

We examined costs to the Medi-Cal program by updating figures reported by Joseph Menzin and colleagues in 1999 by adjusting costs to reflect 2007 dollars.[22] To determine Medi-Cal costs, the Menzin study obtained detailed Medi-Cal enrollment and claims data using a retrospective cohort design to document the cost of Alzheimer's disease and related dementias to Medi-Cal in 1995. Expenditures for an Alzheimer's disease and related dementias group and a comparison group were documented, and differences between these two groups in Medi-Cal service utilization and costs were estimated. The diagnostic breakdown of the Alzheimer's disease and related dementias group included 28% having Alzheimer's disease, 16% with cerebral degeneration, and 50% diagnosed with senile or pre-senile dementia.

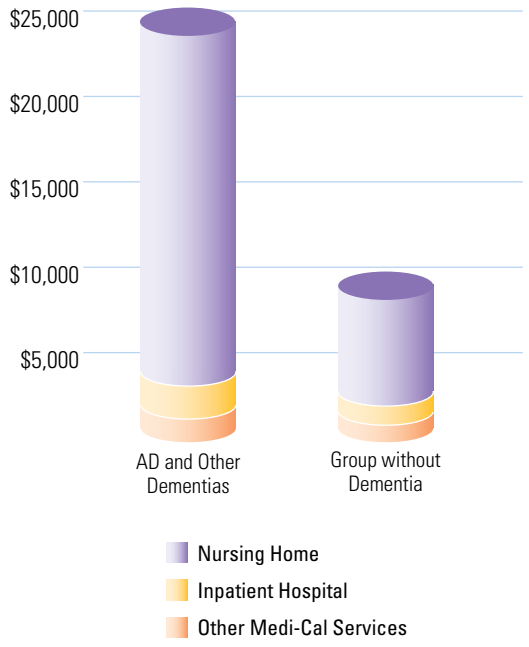
As shown in ***Figure 13***, there will be a significant increase in cost to the Medi-Cal program in per-person spending for individuals diagnosed with Alzheimer's disease and other dementias compared to other Medi-Cal beneficiaries without these diagnoses. The cost to the Medi-Cal programs for an individual with Alzheimer's disease or related dementia is 2.5 times greater than the cost for an individual not having these diagnoses. The majority of this cost difference is accounted for by skilled nursing facility expenditures. For an individual with a diagnosis of Alzheimer's disease or other dementia, the skilled nursing facility expenditures are almost three times greater as compared to an individual without dementia.

Trends in Formal Long-Term Care Provision and Costs

Most people with dementia live at home, usually with help from family and friends. Typically, these caregivers provide more help to their loved ones than caregivers of people with physical disabilities. As the dementia progresses, caregivers provide more and more care until they can no longer manage care responsibilities on their own, often because of their own health decline.

When caregiving responsibilities exceed capacity, families begin to explore long-term care options ranging from hiring home care workers to placing their loved ones in assisted living residences or skilled nursing facilities. The following are some of the types of long-term care services available:[23]

Figure 13: Medi-Cal Costs per Beneficiary 60 Years of Age and Older with Alzheimer's Disease and Other Dementias Compared to Other Medi-Cal Beneficiaries: 2007 Dollars*



*Note: The source for these figures, which have been updated using 2007 dollars, is Menzin, Freidman, Cummings (1999). The Economic Cost of Alzheimer's disease and Related Dementias to the California Medicaid Program (Medi-Cal) in 1995. *American Journal of Geriatric Psychiatry*, 7, 300. Refer to "Use End Notes-Methods" appendix for methods used to update the Medi-Cal costs to 2007 dollars.

Homemaker services allow people to continue to live in their own homes or to return to their homes by helping them complete household tasks that they can no longer manage alone. Homemaker service aides may clean clients' houses, cook meals or run errands.

Home health aides, personal and home aides, provide more extensive personal care than family or friends are able to or have the time or resources to provide. They help those who are elderly, disabled, or ill continue to live in their own homes or in residential care facilities instead of in skilled nursing facilities. There are two categories of home health aides: Medicare certified and non-Medicare certified, licensed. Medicare certified agencies can accept Medicare reimbursements while non-Medicare certified, licensed agencies cannot.

Adult Day Care/Health Care centers can offer a much-needed break to caregivers. This type of care provides services at a community-based congregate center for adults who need assistance or supervision during the day but who do not need round the clock care. The centers may provide health services, therapeutic services and social activities.

Assisted Living Facilities, known in California as Residential Care Facilities, are living arrangements that provide personal care and health services for people who may need assistance with ADLs (activities of daily living), but who wish to live as independently as possible and who do not need the level of care provided by a skilled nursing facility. Assisted living is not an alternative to a nursing home, but an intermediate level of long-term care.

Skilled Nursing Facility Care is for people who may need nursing care or a higher level of supervision and personal care than in an assisted living facility. They offer residents personal care, room and board, supervision, medication, therapies and rehabilitation, as well as skilled nursing care 24 hours a day.

In California, home care can cost between $44,822 and $86,692 annually.

For the past five years, Genworth Financial, Inc. has conducted a survey of long-term care service providers across the country within 90 regions. Each year, using a consistent methodology, the cost of care in more than 10,000 nursing homes, assisted living facilities and among home care providers in all 50 states and 90 geographic regions including the District of Columbia are surveyed. It is the most comprehensive cost analysis in the industry, and the only one that provides comparative data for the past five years. For the first time, this year's survey also includes adult day health care costs. Based on these survey results, some trends have emerged across the long-term care services landscape. Overall, the cost of care within facility-based providers has steadily increased while non-skilled home care costs have remained relatively flat.[23] Long-term care costs in California increased as much as 44% over the past five years (2004-2008) compared to a nationwide costs increase of 17% during the same time period.

While there are a number of long-term care options available to people living with dementia and their families, paying for these services for very long is not affordable for most people. As shown in ***Table 7***, in California home care can cost between $44,822 and $86,692 annually and assisted living averages $36,000 annually. Skilled nursing facility care is even more expensive ranging between $64,068 and $72,919 annually.[23] In California for 2007, there were approximately 37,000 individuals living with dementia who spent some time in a nursing home, approximately six percent of all people with Alzheimer's disease.[24, 25, 26] Medi-Cal will cover the skilled nursing facility stays that most people with dementia will need, but this program requires beneficiaries to be poor to receive coverage. Private long-term care insurance is only an option for those healthy and wealthy enough to purchase policies before developing dementia.

Table 7: Annual Cost of Long-Term Care in California: Assuming 5% Annual Inflation*

Skilled Nursing Facility	**2008**	**2015**	**2030**
Private room	$72,919	$102,604	$213,307
Semi-Private Room	$64,068	$90,150	$187,416
Assisted Living Facility			
Private, 1-Bedroom	$35,870	$50,473	$104,929
Adult Day Health Care Facility[1]			
Adult Day Health Care	$18,923	$26,627	$55,355
Home Care[2]			
Home Health Aide (Medicare-Certified & Licensed)	$86,692	$121,984	$253,597
Home Health Aide (Licensed Only)	$47,384	$66,674	$138,611
Homeaker Services (Licensed Only)	$44,822	$63,069	$131,116

* Annual cost estimates do not reflect Medi-Cal reimbursement rates, which are generally lower.

[1] Based on 8 hours a day, 5 days a week of care

[2] Based on 44 hours per week of care

Source: http://www.genworth.com/content/content/genworth/www_genworth_com/web/us/en/products_we_offer/long_term_care_insurance/long_term_care_overview/what_is_the_cost_of_long_term_care/interactive_cost_of_care_map.html, accessed July 16, 2008.

The cost of long-term care is expected to rise over the years, simply due to inflation. What these estimates do not take into consideration are market forces that may significantly contribute to the rising costs of care. The U. S. will experience an imminent shortage of formal caregivers, and it is estimated that 200,000 new direct-care workers will need to be recruited each year to meet future demand among the 78 million baby boomers as they age.[27] This is further aggrevated by the lack of health professionals who have geriatric training. Although California-specific data are not available, the state will surely feel the impact of this shortage. At the same time, the caregiver workforce is dwindling and faces issues of retention and quality. This gap has the potential to negatively impact Californians and the California health care

system in two ways: the costs of health care may rise significantly as the workforce supply diminishes, and the quality and availability of care providers may decrease, placing added pressures on family members and friends to care for loved ones who may require long term care.

Policymakers at the federal, state and local levels will need to work together to provide financial incentives along with some basic job training and support services, to prevent the decline in the number of qualified long term care workers in relation to the growing need for their services. This is true for both the paid caregiving workforce as well as the millions of unpaid family caregivers who make great personal and financial sacrifices in order to care for their loved ones. Successful solutions revolve around addressing the recruitment and retention of workers while providing adequate support systems for both paid and unpaid caregivers.

In 2000, California responded to this worker shortage by funding the Caregiver Training Initiative (CTI), as part of the Governor's Aging with Dignity Initiative. The goals of the CTI project were to address urgent caregiver workforce shortages through innovative approaches for recruiting, training, and retaining caregivers in the healthcare industry and to enhance the earning potential of these workers to ensure that:

1) California's communities have well-trained caregivers necessary for all levels of care for the elderly population;

2) communities have caregivers necessary for continuity of long-term care; and

3) caregivers have opportunities for entry-level employment, and for career advancement.

Twelve Regional Collaboratives throughout California were awarded grants and the primary participants in the program were Workforce Investment Act (WIA) clients and Welfare-to-Work (WtW) clients. Sites participating in the project implemented recruitment and training approaches that either were novel to the site or used approaches in a novel manner. Some of the approaches included initiating collaborations to improve efficiency by reducing redundant tasks; targeting unique populations (military corpsmen, migrant worker family members, and non-English speaking home care workers); new screening and assessment techniques to determine qualification of health care workers; supportive services (e.g., childcare, transportation and tutoring, to tuition reimbursement, books, uniforms, and lodging); fast-track training; and coordinating services not previously coordinated.

An evaluation of the CTI program indicated that it exceeded expectations by significantly increasing the supply of entry-level and advanced-level healthcare workers.[28] The initiative demonstrated that a long-term care worker shortage can be addressed by supporting programs to recruit,

K To estimate the productivity losses to California businesses, several sources of data were used. [12, 29, 35, 36, 37] Also, refer to Appendix F for an explanation of the methodology used for these calculations. The California median hourly wage used in these calculations was obtained from the May 2007 United States Department of Labor Bureau of Labor Statistics.[35] Productivity losses are based on the 70 percent of California caregivers who work full-time which translates to 386,076 caregivers.[12] To calculate the different components effecting businesses, we followed the model used in "The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business" (2006).[29]

train, and retain individuals not currently in the workforce or who are underemployed. However, these programs may be costly due to pre-training preparation, training, and supportive services needed for individual and program success, thus, a greater focus is needed on the study of factors leading to increasing retention of this workforce.

Cost to California Businesses

Today about 588,000 Californians are living with Alzheimer's disease. Approximately 26,651 (4.53%) of these individuals live in skilled nursing facilities, while the majority live at home in their communities, being cared for by family and friends. Their illness has an immense impact on their families. As noted earlier, one of these impacts is that caregiving causes employees to miss work with resultant losses in economic productivity.

Productivity Losses to California Business[K]

As shown in ***Table 8***, the estimated cost to California employers in lost productivity annually from full-time employed caregivers is $1.4 billion. Studies suggest a wide variation of replacement costs depending upon the status of the worker, the size of the company, and external factors related to supply and demand of skilled workers. We used a national estimate of 3.7 years for the average length of time employed caregivers provide care. Estimating 11% of caregivers quit their jobs, the percentage of caregivers leaving the workplace on an annual basis is three percent, or 11,582 California employees. The loss of these workers costs California businesses an estimated loss in economic productivity in excess of $318 million annually. This monetary loss does not take into consideration part-time employed caregivers who can no longer work due to significant caregiving responsibilities.

Absenteeism is particularly costly to California businesses. Approximately 21% of employed caregivers (81,076) miss work from arriving late to taking three or more days off, and half of these employees missed at least 16 hours of work during a two-week period.[12] This resulted in an estimated 400 hours of work missed annually by caregivers. Using the median wage of $16.91, this resulted in $548 million in caregiver absenteeism costs to California businesses.

In the coming years, as the baby boomers age and life expectancy increases, more workers will be taking on the responsibility of caregiving for loved ones. The costs to California businesses will continue to rise if proactive measures are not taken, such as making eldercare resources available. These resources may include flextime; telecommuting and job-sharing; programs that provide respite care; adult day services and caregiver support groups; information, referral and educational programs; and employee and/or employer funded long-term care insurance.[29] An interesting resource for businesses to determine their productivity cost for working caregivers is the Eldercare calculator developed by MetLife and the National Alliance for Caregiving: http://www.eldercarecalculator.org/ECalc.asp.

Table 8: Total Estimated Cost to California Businesses of Full-Time Employed Caregivers

	Cost per Employee	Total Employer cost
Replacing Employees	$825	$318,512,329
Abesenteeism	$1,420	$548,398,064
Workday Interruptions	$379	$146,239,371
Elder Crisis	$244	$94,010,807
Supervisor Time	$103	$39,630,499
Unpaid Leave	$189	$73,119,516
Full-Time to Part-Time	$346	$133,665,090
Total	$ 3,506	$1,353,575,676

Appendices

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Appendix A

Overview of Alzheimer's Disease and Other Dementias[L]

Overview of Alzheimer's Disease and Other Dementias

This section provides information about the definition of dementia, the characteristics of specific types of dementia, and the symptoms and risk factors for, and treatment of, Alzheimer's disease. Alzheimer's disease is the most common cause of dementia. More detailed information on these topics is available at www.alz.org. Specific information for each of the Alzheimer's Association California chapters can also be accessed through this website and Appendix H lists the California Alzheimer's Association chapters and offices.

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Dementia: Definition and Specific Types

Dementia is a clinical syndrome of loss or decline in memory and other cognitive abilities. It is caused by various diseases and conditions that result in damaged brain cells. To be classified as dementia, the syndrome must meet the following criteria:

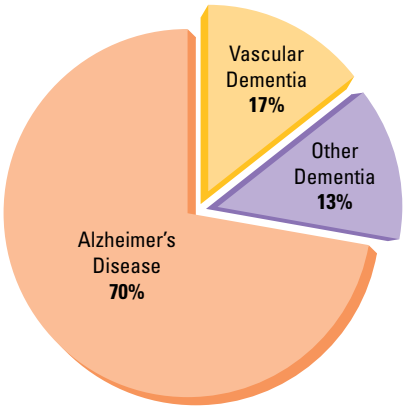
- It must include a decline in memory and impairment in at least one of the following cognitive abilities:
  1. Ability to generate coherent speech and understand spoken or written language;
  2. Ability to recognize or identify objects, assuming intact sensory function;
  3. Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and
  4. Ability to think abstractly, make sound judgments and plan and carry out complex tasks.
- The decline in cognitive abilities must be severe enough to interfere with daily life (e.g., tasks at work; functioning in social situations).

Different types of dementia have been associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. Increasing evidence from long-term epidemiological observation and autopsy studies suggests that many people have microscopic brain abnormalities associated with more than one type of dementia. The symptoms of different types of dementia also overlap and can be further complicated by coexisting medical conditions. ***Table A1*** (on the following pages) provides information about the most common types of dementia.

Causes of Dementia[M]

As shown in ***Figure A1***, Alzheimer's disease is the most common type of dementia. Nationally, Alzheimer's accounts for 70 percent of all cases of dementia in Americans age 71 and over. Vascular dementia accounts for 17 percent of cases of dementia, and other diseases and conditions, including Parkinson's disease, Lewy body disease, frontotemporal dementia and normal pressure hydrocephalus, account for the remaining 13 percent.

Figure A1: Causes of Dementia in People 71 Years of Age and Older: ADAMS, 2002



Source: Plassman, BL; Langa, KM; Fisher, GG; Heeringa, SG; Weir, DR; Ofstedal, MB, et al. "Prevalence of Dementia in the United States: The Aging Demographics, and Memory Study. *Neuroepidemiology* 2007; 29:125-132.31

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Mild cognitive impairment is a condition in which a person has problems with memory, language or another essential cognitive function that is severe enough to be noticeable to others and show up on psychometric tests, but not severe enough to interfere with daily life. Some people with mild cognitive impairment go on to develop dementia. For others, the symptoms of mild cognitive impairment do not progress to dementia, and some people who have mild cognitive impairment at one point in time later revert to normal cognitive status. Due to differences in how mild cognitive impairment is defined, the incidence and prevalence is not yet understood –research actively continues in this area.

Table A1: Common Types of Dementia and Their Typical Characteristics [N]

Type of Dementia	Characteristics
Alzheimer's disease	Most common type of dementia; accounts for 60 to 80 percent of cases. Difficulty remembering names and recent events is often an early clinical symptom; later symptoms may include impaired judgment, disorientation, confusion, behavior changes and trouble speaking, swallowing and walking. Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).
Vascular dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	Considered the second-most-common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed dementia	Characterized by the presence of the hallmark abnormalities of Alzheimer's and another type of dementia, most commonly vascular dementia, but also other types, such as dementia with Lewy bodies, frontotemporal dementia and normal pressure hydrocephalus.
Dementia with Lewy bodies	Pattern of decline may be similar to Alzheimer's, including problems with memory, judgment and behavior changes. Alertness and severity of cognitive symptoms may fluctuate daily. Visual hallucinations, muscle rigidity and tremors are common. Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.

Table A1, con't.

Type of Dementia	Characteristics
Parkinson's disease	20–30 percent of people who have Parkinson's disease develop dementia in the later stages of the disease.[31] The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.
Frontotemporal dementia	Involves damage to brain cells, especially in the front and side regions of the brain. Typical symptoms include changes in personality and behavior and difficulty with language. No distinguishing microscopic abnormality is linked to all cases. Pick's disease, characterized by "Pick's bodies," is one type of frontotemporal dementia.
Creutzfeldt-Jakob disease	Rapidly fatal disorder that impairs memory and coordination and causes behavior changes. "Variant Creutzfeldt-Jakob disease" is believed to be caused by consumption of products from cattle affected by "mad cow disease." Caused by the misfolding of prion protein throughout the brain.
Normal pressure hydrocephalus	Caused by the buildup of fluid in the brain. Symptoms include difficulty walking, memory loss and inability to control urine. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

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More about Alzheimer's Disease

In Alzheimer's disease, as in other types of dementia, increasing numbers of nerve cells deteriorate and die. A healthy adult brain has 100 billion nerve cells, or neurons, with long branching extensions connected at 100 trillion points. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and taken up by the receiving cell. Different strengths and patterns of signals move constantly through the brain's circuits, creating the cellular basis of memories, thoughts and skills.

In Alzheimer's disease, information transfer at the synapses begins to fail, the number of synapses declines and eventually cells die. In a brain with advanced Alzheimer's, there is dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

Scientists do not yet fully understand the processes that result in the catastrophic brain damage associated with Alzheimer's disease. According to a leading theory, called the "amyloid hypothesis," the prime suspect is a tiny protein fragment called beta-amyloid. Trouble begins when yet-to-be-identified factors trigger overproduction of beta-amyloid or reduce the brain's ability to dispose of it. The excess jams signaling at the synapses, blocking information flow and leading to a cascade of damaging events ending in cell death.

Beta-amyloid fragments gradually accumulate into the microscopic "plaques" considered to be one pathological hallmark of Alzheimer's. The other hallmark is "tangles," formed when a different protein called tau twists into strands inside dead and dying neurons. Other abnormalities seen in Alzheimer brain tissue include inflammation and oxidative damage due to highly reactive oxygen-containing products of cellular metabolism.

Symptoms of Alzheimer's Disease

Alzheimer's disease can affect individuals differently, but the most common symptom pattern begins with gradually difficulty in remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals also experience confusion, disorganized thinking, impaired judgment, difficulty expressing themselves and disorientation to time, space and location. As the disease progresses, these symptoms may lead to wandering and difficulty with social interactions. In advanced Alzheimer's, people need help with bathing, dressing, using the bathroom, eating and other daily activities. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on 24/7 care. Alzheimer's disease is ultimately fatal.

An estimated 75 percent of people living with Alzheimer's are cared for at home. While families provide most of the care, some also use home and community-based resources like home care agencies, adult day care, and Caregiver Resource Centers (www.californiacrc.org; see Appendix I for the Caregiver Resource Centers in California). For many families there is a challenge for finding sufficient and affordable community resources to allow them to continue caring for their loved one with Alzheimer's disease at home. In the later stages of the disease, as more assistance is needed than family caregivers can provide, caregivers may decide to move individuals with Alzheimer's disease into a continuing care retirement community having multiple levels of care, a residential care facility for the elderly (assisted living, board and care) or a nursing home.

Risk Factors for Alzheimer's Disease

Although the cause or causes of Alzheimer's disease are not yet known, most experts agree that Alzheimer's, like other common chronic conditions, probably develops as a result of multiple factors rather than a single cause. The greatest risk factor for Alzheimer's disease is advancing age. Most Americans with Alzheimer's disease are age 65 or older, although individuals younger than age 65 can also develop the disease. When Alzheimer's or another type of dementia is recognized in a person under age 65, these conditions are referred to as "early-onset" Alzheimer's or "earlier-onset" dementia. Since 'early-onset' may be confused with 'early diagnosis' of Alzheimer's disease or dementia, the term 'younger-onset' is preferred in this report when referring to individuals who are diagnosed with Alzheimer's disease or dementia before the age of 65.

The Alzheimer's Association estimates that between 220,000 and 640,000 people nationwide are living with younger-onset Alzheimer's.32 While this is a plausible estimate, it is generally acknowledged that significantly more Americans are living with younger-onset Alzheimer's disease but are yet to be diagnosed. Additional research is needed to refine these estimates.

A small percentage of Alzheimer's disease, probably less than five percent, is caused by rare genetic variations found in a small number of families worldwide. In these inherited forms of Alzheimer's, the disease tends to develop before age 65, sometimes in individuals as young as 30.

A genetic factor in Alzheimer's disease that develops after age 65 is Apolipoprotein E-e4 (APOE-e4). APOE-e4 is one of three common forms of the APOE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the APOE gene from each of his or her parents. Those who inherit one APOE e4 gene have increased risk of developing Alzheimer's disease. Those who inherit two APOE e4 genes have an even higher risk, but there is still no certainty that they will develop Alzheimer's.

In addition to genetic risk factors, recent research identifies lifestyle factors that may reduce risk for Alzheimer's disease and vascular dementia including: aerobic exercise; a diet rich in fruits, vegetables, and antioxidents but low in saturated fats; a lifetime of intellectual and cognitive stimulation; social engagement; and, overall maintenance of health. Some data indicate that management of cardiovascular risk factors, such as high cholesterol, type 2 diabetes, high blood pressure and weight, may help avoid or delay cognitive decline. Additional evidence points to a significant role for regular physical exercise in maintaining lifelong cognitive health. Many scientists consider the emerging field of risk reduction one of the most exciting recent developments in the dementia research arena. A growing body of evidence suggests that the health of the brain – one of the body's most highly vascular organs – is closely linked to the overall health of the heart and blood vessels. Attempts to reduce specific risk factors for Alzheimer's disease should also consider methods to disseminate these recommendations to underserved populations who may not have access to this information or the economic means to implement them.

Treatment and Prevention of Alzheimer's Disease

No treatment is available to delay or stop the deterioration of brain cells in Alzheimer's disease. The U. S. Food and Drug Administration has so far approved five drugs that temporarily slow worsening of symptoms for about six to 12 months, on average, for about half of the individuals who take them. Based on deepening insight into the underlying biology of Alzheimer's and emerging conceptual frameworks for understanding the disease, researchers have identified several new treatment strategies that may have the potential to change its course. A number of experimental therapies based on the amyloid hypothesis and other targets have reached various stages of clinical testing in human volunteers.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical and social interventions, and providing a biopsychosocial model of care, of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for diagnosed individuals and their caregivers. Best practices model includes ongoing assessment of symptoms, appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan and utilization by the patient and family caregiver of supportive services, such as counseling, activity and support groups and adult day programs. The California Guideline for Alzheimer's Disease Management, a State-supported practice guideline for primary care providers, recommends that people with Alzheimer's disease be referred to community support organizations such as the Alzheimer's Association (www.alz.org) (Appendix H), the Caregiver Resource Centers (www.californiacrc.org) (Appendix I) or the Family Caregiver Alliance (www.caregiver.org) for patient and caregiver education and support (See Appendix J for a listing of Alzheimer's disease Research Centers of California and Appendix K for a copy of the California Guidelines for Alzheimer's Disease Management).

Appendix B

State and County Alzheimer's Disease Prevalence Estimates

Table B1: Estimated Number and Percent Change in People 55+ with Alzheimer's Disease: 2008, 2015 and 2030, California and Counties

	2008	2015	2030	% change 2008-2015	% change 2015-2030	% change 2008-2030
Alameda	23,748	26,847	47,438	13	77	100
Alpine	33	53	103	61	94	212
Amador	1,040	1,293	2,182	24	69	110
Butte	4,900	5,172	8,175	6	58	67
Calaveras	1,275	1,671	2,820	31	69	121
Colusa	364	421	704	16	67	93
Contra Costa	17,511	20,435	36,895	17	81	111
Del Norte	535	650	1,108	21	70	107
El Dorado	3,287	4,094	7,944	25	94	142
Fresno	12,249	14,216	24,808	16	75	103
Glenn	557	656	1,036	18	58	86
Humboldt	2,341	2,661	4,452	14	67	90
Imperial	2,563	3,444	5,949	34	73	132
Inyo	554	618	893	12	44	61
Kern	9,197	11,418	20,614	24	81	124
Kings	1,458	1,839	3,371	26	83	131
Lake	1,700	2,056	3,386	21	65	99
Lassen	502	645	1,199	28	86	139
Los Angeles	155,575	177,000	289,280	14	63	86
Madera	2,312	3,002	6,274	30	109	171
Marin	5,632	6,194	10,557	10	70	87
Mariposa	478	614	1,106	28	80	131
Mendocino	1,868	2,149	3,594	15	67	92
Merced	3,105	3,764	6,461	21	72	108
Modoc	272	319	544	17	71	100
Mono	179	266	538	49	102	201
Monterey	6,676	7,592	12,465	14	64	87
Napa	3,092	3,236	5,123	5	58	66
Nevada	2,441	2,769	4,914	13	77	101
Orange	46,263	54,109	92,150	17	70	99
Placer	6,834	8,401	14,174	23	69	107
Plumas	603	722	1,048	20	45	74
Riverside	31,992	37,025	60,116	16	62	88

	2008	2015	2030	% change 2008-2015	% change 2015-2030	% change 2008-2030
Sacramento	22,006	25,692	44,181	17	72	101
San Benito	719	904	1,759	26	95	145
San Bernardino	23,680	29,922	56,591	26	89	139
San Diego	49,530	54,490	92,804	10	70	87
San Francisco	17,438	19,206	26,868	10	40	54
San Joaquin	9,796	11,840	20,514	21	73	109
San Luis Obispo	6,082	6,831	10,836	12	59	78
San Mateo	13,684	14,610	23,298	7	59	70
Santa Barbara	8,148	8,682	13,209	7	52	62
Santa Clara	27,658	32,988	58,569	19	78	112
Santa Cruz	3,763	3,931	7,699	4	96	105
Shasta	3,870	4,540	7,482	17	65	93
Sierra	103	117	171	14	46	66
Siskiyou	1,283	1,458	2,126	14	46	66
Solano	6,113	7,458	14,139	22	90	131
Sonoma	8,902	9,169	15,799	3	72	77
Stanislaus	7,575	9,286	16,138	23	74	113
Sutter	1,592	2,035	3,642	28	79	129
Tehama	1,365	1,585	2,320	16	46	70
Trinity	368	475	817	29	72	122
Tulare	5,586	6,692	11,733	20	75	110
Tuolumne	1,684	2,033	3,229	21	59	92
Ventura	12,541	14,819	26,301	18	77	110
Yolo	2,571	3,042	5,712	18	88	122
Yuba	1,016	1,289	2,204	27	71	117
CALIFORNIA	588,208	678,446	1,149,560	15	69	95

Table B2: Estimated Number and Percent Change in People 55+ with Alzheimer's Disease by Race: 2008, 2015 and 2030, California

	2008	2015	2030	% change 2008-2015	% change 2015-2030	% change 2008-2030
Caucasian/non-Latino	386,251	399,324	590,160	3	48	53
Latino/Hispanic	92,242	128,887	276,821	40	115	200
African-American	26,521	31,569	52,369	19	66	97
Asian/Pacific Islander	72,075	101,113	194,266	40	92	170
American Indian	3,219	4,945	10,591	54	114	229
Multirace	7,899	12,608	25,353	60	101	221

Table B3: Estimated Number of People 55+ with Alzheimer's Disease by Race and County, 2008

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Alameda	12,875	2,250	2,992	5,145	92	394
Alpine	29*	0*	0*	0*	4*	0*
Amador	963	42*	4*	7*	13*	12*
Butte	4,450	169	53*	91	54*	82*
Calaveras	1,166	62*	11*	10*	13*	14*
Colusa	265	72	5*	11*	6*	4*
Contra Costa	12,892	1,404	986	1,941	70	218
Del Norte	463	20*	1*	7*	31*	13*
El Dorado	3,002	126	15*	73	22*	49*
Fresno	7,961	2,561	423	1,048	98	159
Glenn	457	65	3*	13*	9*	10*
Humboldt	2,081	75	13*	32*	90	51*
Imperial	848	1,529	68	60*	41*	17*
Inyo	465	33	0*	3*	43*	10*
Kern	6,447	1,657	346	454	106	188
Kings	894	355	76	93	17*	23*
Lake	1,467	91	66*	20*	26*	30*
Lassen	428	30	13*	2*	17*	12*
Los Angeles	79,477	36,934	12,058	24,559	442	2,104
Madera	1,657	453	72*	55*	41*	34*
Marin	4,985	308	76	207	7*	50*
Mariposa	427	22*	3*	4*	12*	11*
Mendocino	1,642	88	11*	25*	68	33*
Merced	2,052	703	104	173	23*	50*
Modoc	239	11*	1*	3*	13*	4*
Mono	155	11*	1*	3*	8*	2*
Monterey	4,475	1,259	154	655	43*	90
Napa	2,622	260	33*	123	14*	40*
Nevada	2,297	72	5*	23*	13*	31*
Orange	33,834	5,069	303	6,396	158	503
Placer	6,071	396	36*	228	35*	67*
Plumas	554	17*	5*	5*	13*	10*
Riverside	24,647	4,535	1,199	1,123	137	350

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Sacramento	15,207	2,250	1,159	2,771	123	495
San Benito	444	219	7*	33*	7*	9*
San Bernardino	15,216	5,185	1,484	1,326	147	322
San Diego	37,349	6,074	1,064	4,335	306	401
San Francisco	7,299	1,619	1,174	7,035	46*	266
San Joaquin	5,927	1,810	416	1,371	64	209
San Luis Obispo	5,435	45*	369	121	36*	78*
San Mateo	9,014	435	1,402	2,625	35*	173
Santa Barbara	6,377	118	1,218	309	48*	79*
Santa Clara	16,776	393*	4,001	6,100	108	279
Santa Cruz	3,019	27	439	206	22*	50*
Shasta	3,527	26*	105	65*	67*	80*
Sierra	94	0*	5*	0*	1*	2*
Siskiyou	1,127	25*	52*	12*	34*	34*
Solano	3,843	495	492	1,118	41*	124
Sonoma	7,696	76	667	295	58	110
Stanislaus	5,462	90	1,477	349	66	130
Sutter	1,147	23*	210	164	18*	31*
Tehama	1,219	5*	82	8*	24*	26*
Trinity	332	1*	7*	1*	14*	12*
Tulare	3,816	72*	1,311	235	60*	92
Tuolumne	1,557	5*	73	10*	16*	23*
Ventura	9,415	147	2,024	762	59*	135
Yolo	1,915	67*	371	158	24*	37*
Yuba	753	34*	101	72*	19*	38*

*Estimate is unreliable; race/ethnicity population for specified group is less than 1,000 individuals.

Table B4: Estimated Number of People 55+ with Alzheimer's Disease by Race and County, 2015

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Alameda	12,667	3,126	3,136	7,178	138	603
Alpine	44*	1*	0*	0*	7*	1*
Amador	1,152	71*	9*	15*	23*	23*
Butte	4,539	220	71*	120	87	134
Calaveras	1,470	102	22*	21*	25*	31*
Colusa	265	112	6*	19*	12*	8*
Contra Costa	13,836	2,028	1,196	2,918	110	347
Del Norte	513	43*	3*	15*	52*	23*
El Dorado	3,657	177	23*	117	38*	82
Fresno	8,143	3,767	490	1,443	133	240
Glenn	491	108	5*	20*	14*	17*
Humboldt	2,261	109	24*	55*	126	86
Imperial	884	2,307	78	85	61*	30*
Inyo	475	54*	0*	5*	71*	14*
Kern	7,342	2,519	475	654	140	288
Kings	1,011	537	101	119	32*	38*
Lake	1,736	125	73*	33*	41*	48*
Lassen	513	53*	20*	5*	31*	22*
Los Angeles	78,318	47,796	13,575	33,360	610	3,341
Madera	1,973	750	79*	77*	65*	59*
Marin	5,225	498	88	292	16*	75
Mariposa	519	39*	4*	8*	24*	21*
Mendocino	1,781	136	17*	46*	112	58*
Merced	2,208	1,079	117	232	40*	88
Modoc	263	20*	2*	5*	19*	10*
Mono	217	23*	2*	5*	15*	5*
Monterey	4,457	1,875	145	892	68*	155
Napa	2,507	415	49*	178	25*	63*
Nevada	2,523	116	8*	41*	27*	55*
Orange	35,278	7,517	441	9,866	216	792
Placer	7,268	570	57*	338	58*	110
Plumas	637	32*	7*	9*	20*	17*
Riverside	25,357	7,251	1,627	1,939	216	635

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Sacramento	16,315	3,183	1,519	3,707	168	799
San Benito	487	325	10*	52*	12*	17*
San Bernardino	16,758	8,033	2,237	2,139	216	540
San Diego	37,286	8,481	1,285	6,418	477	544
San Francisco	6,856	1,974	1,220	8,680	75	402
San Joaquin	6,179	2,775	576	1,915	102	294
San Luis Obispo	5,855	63*	582	155	54*	122
San Mateo	8,019	545	1,925	3,789	58*	274
Santa Barbara	6,202	177	1,713	407	74*	109
Santa Clara	18,040	551	5,237	8,541	177	443
Santa Cruz	2,818	49*	662	283	38*	80
Shasta	4,020	38*	133	110	101	137
Sierra	101	0*	10*	0*	2*	3*
Siskiyou	1,207	37*	81*	19*	59*	55*
Solano	4,142	615	681	1,733	68	220
Sonoma	7,308	92	1,049	444	99	177
Stanislaus	5,908	119	2,344	595	103	217
Sutter	1,296	44*	368	248	30*	48*
Tehama	1,357	10*	118	17*	38*	45*
Trinity	408	1*	15*	3*	26*	22
Tulare	4,071	84	1,981	317	97	142
Tuolumne	1,822	11*	107	21*	30*	42*
Ventura	10,348	198	2,852	1,102	94	225
Yolo	2,100	84*	536	215	39*	67
Yuba	894	54*	146	95	37*	63*

*Estimate is unreliable; race/ethnicity population for specified group is less than 1,000 individuals.

Table B5: Estimated Number of People 55+ with Alzheimer's Disease by Race and County, 2030

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Alameda	20,151	7,032	4,681	9,784	322	1,339
Alpine	81*	4*	0*	1*	16*	2*
Amador	1912	122	18*	32*	52	50
Butte	6,950	536	98	239	168	223
Calaveras	2,429	162	35*	45	56	90
Colusa	406	210	5*	54	26	22
Contra Costa	22,550	4,783	2,205	4,867	205	664
Del Norte	788	109	13*	34	98	59
El Dorado	6,972	428	59*	210	105	179
Fresno	11,570	8,705	937	3,478	265	400
Glenn	724	191	9*	55	31	32
Humboldt	3,691	190	57*	105	222	165
Imperial	958	4,511	114	978	118	60
Inyo	625	107*	1*	26	110	32
Kern	11,278	6,197	1,036	2,057	268	437
Kings	1,592	1,186	239	343	77	79
Lake	2,848	182	84*	62	99	107
Lassen	914	108	29*	30	75	49
Los Angeles	102,136	97,704	19,420	55,539	1,303	6,550
Madera	3,542	2,215	96*	499	136	158
Marin	8,461	1,126	132	556	57	190
Mariposa	907	88*	7*	19	46	37
Mendocino	2,801	298	36*	114	234	119
Merced	3,026	2,540	143	762	93	189
Modoc	429	49*	6*	10	31	21
Mono	400	81	6*	19	27	11
Monterey	6,335	4,186	120	1,605	129	332
Napa	3,492	944	85*	421	61	128
Nevada	4,454	174	19*	71	65	119
Orange	49,398	18,578	1,033	15,816	485	1,596
Placer	11,911	1,008	99*	671	122	243
Plumas	876	68*	8*	18	41	36
Riverside	32,426	17,845	3,196	6,236	476	1,512

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Sacramento	25,417	7,222	2,848	5451	374	1,646
San Benito	819	734	38*	186	29	40
San Bernardino	25,600	19,224	4,976	6,916	494	1,135
San Diego	58,291	17,511	2,390	10,906	1,180	956
San Francisco	9,568	3,171	1,634	6,862	155	701
San Joaquin	9,734	5,522	1,220	2,823	193	447
San Luis Obispo	8,862	1,238	99*	405	114	240
San Mateo	10,478	3,871	909	5,198	128	459
Santa Barbara	8,410	3,464	326	1,057	137	192
Santa Clara	29,539	8,953	1,213	12,529	415	1,130
Santa Cruz	5,029	1,669	103	707	100	221
Shasta	6,513	235	69*	203	171	257
Sierra	140	18*	1*	2	6	6
Siskiyou	1,680	136	49*	43	114	103
Solano	7,070	1,475	1,180	2,560	149	465
Sonoma	11,695	2,392	169	1,065	191	344
Stanislaus	8,869	4,935	292	1,739	193	418
Sutter	2,021	812	87*	452	73	106
Tehama	1,892	186	20*	56	85	93
Trinity	669	36*	5*	10	53	45
Tulare	5,836	4,720	115	1,320	175	257
Tuolumne	2,834	145	34*	48	75	89
Ventura	17,114	6,003	369	2,491	172	438
Yolo	3,652	1,148	116	543	94	203
Yuba	1,394	332	82*	156	102	133

*Estimate is unreliable; race/ethnicity population for specified group is less than 1,000 individuals.

Table B6: Estimated Number and Percent Change in People 65+ with Alzheimer's Disease: 2008, 2015 and 2030, California and Counties

	2008	2015	2030	% change 2008-2015	% change 2015-2030	% change 2008-2030
Alameda	22,347	25,192	45,590	13	81	104
Alpine	32	51	102	61	99	221
Amador	989	1,236	2,127	25	72	115
Butte	4,688	4,909	7,862	5	60	68
Calaveras	1,211	1,599	2,753	32	72	127
Colusa	346	397	677	15	70	96
Contra Costa	16,446	19,190	35,735	17	86	117
Del Norte	508	615	1,081	21	76	113
El Dorado	3,072	3,818	7,688	24	101	150
Fresno	11,570	13,353	23,771	15	78	105
Glenn	533	624	1,000	17	60	88
Humboldt	2,200	2,506	4,320	14	72	96
Imperial	2,440	3,263	5,682	34	74	133
Inyo	531	592	876	11	48	65
Kern	8,634	10,645	19,726	23	85	128
Kings	1,369	1,715	3,200	25	87	134
Lake	1,616	1,961	3,294	21	68	104
Lassen	470	607	1,164	29	92	148
Los Angeles	147,140	166,540	278,806	13	67	89
Madera	2,181	2,821	5,954	29	111	173
Marin	5,298	5,861	10,361	11	77	96
Mariposa	453	584	1,076	29	84	138
Mendocino	1,756	2,039	3,508	16	72	100
Merced	2,937	3,542	6,168	21	74	110
Modoc	259	305	529	18	73	104
Mono	164	247	521	51	111	217
Monterey	6,325	7,186	12,101	14	68	91
Napa	2,951	3,080	4,984	4	62	69
Nevada	2,304	2,609	4,768	13	83	107
Orange	43,644	50,896	88,639	17	74	103
Placer	6,516	7,985	13,721	23	72	111
Plumas	574	692	1,029	21	49	79
Riverside	30,545	34,949	57,460	14	64	88

	2008	2015	2030	% change 2008-2015	% change 2015-2030	% change 2008-2030
Sacramento	20,774	24,138	42,587	16	76	105
San Benito	673	844	1,692	25	100	152
San Bernardino	22,166	27,883	54,245	26	95	145
San Diego	46,889	51,004	88,834	9	74	89
San Francisco	16,711	18,440	25,546	10	39	53
San Joaquin	9,277	11,174	19,811	20	77	114
San Luis Obispo	5,806	6,503	10,601	12	63	83
San Mateo	12,976	13,792	22,413	6	63	73
Santa Barbara	7,785	8,228	12,720	6	55	63
Santa Clara	26,053	30,956	56,270	19	82	116
Santa Cruz	3,503	3,634	7,416	4	104	112
Shasta	3,671	4,301	7,258	17	69	98
Sierra	98	112	168	14	51	72
Siskiyou	1,226	1,396	2,087	14	49	70
Solano	5,716	6,964	13,664	22	96	139
Sonoma	8,368	8,586	15,396	3	79	84
Stanislaus	7,175	8,775	15,601	22	78	117
Sutter	1,513	1,933	3,520	28	82	133
Tehama	1,307	1,514	2,250	16	49	72
Trinity	347	453	797	30	76	129
Tulare	5,277	6,301	11,253	19	79	113
Tuolumne	1,609	1,949	3,165	21	62	97
Ventura	11,771	13,884	25,481	18	84	116
Yolo	2,417	2,845	5,478	18	93	127
Yuba	963	1,220	2,112	27	73	119
CALIFORNIA	556,121	638,435	1,106,640	15	73	99

Table B7: Estimated Number and Percent Change in People 65+ with Alzheimer's Disease by Race: 2008, 2015 and 2030, California

	2008	2015	2030	% change 2008-2015	% change 2015-2030	% change 2008-2030
Caucasian/non-Latino	367,445	378,104	573,571	3	52	56
Latino/Hispanic	85,497	118,626	260,417	39	120	205
African-American	24,749	29,334	50,365	19	72	103
Asian/Pacific Islander	67,931	95,663	187,322	41	96	176
American Indian	2,992	4,638	10,229	55	121	242
Multirace	7,507	12,070	24,736	61	105	230

Table B8: Estimated Number of People 65+ with Alzheimer's Disease by Race and County, 2008

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Alameda	12,147	2,087	2,815	4,845	84	368
Alpine	27*	0*	0*	0*	4*	0*
Amador	916	39*	4*	7*	12*	11*
Butte	4,263	157	51*	86*	51*	79*
Calaveras	1,108	59*	11*	9*	12*	13*
Colusa	254	67*	5*	11*	6*	4*
Contra Costa	12,166	1299	908	1,805	64*	205
Del Norte	440	18*	1*	7*	30*	12*
El Dorado	2,807	116	14*	69*	20*	46*
Fresno	7,594	2,347	394	991	90*	152*
Glenn	438	61*	3*	12*	9*	9*
Humboldt	1,956	70*	12*	30*	84*	48*
Imperial	818	1,446	65*	56*	39*	16*
Inyo	447	32*	0*	2*	41*	9*
Kern	6,092	1,515	321	427	98*	181
Kings	845	327	70*	89*	16*	22*
Lake	1,392	87*	65*	19*	24*	29*
Lassen	400	28*	12*	2*	16*	12*
Los Angeles	75,977	34,218	11,325	23,206	410	2,005
Madera	1,574	413	69*	53*	39*	32*
Marin	4,693	290	70*	192	6*	47*
Mariposa	405	21*	2*	4*	11*	11*
Mendocino	1,546	81*	11*	24*	63*	32*
Merced	1,960	647	98*	162	21	48*
Modoc	227	10*	1*	3*	12*	4*
Mono	142	10*	1*	2*	7*	2*
Monterey	4,263	1,161	150*	627	41*	85*
Napa	2,509	242	32*	117*	13*	38*
Nevada	2,168	67*	5*	22*	12*	30*
Orange	32,184	4,629	265	5,943	146	476
Placer	5,793	378	34*	214	33*	63*
Plumas	527	16*	5*	4*	12*	9*
Riverside	23,753	4,175	1,110	1,046	127	335

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Sacramento	14,403	2,093	1,071	2,625	113*	470
San Benito	417	202	6*	32*	6*	9*
San Bernardino	14,399	4,760	1,351	1,220	134	302
San Diego	35,520	5,661	973	4,071	283	381
San Francisco	6,977	1,543	1,117	6,777	43*	254
San Joaquin	5,616	1,705	384	1,311	59*	202
San Luis Obispo	5,197	345	43*	114	34*	74*
San Mateo	8,613	1,305	408	2,452	33*	165
Santa Barbara	6,116	1,142	111	294	45*	76*
Santa Clara	15,892	3,737	351	5,708	100*	264
Santa Cruz	2,820	399	24*	194	21*	46*
Shasta	3,346	99*	25*	61*	63	77*
Sierra	89*	5*	0*	0*	1*	2*
Siskiyou	1,076	49*	24*	11*	32*	33*
Solano	3,612	452	449	1,050	38*	116*
Sonoma	7,242	623	70*	276	53*	104*
Stanislaus	5,187	1,395	82*	327	61*	123*
Sutter	1,092	199	21*	153	17*	29*
Tehama	1,168	78*	5*	8*	23*	25*
Trinity	314	6*	1*	1*	13*	12*
Tulare	3,640	1,202	68*	222	56*	89*
Tuolumne	1,488	70*	5*	9*	15*	22*
Ventura	8,871	1,874	133	712	55*	127*
Yolo	1,804	344	65*	147	22*	34*
Yuba	714	94*	33*	69*	18*	36*

*Estimate is unreliable; race/ethnicity population for specified group is less than 1,000 individuals.

Table B9: Estimated Number of People 65+ with Alzheimer's Disease by Race and County, 2015

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Alameda	11,913	2,870	2,953	6,762	127	568
Alpine	43*	1*	0*	0*	7*	0*
Amador	1,100	68*	9*	14*	22*	23*
Butte	4,313	200	69*	114*	82*	131*
Calaveras	1,405	98v	22*	20*	24*	30*
Colusa	251	103*	5*	18*	12*	8*
Contra Costa	13,063	1,855	1,103	2,735	103*	330
Del Norte	484	40*	3*	14*	51*	23*
El Dorado	3,410	160	22*	111*	36*	79*
Fresno	7,738	3,446	450	1,364	123	232
Glenn	468	101*	4*	20*	14*	17*
Humboldt	2,127	103*	23*	53*	118*	83*
Imperial	852	2,172	73*	79*	58*	29*
Inyo	453	51*	0*	5*	69*	14*
Kern	6,900	2,281	436	616	131	281
Kings	949	493	91*	113*	31*	37*
Lake	1,652	119*	72*	32*	39*	47*
Lassen	480	51*	19*	4*	30*	22*
Los Angeles	74,517	43,870	12,727	31,648	570	3,207
Madera	1,872	681	77*	74*	61*	56*
Marin	4,949	471	82*	274	14*	72*
Mariposa	491	38*	4*	8*	23*	20*
Mendocino	1,692	124	16*	44*	105*	57*
Merced	2,104	987	110*	218	38*	85*
Modoc	250	19*	2*	5*	19*	9*
Mono	202	20*	2*	5*	14*	4*
Monterey	4,250	1,727	139*	857	65*	146
Napa	2,393	387	47*	169	24*	61*
Nevada	2,373	110*	8*	39*	26*	53*
Orange	33,491	6,801	387	9,262	201	754
Placer	6,913	544	54*	314	55*	105*
Plumas	609	31*	7*	9*	19*	17*
Riverside	24,184	6,637	1,494	1,821	202	611

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Sacramento	15,373	2,939	1,390	3,516	155	765
San Benito	458	299	10*	50*	11*	16*
San Bernardino	15,798	7,343	2,040	1,991	198	512
San Diego	35,000	7,839	1,151	6,061	441	512
San Francisco	6,577	1,869	1,154	8,384	71*	385
San Joaquin	5,811	2,620	527	1,836	95*	285
San Luis Obispo	5,578	548	61*	147	51*	118*
San Mateo	7,604	1,784	512	3,573	56*	264
Santa Barbara	5,905	1,594	167	387	71*	105*
Santa Clara	17,029	4,861	494	7,988	166	418
Santa Cruz	2,612	598	46*	266	36*	76*
Shasta	3,807	124	37*	104*	96*	133
Sierra	96*	10*	0*	0*	2*	3*
Siskiyou	1,154	78*	36*	18*	57*	54*
Solano	3,877	620	554	1,641	63*	208
Sonoma	6,845	979	84*	416	92*	170
Stanislaus	5,591	2,213	106	561	96*	209
Sutter	1,230	351	43*	234	29*	46*
Tehama	1,296	112*	9*	16*	37*	44*
Trinity	388	14*	1*	2*	26*	22*
Tulare	3,879	1,813	80*	300	91*	138
Tuolumne	1,745	104*	11*	20*	28*	41*
Ventura	9,738	2,625	181	1,037	89*	214
Yolo	1,969	495	81*	199	37*	62*
Yuba	847	133	52*	91*	35*	61*

*Estimate is unreliable; race/ethnicity population for specified group is less than 1,000 individuals.

Table B10: Estimated Number of People 65+ with Alzheimer's Disease by Race and County, 2030

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Alameda	19,631	6,511	4,527	13,322	306	1,293
Alpine	80*	4*	0*	0*	15*	2*
Amador	1,862	119*	18*	28*	51*	49*
Butte	6,703	490	95*	193	161	221
Calaveras	2,373	154	35*	48*	55*	88*
Colusa	393	196	5*	34*	26*	22*
Contra Costa	22,076	4,416	2,132	6,258	196	658
Del Norte	768	105*	13*	40*	96*	58*
El Dorado	6,749	402	58*	198	104*	178*
Fresno	11,256	8,155	889	2,820	253	397
Glenn	702	180	9*	47*	30*	32*
Humboldt	3,586	179	55*	124*	213	162
Imperial	937	4,286	107*	177	116*	59*
Inyo	614	104*	1*	17*	108*	32*
Kern	10,930	5,770	987	1,349	258	431
Kings	1,523	1,110	222	193	75*	77*
Lake	2,769	172	83*	66*	98*	106*
Lassen	886	105*	29*	23*	73*	49*
Los Angeles	99,541	92,640	18,829	60,163	1,260	6,374
Madera	3,385	2,066	94*	124*	131*	154*
Marin	8,338	1,077	126	579	56*	186
Mariposa	880	87*	7*	21*	45*	37*
Mendocino	2,752	276	35*	105*	223	118*
Merced	2,946	2,348	138	456	92*	188*
Modoc	415	48*	6*	8*	31*	20*
Mono	390	75*	6*	14*	26*	10*
Monterey	6,247	3,959	116*	1,328	126*	326
Napa	3,423	895	84*	397	60*	125*
Nevada	4,318	168	19*	81*	64*	118*
Orange	48,287	17,081	987	20,271	466	1,547
Placer	11,535	970	97*	759	120*	239
Plumas	860	67*	8*	18*	41*	36*
Riverside	31,365	16,630	3,032	4,487	458	1,488

	Caucasian	Latino/ Hispanic	African-American	Asian/ Pacific Islander	Native American	Multirace
Sacramento	24,648	6,836	2,708	6,430	362	1,603
San Benito	807	683	37*	98*	28*	40*
San Bernardino	24,979	17,980	4,731	4,975	477	1,103
San Diego	56,091	16,413	2,271	12,011	1,127	921
San Francisco	8,859	3,000	1,583	11,282	148	675
San Joaquin	9,443	5,275	1,153	3,315	185	439
San Luis Obispo	8,695	1,188	97*	272	113*	237
San Mateo	10,158	3,632	872	7,172	125*	454
Santa Barbara	8,158	3,273	308	656	134*	190
Santa Clara	28,660	8,474	1,160	16,499	397	1,081
Santa Cruz	4,896	1,551	100*	555	96*	218
Shasta	6,318	225	68*	226	166	254
Sierra	138*	18*	1*	1*	6*	6*
Siskiyou	1,648	132*	49	44*	113*	102*
Solano	6,883	1,358	1,146	3,683	143	451
Sonoma	11,493	2,258	160	965	183	338
Stanislaus	8,628	4,723	274	1,381	185	410
Sutter	1,955	781	85*	522	72*	104*
Tehama	1,838	173	20*	44*	84*	92*
Trinity	651	35*	4*	9*	52*	45*
Tulare	5,689	4,420	111*	612	168	253
Tuolumne	2,777	141*	34*	52*	74*	88*
Ventura	16,757	5,632	356	2,141	167	427
Yolo	3,539	1,068	110*	473	92*	196
Yuba	1,343	303	79*	156	99*	131*

*Estimate is unreliable; race/ethnicity population for specified group is less than 1,000 individuals.

Appendix C

State and County Alzheimer's Disease and Dementia Lifetime Risk Estimates

Table C1: Lifetime Risk for Baby Boomers to Develop Alzheimer's Disease and Dementia; California and Counties

	Population Aged 44-62 Who Will Develop:	
	Dementia	**Alzheimer's Disease**
Alameda	70,519	52,517
Alpine	77	57
Amador	2,053	1,519
Butte	9,811	7,311
Calaveras	2,570	1,917
Colusa	903	671
Contra Costa	51,076	38,094
Del Norte	1,351	999
El Dorado	10,474	7,795
Fresno	34,908	25,963
Glenn	1,233	915
Humboldt	6,292	4,684
Imperial	7,091	5,248
Inyo	1,010	751
Kern	31,077	23,050
Kings	5,366	3,951
Lake	3,439	2,561
Lassen	1,603	1,175
Los Angeles	443,173	329,650
Madera	6,663	4,972
Marin	14,133	10,548
Mariposa	1,046	775
Mendocino	4,540	3,381
Merced	9,073	6,747
Modoc	548	407
Mono	732	541
Monterey	16,883	12,544
Napa	6,298	4,688
Nevada	5,926	4,421
Orange	136,331	101,450
Placer	16,295	12,143
Plumas	1,165	868
Riverside	81,771	60,819

	Population Aged 44-62 Who Will Develop:	
	Dementia	**Alzheimer's Disease**
Sacramento	63,383	47,231
San Benito	2,477	1,843
San Bernardino	82,446	61,377
San Diego	140,517	104,415
San Francisco	33,915	25,002
San Joaquin	26,599	19,805
San Luis Obispo	12,652	9,409
San Mateo	35,059	26,085
Santa Barbara	18,388	13,638
Santa Clara	83,830	62,129
Santa Cruz	12,660	9,396
Shasta	9,109	6,794
Sierra	206	153
Siskiyou	2,409	1,797
Solano	20,041	14,889
Sonoma	24,148	17,994
Stanislaus	20,754	15,476
Sutter	3,893	2,901
Tehama	2,772	2,065
Trinity	829	617
Tulare	15,758	11,727
Tuolumne	3,010	2,230
Ventura	38,034	28,297
Yolo	7,837	5,841
Yuba	2,808	2,087
CALIFORNIA	1,648,965	1,226,329

Source: Lifetime Risk calculations are based on the California Department of Finance population estimates and applying risk proportions for Alzheimer's disease and dementia indicated in the Alzheimer's Association, *2008 Alzheimer's Disease Facts and Figures*, p. 33-34.

Appendix D

State and County Alzheimer's Disease Mortality Estimates

Table D1: Alzheimer's Disease Deaths in California: 2003-2005, By County

	2003-2005 Deaths (Average)	%	2004 Population	Crude Rate†	Age-Adjusted Rate‡	95% Confidence Limits Lower	Upper
Humboldt°	52.3	0.7	130,859	40.0	42.0	30.6	53.4
Napa°	73.0	1.0	132,753	55.0	39.1	30.0	48.2
San Diego°	1,068.0	15.1	3,031,055	35.2	38.6	36.3	41.0
Solano°	119.0	1.7	418,097	28.5	38.3	31.4	45.2
Madera°	41.0	0.6	139,398	29.4	35.5	24.6	46.3
Kern°	140.3	2.0	744,489	18.8	31.4	26.2	36.6
Butte°	85.3	1.2	213,143	40.0	29.6	23.3	35.9
Riverside°	474.3	6.7	1,845,185	25.7	28.6	26.1	31.2
Tehama	19.7	0.3	59,942	32.8	27.8	15.5	40.1
Sonoma°	150.0	2.1	477,419	31.4	27.5	23.0	31.9
San Bernardino°	299.3	4.2	1,922,467	15.6	26.1	23.2	29.1
San Joaquin	126.3	1.8	645,560	19.6	25.0	20.6	29.3
Sacramento	283.0	4.0	1,357,367	20.8	24.5	21.7	27.4
Placer	85.0	1.2	302,199	28.1	24.1	19.0	29.3
Yolo	33.0	0.5	186,751	17.7	24.1	15.9	32.3
Stanislaus	94.0	1.3	499,864	18.8	24.0	19.2	28.9
Contra Costa	229.7	3.2	1,014,992	22.6	23.9	20.8	26.9
Fresno	153.0	2.2	874,745	17.5	23.4	19.7	27.1
San Luis Obispo	79.7	1.1	259,709	30.7	23.4	18.3	28.6
Shasta	46.3	0.7	177,465	26.1	23.2	16.5	29.9
Orange	564.7	8.0	3,038,670	18.6	22.2	20.4	24.0
Santa Barbara	107.3	1.5	416,662	25.8	22.2	18.0	26.4
El Dorado	36.7	0.5	172,320	21.3	22.0	14.8	29.1
Santa Clara	311.0	4.4	1,747,295	17.8	20.8	18.5	23.2
Ventura	136.0	1.9	808,735	16.8	20.0	16.6	23.4
San Mateo	156.0	2.2	720,229	21.7	18.9	15.9	21.9
Merced	27.3	0.4	237,550	11.5	17.6	11.0	24.1
Santa Cruz	42.3	0.6	259,942	16.3	17.4	12.1	22.7
Marin°	57.7	0.8	251,812	22.9	16.8	12.4	21.2
Los Angeles°	1,391.7	19.7	10,152,410	13.7	16.3	15.4	17.1
Nevada	21.3	0.3	98,436	21.7	16.2	9.3	23.1
Alameda°	212.3	3.0	1,497,316	14.2	15.8	13.6	17.9
Monterey°	50.0	0.7	423,137	11.8	13.6	9.8	17.3

Source: Jew-Lochman, S. (2008). *Alzheimer's disease Deaths California, 2005.* California Department of Public Health, Office of Health Information and Research.

State of California, Department of Finance. *Race/Ethnic Population with Age and Sex Detail, 2000-2005*, July 2007. State of California, Department of Public Health, Death Records.

	2003-2005 Deaths (Average)	%	2004 Population	Crude Rate†	Age-Adjusted Rate‡	95% Confidence Limits Lower	Upper
San Francisco°	134.3	1.9	793,564	16.9	13.3	11.1	15.6
Tulare°	29.0	0.4	406,003	7.1	10.0	6.3	13.6
Tuolumne	13.3	0.2	57,186	23.3*	15.4*	7.1	23.6
Kings	13.0	0.2	143,970	9.0*	17.6*	8.0	27.2
Lake	12.7	0.2	62,994	20.1*	14.8*	6.6	22.9
Mendocino	12.7	0.2	89,966	14.1*	12.3*	5.5	19.1
Sutter	11.7	0.2	87,881	13.3*	14.3*	6.1	22.6
Imperial	10.7	0.2	159,844	6.7*	9.5*	3.7	15.2
Siskiyou	10.3	0.1	45,644	22.6*	15.1*	5.9	24.2
Amador	10.0	0.1	37,507	26.7*	19.3*	7.3	31.2
Calaveras	9.0	0.1	44,243	20.3*	14.0*	4.8	23.2
Colusa	8.7	0.1	20,927	41.4*	45.2*	15.1	75.4
Glenn	7.0	0.1	28,115	24.9*	23.4*	6.0	40.7
Yuba	5.3	0.1	66,682	8.0*	11.7*	1.7	21.6
Del Norte	5.0	0.1	29,162	17.1*	18.2*	2.2	34.2
Plumas	4.3	0.1	21,478	20.2*	14.9*	0.8	29.0
San Benito	3.3	a	57,307	5.8*	8.9*	0.0	18.4
Mariposa	3.0	a	18,066	16.6*	12.2*	0.0	26.0
Modoc	3.0	a	10,178	29.5*	21.9*	0.0	46.7
Lassen	2.7	a	35,626	7.5*	11.3*	0.0	25.0
Trinity	2.0	a	13,961	14.3*	10.6*	0.0	25.2
Inyo	1.3	a	18,923	7.0*	4.3*	0.0	11.5
Mono	1.0	a	13,727	7.3*	12.9*	0.0	38.3
Sierra	0.3	a	3,716	9.0*	4.4*	0.0	19.4
Alpine	0.0	-	1,304	-	-	-	-
CALIFORNIA	7,080.3	100.0	36,525,947	19.4	22.1	21.6	22.6

Note: Rates are per 100,000 population. ICD-10 codes G30.
Year 2000 U.S. Standard Population is used for age-adjusted rates.

° County age-adjusted rate is significantly different from the state age-adjusted rate.

* Death rate unreliable, relative standard error is greater than or equal to 23 percent.

a Represents a percentage of more than zero but less than 0.05.

- Percentages, rates, and confidence limits are not calculated for zero events.

† A crude death rate is defined as the number of cause-specific events (e.g. deaths, disease cases, individuals at risk) over a specified period of time (e.g. a year) divided by the total population. Crude death rates are sometimes expressed as annual rates per 100,000 population and may be calculated for males, females, or some other subset of the population.

‡ The OHIR report calculated age-specific death rates. Age-specific death rates are the number of deaths per 100,000 people in a specific age group, and are used along with standard population proportions to develop a weighted average rate. The weighted average rate is referred to as an age-adjusted death rate and removes the effect of different age structures of the populations whose rates are being compared. Age-adjusted death rates therefore provide the preferred method for comparing different race/ethnic groups, sexes, and geographic areas, and for measuring death rates over time.

Table D2: Alzheimer's Disease Deaths in California: 2005, By Race/Ethnicity

	2003-2005 Deaths (Average)	%	2005 Population	Crude Rate†	Age-Adjusted Rate‡	95% Confidence Limits Lower	Upper
Caucasian	6,429	83.6	16,408,477	39.2	27.8	27.1	28.5
Latino/ Hispanic	577	7.5	12,905,840	4.5	13.0	11.9	14.0
African-American	394	5.1	2,255,281	17.5	27.3	24.6	30.1
Asian/Pacific Islander	267	3.6	4,263,720	6.3	8.0	7.1	9.0
CALIFORNIA*	7,694	100.0	36,957,436	19.4	23.4	22.9	23.9

Note: Rates are per 100,000 population. ICD-10 codes G30. Year 2000 U.S. Standard Population is used for age-adjusted rates. American Indian, Asian, Black, Pacific Islander, White, and Two or More Races exclude Hispanic ethnicity. Hispanic includes any race category.

* Total includes Native American (7), Pacific Islander (5), and Two or More Races (15) not shown individually due to unreliable rates.

Source: Jew-Lochman, S. (2008). *Alzheimer's disease Deaths California, 2005*. California Department of Public Health, Office of Health Information and Research.

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Appendix E

State Formal and Informal Alzheimer's Disease Cost of Care Projections

Table E1: Projections of the Cost of Caring for Community-Resident and Institutionalized People with Alzheimer's Disease in California 55 + (2007 $US): 2008, 2015, 2030

					Informal Care		Formal Care		
		# of Individuals	Impairment Level	# of Individuals by Impairment Level	Cost per Individual	Cost ($100,000,000 million)	Cost per Individual	Cost ($100,000,000 million)	Total Cost ($100,000,000 million)
COMMUNITY									
	2008	563,143	mild-mod	391,461	$62,916	$246.3	$17,936	$70.2	$505.3
			severe	171,681	$71,686	$123.1	$38,309	$65.8	
	2015	649,507	mild-mod	451,763	$62,916	$284.2	$17,936	$81.0	$582.8
			severe	197,746	$71,686	$141.8	$38,309	$75.8	
	2030	1,100,760	mild-mod	763,429	$62,916	$480.3	$17,936	$136.9	$988.3
			severe	337,332	$71,686	$241.8	$38,309	$129.2	
INSTITUTIONALIZED									
	2008	25,065			$10,918	$2.7	$96,675	$24.2	$2.7
	2015	28,939			$10,918	$3.2	$96,675	$28.0	$3.1
	2030	48,800			$10,918	$5.3	$96,675	$47.2	$5.3
ALL SETTINGS									
	2008	588,208				$372.1		$160.2	$532.3
	2015	678,446				$429.2		$184.8	$613.9
	2030	1,149,560				$727.4		$313.3	$1040.8

Note: An assumption of these calculations is that the distributions will remain constant into the future. We applied the 2007 per capita AD formal and informal cost estimates to AD prevalence estimates by residence. We made all cost projections in 2007 dollars which assumes no inflation from 2008-2030. The value of informal care is based on the replacement cost approach and therefore does not represent an actual expenditure, but rather the cost to replace informal caregivers' labor.

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Table E2: Projections of the Cost of Caring for Community-Resident and Institutionalized People with Alzheimer's Disease in California 65 + (2007 $US): 2008, 2015, 2030

				Informal Care		Formal Care		
	# of Individuals	Impairment Level	# of Individuals by Impairment Level	Cost per Individual	Cost ($100,000,000 million)	Cost per Individual	Cost ($100,000,000 million)	Total Cost ($100,000,000 million)
COMMUNITY								
2008	532,708	mild-mod	367,622	$62,916	$231.3	$17,936	$66.9	$479.7
		severe	165,086	$71,686	$118.3	$38,309	$63.2	
2015	611,557	mild-mod	422,036	$62,916	$265.5	$17,936	$75.7	$549.7
		severe	189,522	$71,686	$135.9	$38,309	$72.6	
2030	1,060,050	mild-mod	731,541	$62,916	$460.5	$17,936	$131.2	$953.0
		severe	328,510	$71,686	$235.5	$38,309	$125.8	
INSTITUTIONALIZED								
2008	23,413			$10,918	$2.6	$96,675	$22.6	$25.2
2015	26,878			$10,918	$2.9	$96,675	$26.0	$28.9
2030	46,590			$10,918	$5.1	$96,675	$45.0	$50.1
ALL SETTINGS								
2008	556,121				$352.2		$152.7	$504.9
2015	638,435				$404.3		$174.3	$578.6
2030	1,106,640				$701.1		$302.0	$1003.1

Note: An assumption of these calculations is that the distributions will remain constant into the future. We applied the 2007 per capita AD formal and informal cost estimates to AD prevalence estimates by residence. We made all cost projections in 2007 dollars which assumes no inflation from 2008-2030. The value of informal care is based on the replacement cost approach and therefore does not represent an actual expenditure, but rather the cost to replace informal caregivers' labor.

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Appendix F

Methodological Notes and Data Sources

Methodological Notes and Data Sources

F1. Alzheimer's Disease Prevalence Projection Methods

The prevalence of Alzheimer's disease in residents aged 65 and older in California and its counties was calculated using prevalence rates published by the Alzheimer's Association[19] that were based upon published studies conducted in Chicago by Hebert and colleagues (2003)33—refer to p. 5 of the Alzheimer's Disease Facts and Figures, 2007 report. The age breakdown of the prevalence rates are: (a) 2 percent for age 65-74, (b) 19 percent for age 75-84 and (c) 42 percent for age 85 and older. These prevalence rates were applied to California Department of Finance population projections for the years 2008, 2015, and 2030.[34]

For California residents under the age of 65, estimates of Alzheimer's disease were calculated using prevalence rates published in the Alzheimer's Association 2006 report *Early Onset Dementia: A National Challenge, A Future Crisis*[32] and the Alzheimer's Disease Facts and Figures, 2007 report.[19] An estimate of the number of individuals with dementia was first calculated and then the number of individuals with Alzheimer's disease was computed. *The Early Onset Dementia: A National Challenge, A Future Crisis* report indicates the proportion of people between the age of 55-59 with disabling cognitive impairment was 1.9 percent and the prevalence increased slightly to 2.2 percent for people age 60-64. The California prevalences for dementia for individuals age 55-59 and 60-64 were determined using these figures on the California Department of Finance population projections for the years 2008, 2015, and 2030.34 The Alzheimer's Disease Facts and Figures, 2007 report indicated that a conservative estimate of the number of individuals younger than 65 with dementia who are likely to have Alzheimer's disease ranges between 40 to 50 percent. To arrive at an approximation of the number of Californians with Alzheimer's disease between 55-64 of age, we applied the lower range of this estimate, 40 percent, to the previously calculated dementia frequencies.

F2. Lifetime Risk of Alzheimer's Disease and Dementia Projection Methods

The estimate of the lifetime risk of Alzheimer's disease and dementia for California baby boomers, individuals born between 1946 through 1964, was arrived at using figures published in the Alzheimer's Disease Facts and Figures, 2008 report2—refer to p. 33-34. The Alzheimer's Disease Facts and Figures, 2008 report indicated that 17 percent of women and 9 percent of men will develop Alzheimer's disease in their remaining lifetime if they lived to be at least age 55; and that 21 percent of women and 14 percent of men will develop dementia in their remaining lifetime if they lived to be at least age 55. These figures were applied to the California Department of Finance population projections for baby boomers for the years 2008, 2015, and 2030.34

F3. Formal and Informal Caregiving Costs

Data on the formal and informal costs of caring for people with AD were derived using figures from a California study by Rice and colleagues conducted in 1993.[21] Formal and informal costs of caring were calculated separately for people with mild/moderate Alzheimer's disease and severe Alzheimer's disease (MMSE <=17 is severe; above 17 mild/moderate).

Annual costs for each category were converted in 2007 dollars by using economic indices reported by the United States Department of Labor and the United States Census Bureau (US Department of Labor. Bureau of Labor Statistics. Hourly Compensation in the Business Sector. http://data.bls.gov/cgi-bin/regate . Accessed 3/6/08; US Census Bureau, Statistical Abstract of the United States: 2003. Table No. 715. Consumer Price Indexes for all Urban Consumers (CPI-U) for Selected Items and Groups: 1980 - 2002 ; Bureau of Labor Statistics, News. Table 1. Consumer Price Index for All Urban Consumers (CPI-U): US City Average, by Expenditure Category, http://www.bls.gov/news.release/cip.t01.htm . Accessed on 3/6/08).

Informal costs were converted using changes in the hourly compensation in the business sector (U. S. Department of Labor). Formal costs were converted using Consumer Price Indexes for hospital and related services; medical care services; professional services (physicians); medical care commodities; and medical care services (U. S. Census Bureau). Each component of costs from the Rice et al. (1993) study was converted into 2007 dollars as follows:

- Hourly compensation in the business sector – informal services (1.97)
- Hospital – hospital and related services (2.90)
- Nursing Home – medical care services (2.32)
- Physician visits – professional services (1.95)
- Medications – medical care commodities (1.80)
- Medical items – medical care commodities (1.80)
- Social services – medical care services (2.32)
- Other – medical care services (2.32)

Determining the percentage of individuals with mild/moderate Alzheimer's disease and severe Alzheimer's disease was based on data from the California Department of Public Health's Alzheimer's disease Research Centers of California (ARCCs) Minimum Uniform Data Set for the years 1998-2008 for patients 65 years and older who were diagnosed with Alzheimer's disease. The ARCCs are state-funded clinics located primarily at university medical centers within California. The sites include the University of Southern California (2 sites), Stanford University, and the University of California at Davis (2 sites), Irvine, Los Angeles, San Diego, and San Francisco (2 sites). The ARCC sites have been closely collaborating and using a standardized research data collection protocol (Minimum Uniform Data Set [MUDS]) for over 10 years. Demographic, diagnostic, and medication data are collected using the MUDS. Data are processed centrally through the Institute for Health and Aging at the University of California in San Francisco. To increase inter-site reliability and accuracy, training and recalibration exercises are held with case reports, videos, and autopsy findings.

The various severity cost components were applied to the California prevalence rates as follows: severely impaired patients evaluated—30.9 percent of the total; mild/moderately impaired patients—69.01 percent of the total.

F4. Cost to the Medi-Cal Program

In 1999 Menzin and colleagues published a study looking at California Medi-Cal administrative claims data for the purposes of evaluating the costs to the Medi-Cal program for individuals with Alzheimer's disease and other dementias compared to individuals without dementia.[22] To obtain the Medi-Cal estimates discussed in this report, we extracted the costs reported by Menzin and colleagues, that were in 1995 dollars, and updated the costs to 2007 dollars using United States Census Bureau reported price indices—see method note F3 for the listing of indices used (US Census Bureau, Statistical Abstract of the United States: 2003. Table No. 715. Consumer Price Indexes for all Urban Consumers (CPI-U) for Selected Items and Groups: 1980-2002 ; Bureau of Labor Statistics, News. Table 1. Consumer Price Index for All Urban Consumers (CPI-U): US City Average, by Expenditure Category, http://www.bls.gov/news.release/cip.t01.htm. Accessed on 3/6/08).

F5. Costs to California Businesses

To calculate the different components effecting businesses, we followed the model used in The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business.29 To estimate the productivity losses to California businesses, several sources of data were used.29, 12, 35, 36, 37 Productivity losses are based on the 70 percent of California caregivers who work full-time which translates to 386,076 caregivers. This figure is derived from the Alzheimer's Disease Facts and Figures, 2008 report estimating that there are approximately 1,103,073 Alzheimer and dementia caregivers in California. Scharlach and colleagues estimated that 50 percent of caregivers work outside of the home and that 70 percent of these caregivers work full-time.[12]

Replacement Costs

To estimate the number of caregivers who leave the workplace on an annual basis, we used the Alzheimer's Association Fact Sheet California Caregivers: Who Are California's Informal Caregivers?20 which estimates that approximately 11 percent of caregivers leave the workplace over the course of caregiving, and the average length of time providing care for employed caregivers is 3.7 years.[29] Thus, the estimated number of caregivers leaving the workplace on an annual basis is 2.97 percent. The median income was based on information from the California Department of Finance website, http://www.dof.ca.gov/HTML/FS_DATA/LatestEconData/FS_Income.htm (last accessed on August 18, 2008), item #2 Census Bureau's measure of money income. The latest year for median income data was 2006 when the median income was $55,000—50 percent of this salary was used to calculate replacement cost.

Absenteeism Costs

To estimate absenteeism costs we used the figures reported by Scharlach and colleagues that 21 percent of employed caregivers missed work from arriving late to taking 3 or more days off, and 50 percent missed at least 16 hours of work in 2 weeks prior to the study interview. This resulted in 81,076 employed caregivers missing approximately 400 hours per year. The costs were then derived by applying the California median hourly wage, $16.91, obtained from the May 2007 United States Department of Labor Bureau of Labor Statistics.[35]

Workday Interruptions

The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business estimates that 44.8 percent of employed caregivers experience workday interruptions and the number of interrupted hours is 50 per year.29 The costs were then derived by applying the California median hourly wage, $16.91, obtained from the May 2007 United States Department of Labor Bureau of Labor Statistics.[35]

Elder Crisis

The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business estimates that 60 percent of employed caregivers experience workday interruptions which results in an estimated 3 days (24 hours) per year loss of work.29 The costs due to elder crisis were then derived by applying the California median hourly wage, $16.91, obtained from the May 2007 United States Department of Labor Bureau of Labor Statistics.[35]

Reducing Time From Full-time to Part-time Status

These costs were estimated separately for small businesses (0-499 employees) and large businesses (500+ employees). Scharlach and colleagues estimated that 13 percent of caregivers need to reduce their hours of employment.[12] The California Employment Development Department estimates that 79.1 percent of Californians are employed in small business and approximately 20.8 percent are employed in large businesses (California Employment Development Dept, Labor Market Information Division, Third Quarter 2006, http://www.labormarketinfo.edd.ca.gov/?pageid=138, accessed July 11, 2008). Using these estimates results in 39,650 caregivers employed in small businesses and 10,540 caregivers in large businesses who will likely reduce the amount of time that they work due to caregiver responsibilities. Fifty percent of the average monthly salary for small and large businesses was obtained to calculate the costs associated with going from full- to part-time employment—$2,532 for small businesses and $3,408 for large businesses (http://www.payscale.com/research/US/State=California/Salary/show_all).

Supervision Costs

The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business estimates that 45.9 percent of employed caregivers have supportive supervisors. This resulted in 177,556 caregivers with supportive supervisors. Similar to the procedures in *The MetLife Caregiving Cost Study* we took the California median hourly wage and increased this by 10 percent to estimate a supervisors' wage. It is estimated that supervisors spent one hour per month (12 hours per year) supervising these employees.[29]

Unpaid Leave Costs. The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business estimates that 16 percent of employed caregivers take unpaid leave—61,772 California caregivers—for a total of 10 days per year. The California median hourly wage was used to calculate the cost of unpaid leave based on a seven hour day.

Appendix G

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Appendix H

Alzheimer's Association Chapter Offices in California

Alzheimer's Association Chapters and Service Offices

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Their 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.

The core services of the Alzheimer's Association are:

- Information & Referral
- Family Care Consultations
- Medic Alert+Safe Return Wanderer's Registry & I.D.
- Caregiver Education
- Support Groups
- Professional Training
- Early Stage Programs

Alzheimer's Association Chapters and the Regions They Serve

CALIFORNIA SOUTHLAND
5900 Wilshire Blvd., Ste. 1100
Los Angeles, CA 90036
(323) 938-3379

Greater East Los Angeles
133 North Sunol Drive, Ste. 243
Los Angeles, CA 90063
(323) 881-0574

Greater San Fernando Valley
16933 Parthenia St., Ste. 200
Northridge, CA 91343
(818) 830-8590

Inland Empire
1365 West Foothill Blvd., Ste. 3
Upland, CA 91786
(909) 931-1580

Coachella Valley
69730 Hwy 111, Ste. 202
Rancho Mirage, CA 92270
(760) 328-6767

NATIONAL HEADQUARTERS
Alzheimer's Association
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601
website: http://www.alz.org

24/7 HELPLINE
Contact us for information, referral and support.
tel: 1.800.272.3900
tdd: 1.866.403.3073
e-mail: info@alz.org

NORTHERN CALIFORNIA
1060 La Avenida
Mountain View, CA 94043
(650) 962-8111

North Valley–Chico
2105 Forest Avenue, Ste. 130
Chico, CA 95928
(530) 895-9661

Sacramento Valley
530 Bercut Drive, Ste. A
Sacramento, CA 95811
(916) 930-9080

North Bay–Santa Rosa
1211 North Dutton Ave., Ste. A
Santa Rosa, CA 95401
(707) 573-1210

North Bay–San Rafael
4340 Redwood Hwy, Ste. D314
San Rafael, CA 94903
(415) 472-4340

East Bay–Lafayette
251 Lafayette Circle, Ste. 250
Lafayette, CA 94549
(925) 284-7942

Santa Cruz
1777 A-Capitola Road
Santa Cruz, CA 95062
(831) 464-9982

Monterey
182 El Dorado Street
Monterey, CA 93940
(831) 647-9890

CENTRAL COAST
1528 Chapala Street, Ste. 204
Santa Barbara, CA 93101
(805)892-4259

Santa Barbara North
528 South Broadway
Santa Maria, CA 93454
(805) 636-6432

San Luis Obispo
3480 South Higuera St., Ste. 120
San Luis Obispo, CA 93401
(805) 547-3830

Ventura County
1339 Del Norte Rd.
Camarillo, CA 93010
(805) 485-5597

ORANGE COUNTY
17771 Cowan, Ste. 200
Irvine, CA 92614
(949) 955-9000

SAN DIEGO/IMPERIAL
4950 Murphy Canyon Rd., Ste. 250
San Diego, CA 92123
(858) 492-4400

Imperial Valley
584 E. Main Street
El Centro, CA 92243
(760) 335-3725

Appendix I

Caregiver Resource Centers in California

Caregiver Resource Centers (CRC)

Wherever you live, there's help information, education, respite, care planning and support for families and friends, caring for adults with chronic, disabling health conditions.

- Specialized Information
- Family Consultation & Planning
- Respite
- Counseling
- Support Groups
- Legal & Financial Consultation
- Education
- Professional Training

Caregiver Resource Centers and the Regions They Serve

Bay Area Caregiver Resource Center/ Family Caregiver Alliance
Statewide Resources Consultant
180 Montgomery Street, Suite 1100
San Francisco, California 94104
Phone: (415) 434-3388 or (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org
Alameda, Contra Costa, Marin, San Francisco, San Mateo & Santa Clara Counties

Caregiver Resource Center of Orange County
2767 E. Imperial Hwy., 2nd Floor
Brea, CA 92821
Phone: (714) 870-3530 or (800) 543-8312
Website: www.caregiveroc.org
E-mail: ocrc@sjf.stjoe.org
Orange County

Coast Caregiver Resource Center
1528 Chapala Street, Suite 302
Santa Barbara, CA 93101
Phone: (805) 962-3600 or (800) 443-1236
Website: www.coastcrc.org
E-mail: info@coastcrc.org
San Luis Obispo, Santa Barbara & Ventura Counties

Del Mar Caregiver Resource Center
736 Chestnut Street, Suite F
Santa Cruz, California 95060
Phone: (831) 459-6639 or (800) 624-8304
Website: www.delmarcaregiver.org
E-mail: info@delmarcaregiver.org
Monterey, San Benito & Santa Cruz Counties

Del Oro Caregiver Resource Center
5723A Marconi Avenue
Carmichael, California 95608
Phone: (916) 971-0893 or (800) 635-0220
Website: www.deloro.org
E-mail: crc@deloro.org
Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Sutter, Yolo & Yuba Counties

www.californiacrc.org

Inland Caregiver Resource Center
1420 East Cooley Drive, Suite 100
Colton, California 92324
Phone: (909) 514-1404 or (800) 675-6694
Website: www.inlandcaregivers.com
E-mail: info@inlandcaregivers.org
Inyo, Mono, Riverside & San Bernardino Counties

Los Angeles Caregiver Resource Center
3715 McClintock Avenue
Los Angeles, California 90089-0191
Phone: (213) 821-7777 or (800) 540-4442
Website: www.losangelescrc.org
E-mail: lacrc@usc.edu
Los Angeles County

Mountain Caregiver Resource Center
2491 Carmichael Drive, Suite 400
Chico, California 95928
Phone: (530) 898-5925 or (800) 995-0878
Website: www.caregiverresources.org/MCRC_home
E-mail: nkhanchandani@csuchico.edu
Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama & Trinity Counties

Redwood Caregiver Resource Center
141 Stony Circle, Suite 200
Santa Rosa, California 95401
Phone: (707) 542-0282 or (800) 834-1636
Website: www.redwoodcrc.org
E-mail: rcrc@redwoodcrc.org
Del Norte, Humboldt, Lake, Mendocino, Napa, Solano & Sonoma Counties

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, California 92123
Phone: (858) 268-4432 or (800) 827-1008
Website: www.scrc.signonsandiego.com
E-mail: scrc@caregivercenter.org
San Diego & Imperial Counties

Valley Caregiver Resource Center
3845 North Clark Street, Suite 201
Fresno, California 93726
Phone: (559) 224-9154 or (800) 541-8614
Website: www.valleycrc.org
E-mail: info@valleycrc.org
Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare & Tuolumne Counties

Appendix J

Alzheimer's Disease Research Centers of California

Alzheimer's Disease Research Centers of California (ARCCs)

How is California helping persons with Alzheimer's disease and their families?

In 1984, legislation was enacted which established the Alzheimer's Disease Program. The mission of the Program is to reduce the human burden and economic cost associated with Alzheimer's disease and related disorders, and to assist in ultimately discovering the cause and cure of these diseases by:

- Providing diagnostic and treatment services
- Improving the quality of care for persons with Alzheimer's disease
- Providing education and support to the families of persons with Alzheimer's disease
- Increasing and improving the training of health care professionals with respect to Alzheimer's disease
- Increasing research to discover the cause of and cure for Alzheimer's disease—collecting and analyzing accurate and standardized information relative to the disease
- Translating research findings and technical advances into clinical practice, medical education, and the community

What are the Alzheimer's Disease Research Centers of California?

To accomplish the above objectives, the Alzheimer's Disease Program has established and administers ten ARCCs at university medical centers throughout California. These Centers are dedicated to improving the quality of life of persons affected with Alzheimer's disease and their families by providing:

- Comprehensive assessment of individuals with memory problems, typically including medical, neurological, psychological and psychosocial evaluations
- In-home assessment of functional abilities and safety concerns
- Family conference and treatment planning following the evaluation
- Information and referrals to community health and social services
- Appropriate follow-up
- Support groups for caregivers
- Training and education for professionals and lay audiences
- Medical, pharmacological, social and behavioral research

Who provides these services at the Centers?

Services are provided by multi-disciplinary teams which may include neurologists, psychiatrists, physician assistants, psychologists, nurse specialists, neuropsychologists and social workers. Patients continue to see their private physician for primary care.

Who is eligible for these services?

Any individual with symptoms of memory loss, disorientation and confusion may contact one of the Centers for an evaluation. Patients may be self-referred or referred by a family member, private physician or community agency.

Are these services covered by insurance?

Most of the costs of the services and diagnostic tests are covered by insurance. Medicare, Medi-Cal and supplemental or private insurance are accepted. Unless prior arrangements for financial assistance are made with the Center, patients or their families are responsible for fees not covered by insurance.

Where are the Alzheimer's Disease Research Centers of California located?

Northern California Centers:

Fresno ARCC
UC San Francisco/Fresno Alzheimer's and Memory Center
3313 North Hilliard Lane
Fresno, California 93726
PH: 559-227-4810
FX: 559-227-4167
Email: alz@fresno.ucsf.edu
Website: http://fserve.fresno.ucsf.edu/alzheimer/

Sacramento ARCC
UC Davis/Sacramento
4860 Y Street, Suite 3900
Sacramento, CA 95817
PH: 916-734-5496
FX: 916-456-9350
Website: http://alzheimer.ucdavis.edu/

Martinez ARCC
UC, Davis/Martinez
150 Muir Road (127A)
Martinez, CA 94553
PH: 925-372 -2485
FX: 925-372-2884
Website: http://alzheimer.ucdavis.edu/

San Francisco ARCC
UC, San Francisco
350 Parnassus Avenue, Suite 905
San Francisco, CA 94143
PH: 415-476-6800
FX: 415-476-4800
Website: http://www.memory.ucsf.edu/

Palo Alto ARCC
Stanford University
Department of Psychiatry (116F-PAD)
3801 Miranda Avenue
Palo Alto, CA 94304
PH: 650-858-3915 (Clinic)
FX: 650-849-0183
Website: http://arcc.stanford.edu/

Southern California Centers:

ARCC General Information Contact:
PH: (916) 558-1784.
For relay services for the hearing impaired
or speech impaired, please call:
MCI from TDD 1-800-735-2929 or MCI from voice telephone 1-800-735-2922
Sprint from TDD 1-888-877-5378 or Sprint from voice telephone 1-888-877-5379

Irvine ARCC
UC, Irvine Institute for Brain Aging and Dementia
1113 Gillespie, N.R.F.
Irvine, CA 92697-4540
PH: 949-824-5847
FX: 949-824-2071
Website: http://www.alz.uci.edu/

USC/LA ARCC
1510 San Pablo Street, HCC 600
Los Angeles, California 90033
General Information/Appointments:
PH: 323-442-7600
FX: 323-442-7601
Email: gsc@usc.edu
Website: http://www.usc.edu/schools/
medicine/departments/psychiatry_
behavioralsciences/research/gsc/

Los Angeles/UCLA ARCC
Los Angeles/San Fernando Valley
Reed Neurological Research Building
10911 Weyburn Avenue, 2nd Floor
Los Angeles, CA 90095-7226
General Information: (310) 794-3665
Fax: (310) 794-3148
UCLA Appointments: (310) 794-1195
Centinela Freeman: (323) 563-5915
Olive View/UCLA Center: (818) 895-954
Email: adc@ucla.edu
Website: http://www.adc.ucla.edu/

USC/Rancho ARCC
USC/Rancho Los Amigos
Rancho Los Amigos National Rehabilitation Center
7601 East Imperial Highway
(800 West Annex)
Downey, California 90242
PH: 562-401-8130
FX: 562-803-6900

San Diego ARCC
UC, San Diego
SOCARE/UCSD ARCC
9500 Gilman Drive - 0948
La Jolla, CA 92093-0948
PH: 858-622-5800
FX: 858-552-7513

Appendix K

California Guideline for Alzheimer's Disease Management

2008 California Guideline for Alzheimer's Disease Management

This is the third edition of this Guideline for Alzheimer's Disease Management. The first was disseminated in 1998 and updated in 2002. The California Workgroup on Guidelines for Alzheimer's Disease Management, consisting of a collaborative effort of healthcare providers, consumers, academicians, and representatives of professional and volunteer organizations developed the Guideline through a review of scientific evidence that was supplemented by expert opinion when research was unavailable or inconsistent. This Guideline presents core care recommendations for the management of Alzheimer's disease. It assumes that a proper diagnosis has been made using reliable and valid diagnostic techniques. The Guideline is also available through the Alzheimer's Association's California website http://www.caalz.org/Guidelines.htm.

Guideline for Alzheimer's Disease Management

ASSESSMENT

Monitor Changes
Conduct and document an assessment and monitor changes in:

- Daily functioning, including feeding, bathing, dressing, mobility, toileting, continence, and ability to manage finances and medications
- Cognitive status using a reliable and valid instrument
- Comorbid medical conditions which may present with sudden worsening in cognition, function, or as change in behavior
- Behavioral symptoms, psychotic symptoms, and depression
- Medications, both prescription and non-prescription (at every visit)
- Living arrangement, safety, care needs, and abuse and/or neglect
- Need for palliative and/or end-of-life care planning

Reassess Frequently
Reassessment should occur *at least* every 6 months, and sudden changes in behavior or increase in the rate of decline should trigger an urgent visit to the PCP.

Identify Support
Identify the primary caregiver and assess the adequacy of family and other support systems, paying particular attention to the caregiver's own mental and physical health.

Assess Capacity
Assess the patient's decision-making capacity and determine whether a surrogate has been identified.

Identify Culture & Values
Identify the patient's and family's culture, values, primary language, literacy level, and decision-making process.

TREATMENT

Develop Treatment Plan
Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family:

- Use of cholinesterase inhibitors, NMDA antagonist, and other medications, if clinically indicated, to treat cognitive decline
- Referral to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation

Treat Behavioral Symptoms
Treat behavioral symptoms and mood disorders using:

- Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, *etc.*
- Referral to social service agencies or support organizations, including the *Alzheimer's Association's MedicAlert® + Safe Return®* program for patients who may wander

Non-Pharmacological Treatment First
IF non-pharmacological approaches prove unsuccessful, *THEN* use medications, targeted to specific behaviors, if clinically indicated. Note that side effects may be serious and significant.

Treat Co-Morbid Conditions
Provide appropriate treatment for comorbid medical conditions.

Provide End-of-Life Care
Provide appropriate end-of-life care, including palliative care as needed.

PATIENT & FAMILY EDUCATION & SUPPORT

Integrate Medical Care & Support
Integrate medical care with education and support by connecting patient and caregiver to support organizations for linguistically and culturally appropriate educational materials and referrals to community resources, support groups, legal counseling, respite care, consultation on care needs and options, and financial resources.

Organizations include:

- **Alzheimer's Association**
  (800) 272-3900 www.alz.org
- **Caregiver Resource Centers**
  (800) 445-8106 www.caregiver.org
- or your own social service department

Discuss Diagnosis & Treatment
Discuss the diagnosis, progression, treatment choices, and goals of Alzheimer's Disease care with the patient and family in a manner consistent with their values, preferences, culture, educational level, and the patient's abilities.

Involve Early-Stage Patients
Pay particular attention to the special needs of early-stage patients, involving them in care planning, heeding their opinions and wishes, and referring them to community resources, including the Alzheimer's Association.

Discuss Stages
Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making.

Discuss End-of-Life Decisions
Discuss the intensity of care and other end-of-life care decisions with the Alzheimer's Disease patient and involved family members while respecting their cultural preferences.

LEGAL CONSIDERATIONS

Planning
Include a discussion of the importance of basic legal and financial planning as part of the treatment plan as soon as possible after the diagnosis of Alzheimer's Disease.

Capacity Evaluations
Use a structured approach to the assessment of patient capacity, being aware of the relevant criteria for particular kinds of decisions.

Elder Abuse
Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment, abduction) to Adult Protective Services, Long Term Care Ombudsman, or the local police department, as required by law.

Driving
Report the diagnosis of Alzheimer's Disease in accordance with California law.

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Guideline for Alzheimer's Disease Management

Alzheimer's Disease and Its Impact

Alzheimer's Disease (AD) currently afflicts over 5.2 million Americans, including an estimated 200,000 patients under the age of 65. The number of those afflicted is increasing annually as the population continues to age. Following the aging of the baby boomers, prevalence will escalate rapidly and is expected to double by 2020. The burden on families and the health care system will be substantial as one out of every eight baby boomers develops this disease.

About the Guideline

This Guideline presents core care recommendations for the management of Alzheimer's Disease. It assumes that a proper diagnosis has been made using reliable and valid diagnostic techniques. The main audience for the Guideline is primary care practitioners. However, many of the activities recommended in the Guideline do not require a physician and can be done by other members of the treatment team (care managers, nurses, community support organizations) working closely with the patient and caregiving family. The recommended activities do not have to be done in one visit.

The *California Workgroup on Guidelines for Alzheimer's Disease Management*, which consists of healthcare providers, consumers, academicians and representatives of professional and volunteer organizations, developed the Guideline through a review of scientific evidence supplemented by expert opinion when research has been unavailable or inconsistent. An expanded companion document, providing more in-depth background information, is available through the Alzheimer's Association's California website **www.caalz.org**.

Prepared by the
California Workgroup on Guidelines
for Alzheimer's Disease Management
April 2008

This is the third edition of this ***Guideline for Alzheimer's Disease Management.*** The first was disseminated in 1998 and updated in 2002. In the current version there are four substantive changes:

- The advent of a new class of medication (NMDA Antagonists) for the management of moderate to advanced AD
- Support for a team approach (medical and social support strategies) to quality management of AD
- Strong evidence linking positive patient outcomes to caregiver education and support
- New evidence on management of the disease in the very early and end stages (see the recommendations below)

Early-Stage Recommendations

Patients in early-stage AD have unique concerns. AD may progress slowly in the early stage. Follow up two months after diagnosis and every six months thereafter. Pay particular attention to the special needs of early-stage patients, involving them in care planning and referring them to community resources. Discuss implications with respect to work, driving, and other safety issues with the patient. Initiate pharmacologic therapy early. Recommend interventions to protect and promote continuing functioning, assist with independence, and maintain cognitive health including physical exercise, cognitive stimulation and psychosocial support.

Late Stage and End-of-Life Recommendations

As the patient's dementia worsens and the ability to understand treatments and participate in medical decision-making declines, care shifts to focus on the relief of discomfort. The advisability of routine screening tests, hospitalization, and invasive procedures, including artificial nutrition and hydration, will depend upon previously discussed care plan and the severity of the dementia. Predicting the end-of-life for a patient with severe AD is difficult. Referral to hospice should be considered.

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