



CALIFORNIA'S STATE PLAN FOR ALZHEIMER'S DISEASE:

An Action Plan for 2011-2021

GUIDING PRINCIPLES

The guiding principles emphasized throughout California's State Plan for Alzheimer's Disease stress the urgent and ongoing need to:

- Promote person-centered care that is responsive to individual need.
- Address the broad cultural, ethnic, racial, socio-economic and demographic diversity of California's population.
- Integrate the social and medical needs of this and other aging populations living with multiple chronic diseases and disabling conditions.



“The truth is we simply must put Alzheimer's on the front burner because if we don't, Alzheimer's will not just devour our memories. It will also break our women, cripple our families, devastate our healthcare system and decimate the legacy of our generation.”

—*Maria Shriver, author of The Shriver Report: A Woman's Nation Takes on Alzheimer's*



TABLE OF CONTENTS

2	Summary of Goals and Recommendations
4	Why Develop a State Plan for Alzheimer's Disease?
6	Action Plan 2011-2021
22	Financing the State Plan: Recommendations, Challenges and Opportunities
28	Measures of Success
29	References
30	Appendices
30	Overview of Alzheimer's Disease and Other Dementias
32	Resources for Families in California
34	Historical Context and Recent Efforts
36	Guideline for Alzheimer's Disease Management
38	Glossary of Terms
40	Acknowledgements



California's State Plan for Alzheimer's Disease:
An Action Plan for 2011-2021

SUMMARY OF GOALS AND RECOMMENDATIONS

GOAL 1 Eliminate Stigma



RECOMMENDATIONS:

- 1A:** Heighten public awareness through culturally appropriate public education campaigns.
- 1B:** Ensure established clearinghouses have reliable information.
- 1C:** Promote consumer access to established clearinghouses.

GOAL 2 Ensure Access to High Quality, Coordinated Care in the Setting of Choice



RECOMMENDATIONS:

- 2A:** Develop a comprehensive, accessible network of medical care and long-term services and support from diagnosis through end-of-life.
- 2B:** Advocate for accessible transportation systems.
- 2C:** Address the affordability of services across the long-term care continuum.

GOAL 3 Establish a Comprehensive Approach to Support Family Caregivers



RECOMMENDATIONS:

- 3A:** Acknowledge and invest in the informal, unpaid caregiver as a vital participant in care.
- 3B:** Sustain and expand California's statewide caregiver support network.

GOAL 4 **Develop an Alzheimer’s Proficient, Culturally Competent Workforce**

RECOMMENDATIONS:

- 4A:** Build and expand workforce capacity and competency throughout the continuum of care.
- 4B:** Improve dementia care capacity and competency of primary care providers.

GOAL 5 **Advance Research**



RECOMMENDATIONS:

- 5A:** Sustain and expand existing research efforts.
- 5B:** Increase participation in research.

GOAL 6 **Create a Coordinated State Infrastructure that Enhances the Delivery of Care**

RECOMMENDATIONS:

- 6A:** Implement a statewide strategy to coordinate, integrate, deliver and monitor the continuum of care and services.
- 6B:** Incorporate public health approaches to prepare for significant growth in Alzheimer’s disease.
- 6C:** Collect and use data to drive service development and delivery.



WHY DEVELOP A STATE PLAN FOR ALZHEIMER'S DISEASE?

Within the next twenty years, the number of Californians living with Alzheimer's disease will nearly double, growing to over 1.1 million. Due to a rapidly aging population, the increase will be even more dramatic among California's Asians and Latinos, who will see a tripling in those affected by 2030.

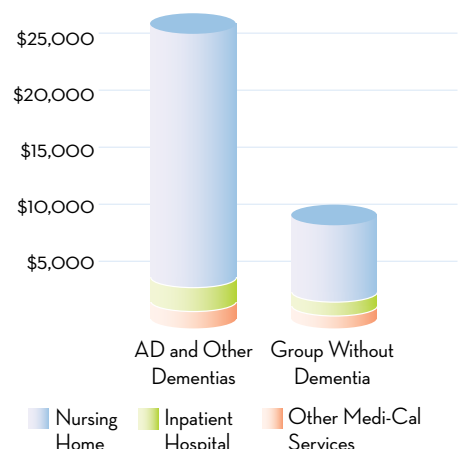
With the enormous growth in the number of Californians living with Alzheimer's disease there will be a substantial increase in family caregiving demands, both emotionally and financially. The economic value of unpaid care is expected to rise from \$37.2 billion to \$72.7 billion. Costs of formal services, including traditional medical and social supports, are expected to jump from \$16 billion to \$31.3 billion by 2030. Demographic data indicates that more older Californians are now living alone—without the support of a spouse, adult child or other relative—placing new demands on more costly, formal services.

The care and support of people living with Alzheimer's and related disorders also impacts state and federal governments. The cost to Medicare of patients with dementia is estimated to be three times the cost of enrollees without dementia.^{1,2} The cost to Medi-Cal is 2.5 times higher for these patients than for age-matched enrollees with much of the cost driven by nursing home expenditures. Unless the State takes steps to provide better support in the home and community for those who are affected by this condition, volume alone will cripple public resources.



"We need their help up in Sacramento. There's no way we can handle this on our own."
—63-year-old man, Inglewood

MEDI-CAL COSTS PER BENEFICIARY 60+ WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS COMPARED TO OTHER MEDI-CAL BENEFICIARIES: 2007 DOLLARS



*Note: The figures have been updated from the source using 2007 dollars³

What is the Status Quo in California?

Today, more than 10% of the 5.3 million Americans affected by Alzheimer's disease live in California. An estimated 1.1 million California family caregivers provide 952 million hours of unpaid care per year, with an annual economic value of slightly more than \$10 billion. The disease is now the sixth leading cause of death in California, having increased by 58.3% from 2000 to 2004 (the most recent period for which data is available) at a rate much higher than other leading causes of death.

The cost of caring for someone with Alzheimer's is staggering. Families provide almost three-quarters of care for Californians living with the disease, estimated to be worth \$72.7 billion annually. Yet, the State also incurs huge costs in managing the complexities of dementia. Most of these costs are driven by skilled nursing home expenditures.

Arguably, these costs could be reduced by an investment in home and community-based care.

Families and government are not alone in shouldering the rising cost of Alzheimer's care. California's business community faces as much as \$1.4 billion in lost productivity per year, as many employed caregivers must miss work, reduce their work hours, or change jobs. This, in turn, puts the caregiver at risk of losing health insurance and vital financial resources for his or her own future.



Planning for California's Future

The impact of Alzheimer's disease is already being felt across all sectors of society but the sheer number of aging baby boomers means the worst is yet to come. Nationally, there is a concerted effort to plan and prepare for the imminent public health threat of Alzheimer's disease. The U.S. Congress, the National Institutes of Health, The Centers for Disease Control and the Administration on Aging, among others, are working with the Alzheimer's Association—the leading voluntary health organization

in Alzheimer's care and support and the largest, private nonprofit funder of Alzheimer's research—to reduce the risk of dementia through the promotion of brain health and to improve care and support for all who are affected. The national effort is bolstered by careful planning at the state level. California joins 25 other states in developing its own Alzheimer's Disease State Plan designed to be an action plan for the next decade, 2011–2021.



ACTION PLAN 2011-2021

Whether you call it the “Silver Tsunami” or the “Gray Wave,” California is home to more people over age 65 than any other state, and that number will increase exponentially as the population ages.

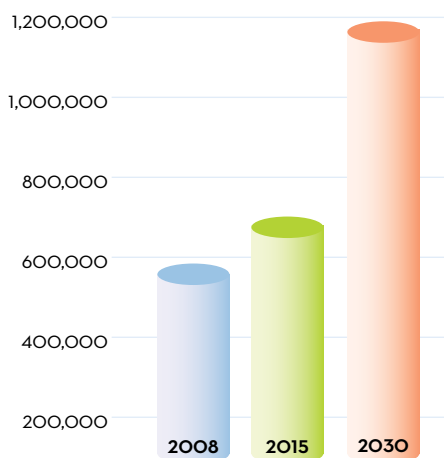
Among the approximately 3.3 million seniors in California are more than 588,000 people living with Alzheimer’s disease and related dementias. California also is home to 1.1 million family members who provide daily care for people with Alzheimer’s—a progressive, fatal brain disease for which there is no cure.

As staggering as these statistics are, they pale in comparison to the explosive growth of Alzheimer’s that will occur over the next 20 years as life expectancy increases and as people live longer with chronic, once fatal conditions. By the year 2030 the number of Californians with Alzheimer’s disease will double to nearly 1.2 million. Among Asian-Americans and

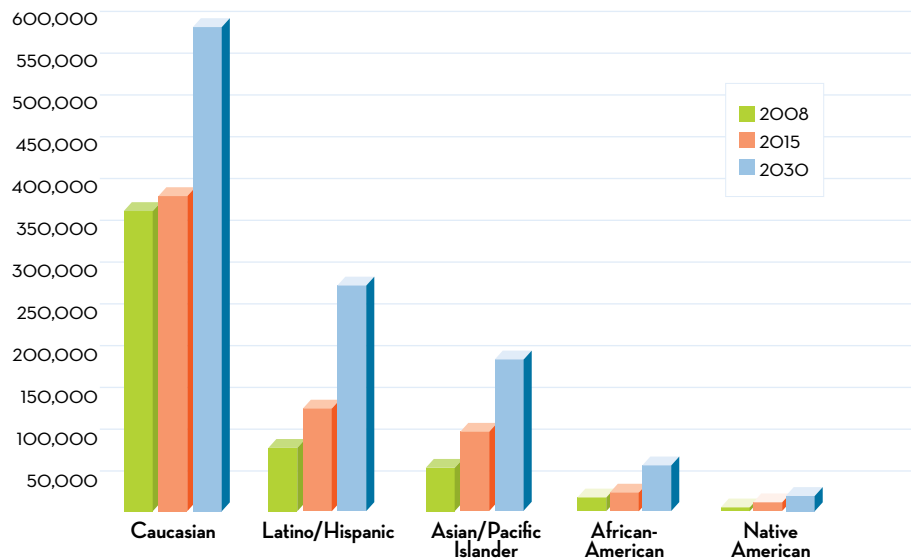
Latinos the numbers will triple. No matter what the ethnicity, one in six California baby boomers (those born between 1946 and 1964) will have Alzheimer’s disease.

This impending public health crisis presents challenges that compel policy leaders and key stakeholders to act. Many people with Alzheimer’s suffer from multiple chronic conditions, and the need for support is great. However, in recent years, many State programs and services for this population have been reduced, eroded or eliminated due to state budget actions. As California prepares for the “silver tsunami” and a doubling in the number of people living with Alzheimer’s disease, there is a significant, urgent need for a comprehensive strategic plan.

ESTIMATED NUMBER OF PEOPLE 55+ WITH ALZHEIMER’S DISEASE; 2008, 2015, 2030



**ESTIMATED NUMBER OF CALIFORNIANS 55+ WITH ALZHEIMER'S DISEASE
BY RACE/ETHNICITY; 2008, 2015, 2030**



In 2008, the Legislature began to address this crisis when it enacted Senate Bill 491 (Alquist), calling for California to develop an Alzheimer's Disease State Plan.⁴ Under the leadership of the State Alzheimer's Disease and Related Disorders Advisory Committee, a broad-based task force was appointed. Working with the Alzheimer's Association and the California Health and Human Services Agency, the task force engaged more than 2,500 individuals in plan development, including people living with the disease, under-represented communities, providers, family caregivers, researchers and educators.

The task force made special efforts to address the unique needs of California's culturally diverse population, in particular those who are at greater risk of developing Alzheimer's disease. Moreover, the task force sought out new ways to assist people living with dementia and their families through technological advances. This year-long effort to tackle the explosive growth of this disease and the enormous challenges it presents to families, businesses, government, and health and social service providers was launched on World Alzheimer's Day, September 21, 2009. It has yielded a 10-year action plan with guiding principles, goals and recommendations to address the escalation of Alzheimer's among California's population.

GOAL 1

Eliminate Stigma



Examples abound of fatal diseases that were previously considered taboo to discuss in public but are now in the mainstream, including HIV/AIDS, breast and prostate cancer. Through the courage of individuals suffering with these diseases who were willing to speak publicly, there is now increased awareness, education, and support. Because the public has gained a better understanding, many who once would have struggled in silence are now accepted and supported.

Unfortunately, Alzheimer's disease has not achieved this level of understanding and acceptance—negative stereotypes persist. It is now the most feared disease in America. This is compounded by discrimination against older adults, bias against people with cognitive impairments, and lack of awareness which has fueled continued stigmatization of people living with Alzheimer's disease and their families. Sadly, this stigma is prevalent not only among the public but among physicians and the families of those affected.



“It didn’t take long before my regular lunch group stopped calling. Soon, the phone stopped ringing altogether and it was just my husband and me all alone.”

—58-year-old Los Angeles woman with early onset Alzheimer’s disease

RECOMMENDATION 1A:

Heighten public awareness through culturally appropriate public education campaigns.

Strategies:

1. Pursue public, private, corporate and philanthropic funding sources for broad-based, statewide educational campaigns.
2. Develop content for public awareness campaigns to address a wide range of issues and audiences, including, but not limited to:
 - Identify early warning signs and effective strategies for obtaining diagnosis, treatment and support.
 - Educate on the cost of long-term care, limits of Medicare/ Medi-Cal coverage, personal responsibility, the importance of financial planning and the availability of the Community Living Assistance Services and Support Act (CLASS ACT), part of the national public education campaign Advance CLASS.
 - Collaborate with the Coalition for Compassionate Care and other organizational efforts to inform Californians of end-of-life care options and encourage appropriate use of advance health care directives and Physician Orders for Life Sustaining Treatment (POLST)⁵.
3. Promote positive images of people living with Alzheimer's disease and their caregivers to combat stigma and improve societal acceptance and integration.
4. Partner with the Department of Education to advance elementary and secondary level curriculum in schools to educate young Californians on the facts of aging with an emphasis on sensitivity to functional, physical and cognitive limitations.





RECOMMENDATION 1B:

Ensure established clearinghouses have reliable information.

Strategies:

1. Support public education campaign messages with an array of accessible websites that contain standardized Alzheimer's content.
2. Develop electronic links within existing state-supported websites to ensure that evidence-based and reliable Alzheimer's related educational information is available via the California Health and Human Services Agency and its departments: Aging, Health Care Services, Mental Health, Office of Statewide Health Planning and Development, Public Health and Social Services, as well as the Department of Motor Vehicles. Encourage date stamping for all web pages to promote current and relevant information.
3. Promote internet-based links to private websites and contact centers available on-demand 24/7, such as the Alzheimer's Association at 1-800-272-3900 and www.alz.org, for access after-hours and from remote locations.
4. Fully develop CalCare Net to cover all 58 California counties to augment and strengthen existing statewide consumer resources such as: 2-1-1 information line, Aging and Disability Resource Centers, Area Agencies on Aging, Caregiver Resource Centers and the California Alzheimer's Disease Centers as community resources affiliated with statewide entities. Disseminate these phone numbers, physical addresses and websites to the public.
5. Provide state-approved forms such as Durable Power of Attorney for Healthcare, Physician Orders for Life Sustaining Treatment (POLST) and other documents with helpful instructions and Frequently Asked Questions at no cost to the consumer via public libraries, resource centers and easily accessible websites.

RECOMMENDATION 1C:

Promote consumer access to established clearinghouses.

Strategy:

Consider adopting a template for information and educational materials to ensure they are available at appropriate literacy, language and legibility (font size) for a diverse population.

GOAL 2

Ensure Access to High Quality, Coordinated Care in the Setting of Choice



The public's perception, as well as that of many medical and health professionals, is that Alzheimer's disease diagnosis inevitably results in nursing home placement, which is outdated and wrong. Today less than 6% of those with Alzheimer's live in nursing homes. This is due in large part to the evolution of an array of home and community-based services in the 1980s and 1990s. At the same time, assisted living has emerged as a desirable residential alternative to nursing homes, often with a specialty focus on dementia care. Understanding care options, access to appropriate services and affordability of services are key to adequate caregiver support and enabling individuals with Alzheimer's disease to remain in their own homes.

RECOMMENDATION 2A:

Develop a comprehensive, accessible network of medical care and long-term services and support from diagnosis through end-of-life.

Strategies:

1. Advocate for adoption of the concept and characteristics of the "medical home" and "health care home" which provide coordinated, interdisciplinary team-based, person-centered Alzheimer's care, which includes comprehensive assessments, clear goals of care and regular re-evaluation to adapt to changing individual needs as the disease progresses.
2. Invest in and promote care management and care coordination to ease care transitions.



3. Maximize the availability of medical, preventive and home-based support services by promoting use of telemedicine and other technology that brings Alzheimer's expertise to sites that lack specialized skills or advanced training.



“Without the Adult Day Health Care program for my mother, I would have to quit my job and move in with her full-time or go against everything I was raised to believe and move her to a facility.”
—55-year-old male from El Centro

RECOMMENDATION 2B:

Advocate for accessible transportation systems.

Strategies:

1. Offer specialized dementia training to mobility managers in each Area Agency on Aging to promote development and ensure awareness of the transportation needs of people living with Alzheimer’s disease.
2. Ensure input to the state interagency group and the Project Advisory Committee working to improve human services transportation coordination, and implement the Mobility Action Plan in order to reflect the needs of people with Alzheimer’s.
3. Mandate that the Department of Motor Vehicles refers affected persons to transportation resources upon involuntary surrender, expiration or loss of driving privileges (e.g., license revocation) to address the unique transportation needs of persons in the early stages of Alzheimer’s disease.
4. Offer voluntary dementia training and certification of bus drivers, cab drivers and others who work in public transportation. Include large print signs and clear audio messages as criteria of certification.

RECOMMENDATION 2C:

Address the affordability of services across the long-term care continuum.

Strategies:

1. Preserve, restore and increase established home and community-based programs that effectively serve people with dementia and support their caregivers, including Alzheimer’s Day Care Resource Centers, Adult Day Health Care, In Home Supportive Services and the Program for All-Inclusive Care for the Elderly.
2. Improve licensed facilities that serve people with Alzheimer’s disease and related dementias, such as Residential Care Facilities for the Elderly and Nursing Facilities.
3. Promote best practices (such as Dementia Care Networks) to meet existing needs and foster replication and innovation to meet emerging needs.
4. Enhance legal protections for people living with the disease and caregivers to protect against abuse and neglect.

GOAL 3

Establish a Comprehensive Approach to Support Family Caregivers



The strain of caregiving takes an emotional and physical toll on women and men of all ages. It is well documented that often the person with Alzheimer's disease lives longer than their caregiver as the caregiver's own physical and mental health needs take a back seat to the daily demands and challenges of caregiving for a loved one. In the case of adult children who are working, caregiving negatively impacts the individual's ability to work outside the home. Adequate support can preserve the health status of the caregiver, improve care for their loved one and postpone or avoid residential placement.

RECOMMENDATION 3A:

Acknowledge and invest in the informal, unpaid caregiver as a vital participant in care.

Strategies:

1. Support, fund and expand the availability of professional guidance to help family caregivers navigate and manage myriad safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies and other effective interventions.
2. Empower family caregivers to register for, participate in and complete training in established educational programs offered by reliable public and not-for-profit organizations with specialized expertise in Alzheimer's disease.
3. Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings.
4. Encourage businesses and other workplace sites to offer family caregiver support services, e.g. flexible work hours, referrals and counseling through Employee Assistance Programs and other employee initiatives.
5. Secure foundation, corporate and nonprofit funding for effective statewide family caregiver training programs.



“I feel overwhelmed by caregiving responsibilities. I am plagued by grief, anger and depression. The disease has not only ruined my husband’s life, but mine too.”

—78-year-old woman, Santa Cruz

RECOMMENDATION 3B:

Sustain and expand California’s statewide caregiver support network.

Strategies:

1. Expand upon care coordination infrastructures that assist families in understanding the diagnosis, how to access services, future challenges and other issues.
2. Invest in the future of the Caregiver Resource Centers, Alzheimer’s Day Care Resource Centers, California Alzheimer’s Disease Centers, and other programs tailored to the unique needs of family caregivers.
3. Increase the availability of and referral to face-to-face and web-based support groups for family caregivers and persons in the early stage of the disease. Encourage referral by physicians, health professionals and community-based organizations.
4. Educate and enlist the faith community as community resources that can help reach out to and support family caregivers.
5. Promote the critical importance of establishing meaningful activities across the care continuum that are specifically adapted for the person with Alzheimer’s disease. This may include vocational, rehabilitative, social and recreational activities.

GOAL 4

Develop an Alzheimer's Proficient, Culturally Competent Workforce



Over the 3 to 20 year course of Alzheimer's disease, the individual affected will encounter the full spectrum of care providers from the least skilled and untrained to the most specialized in the medical field. Despite the reliance on paid staff and health professionals at every stage of the disease, there is a startling lack of training and basic information on detection, diagnosis, care, treatment and support services for Alzheimer's that cuts across every level of licensure. The dementia-knowledge gap leaves patients and families to their own devices to educate themselves and navigate a complex system of services and supports at a time when they most need professional guidance and advice.

RECOMMENDATION 4A:

Build and expand workforce capacity and competency throughout the continuum of care.

Strategies:

1. Support certification, licensure and degree programs that encourage working with older adults and persons with Alzheimer's disease and their caregivers.
2. Integrate a basic level of dementia sensitivity and disease education for all trainees in health related fields at the student and residency level.
3. Partner with licensing boards to mandate continuing education on Alzheimer's and related dementias as a condition of license renewal for doctors, nurses and other health professionals.
4. Establish public-private educational training partnerships that support health care workers with career ladders while offering employers a professional pipeline to aid in job recruitment and employee retention efforts.
5. Protect and promote the 10 California Alzheimer's Disease Centers as a training resource for community providers and licensed health professionals.
6. Mandate competency-based training for employees in specific settings (e.g., hospitals, nursing homes, home care workers, first responders), recognizing there are different strategies for different settings, levels of skill and licensure.

“My wife was seen by five different doctors before we finally got a diagnosis after nearly two years of pushing for answers.”
—52-year-old man, Chico



Recommendation 4A, cont'd.

7. Provide guidance on the new Medicare benefit that reimburses for an annual cognitive exam.
8. Create financial incentives (through tuition assistance, loan forgiveness, housing subsidies and stipends) to increase the number of health care professionals who pursue education and training to specialize in gerontology and geriatrics, particularly those who make a commitment to work in underserved communities.
9. Promote the use of Medicare coding to reimburse physicians and allied health professionals for family conferences and care planning meetings that educate and support family caregivers, promote future planning, and enhance the quality of medical care and support services.

RECOMMENDATION 4B

Improve dementia care capacity and competency of primary care providers.

Strategies:

1. Explore, endorse and disseminate dementia-specific curriculum and training programs tailored to primary care physicians, internists, general practitioners, physician assistants and nurse practitioners.
2. Regularly update and disseminate California's evidence-based *Guidelines for Alzheimer's Disease Management* to continually improve assessment, treatment, care coordination and follow-up support of the patient.
3. Strengthen primary care practices by dedicating staff support (or by providing access to a Dementia Care Manager) to coordinate care, manage individual cases, and develop formal mechanisms for referral to health care homes and community-based agencies that offer specialized expertise, social supports and mental health services.
4. Engage community physicians in research to encourage referral to and participation in clinical trials.
5. Protect and promote the California Alzheimer's Disease Centers as a tertiary referral resource for community physicians to support diagnosis and management of complex cases.
6. Educate clinicians on the criteria needed to refer and qualify a patient for hospice care to ensure that patients receive full benefit of the medical, health services and social supports offered at end-of-life.
7. Incorporate Alzheimer's educational materials for patients and family caregivers into digital libraries to enable physicians to store and forward information on electronic medical records.

GOAL 5

Advance Research



Research that discovers a way to delay the debilitating symptoms of Alzheimer's by just five years could cut prevalence rates in half.

Research is also the only means by which we will be able to cure and ultimately prevent this tragic disease. California has been a national leader in Alzheimer's disease research, and since 1985 the state has invested more than \$90.7 million in a network of ten California Alzheimer's Disease Centers that have leveraged the funds to raise more than \$544.5 million in federal and private research money. The voluntary income tax check-off has generated more than \$10 million in contributions for Alzheimer's research. But in 2009 the California Alzheimer's Disease Centers suffered deep cuts in state funding and all state-funded research and data collection were eliminated. Our prominence has diminished and California now stands to lose critical federal research funding because the state Alzheimer's infrastructure is disintegrating.



"Our central valley research center is at risk of losing its federal Alzheimer's distinction because our charge to conduct research and collect data was eliminated."

—psychologist, Fresno Alzheimer's Disease Center



RECOMMENDATION 5A:

Sustain and expand existing research efforts.

Strategies:

1. Preserve, restore and expand state funding of the ten California Alzheimer's Disease Centers, including the mandate to conduct research.
2. Promote increased taxpayer contributions to the tax check-off for Alzheimer's disease research.
3. Renew California's commitment to lead the nation in research, attracting world-class talent, federal research dollars and economic multipliers that create jobs and drive innovation by:
 - Exploring opportunities for California's special funds for research to support competitive funding for Alzheimer's disease, e.g., funds awarded by the California Institute for Regenerative Medicine.
 - Promoting research focused on the development of assistive technology, including both high and low tech assistive devices that adapt everyday environments for people with Alzheimer's.
 - Collaborating with industry and the life and biosciences sector.



RECOMMENDATION 5B:

Increase participation in research.

Strategies:

1. Educate the public on the availability, purpose and value of research, and encourage participation in clinical trials and other studies. Promote the Alzheimer's Association's TrialMatch™ as a resource for increasing participation in Alzheimer's clinical trials.
2. Collaborate with private, state and federal partners to increase participation of diverse populations in research studies.
3. Partner with the Coalition for Compassionate Care of California to include and promote sample language regarding research participation in standard advance health care directive forms.

GOAL 6

Create a Coordinated State Infrastructure that Enhances the Delivery of Care



The need for a strategic plan is more urgent in 2011 than ever before as the first baby boomers turn age 65. Furthermore, Healthy People 2020, which represents the nation's highest priorities for health promotion and disease prevention over the next decade, has now included Alzheimer's disease for the first time. The framework establishes measurable national public health goals and has underscored the recognition of the growing public health threat Alzheimer's and dementia pose to the nation. It also recognizes the health risks associated with the burden of family caregiving and compels California to develop more reliable measures of both Alzheimer's and family caregiving.

California funds multiple state departments within the California Health and Human Services Agency that oversee programs that serve similar and sometimes identical clients, with little or no coordination to ensure efficiency, improve outcomes, or gain economies of scale. Over several decades there have been numerous attempts to "realign," "reform," or "redesign" the broadly defined long-term care continuum in state government. There is a need for better cross-departmental collaboration on data collection and service oversight.



"My nonprofit agency reports to at least a dozen state and local departments and we have surveyors and evaluators from multiple jurisdictions in our center several times a year. It's maddening!"

—Licensed care provider,
Huntington Beach

RECOMMENDATION 6A:

Implement a statewide strategy to coordinate, integrate, deliver and monitor the continuum of care and services.

Strategies:

1. Establish mechanisms that will result in better coordination between state and local agencies, government departments and voluntary health organizations to enable California to better serve its aging and disabled population. For example, promote cross-training and joint visits by state regulators.
2. Create an integrated state long-term care financing budget that provides incentives for people to receive care in home and community-based settings and enables California to retain and reinvest cost savings back into the state's long-term care infrastructure.
3. Recognize and address the financial burden of caregiving and work to protect spouses from impoverishment at all levels of care.
4. Provide regular training to regulators on best practices in dementia care to improve consistency and continuity between settings.
5. Increase funding for medical care and long-term services and support through alternative financing mechanisms such as expansion of the use of Medicaid waivers or "provider fees."





RECOMMENDATION 6B:
Incorporate public health approaches to prepare for significant growth in Alzheimer’s disease.

Strategies:

1. Recognize caregiving as a health risk factor that warrants public health attention to incentivize health professionals to acknowledge and address the issue.
2. Coordinate with organizations that are actively working to reduce risk factors such as diabetes and heart disease to promote disease prevention and brain health.
3. Promote brain health initiatives to reduce risk factors, especially in ethnically diverse communities.
4. Collaborate with nonprofit hospitals to assist in meeting their legislative mandate to conduct a community needs assessment and disperse community benefit funds to local agencies working to improve health status of people living with Alzheimer’s disease and their caregivers.⁶

RECOMMENDATION 6C:
Collect and use data to drive service development and delivery.

Strategies:

1. Increase surveillance of incidence of Alzheimer’s disease and the impact of caregiving through the Behavioral Risk Factor Surveillance System (BRFSS), California Health Interview Survey (CHIS), the Healthcare Effectiveness Data and Information Set (HEDIS) and other surveys.
2. Promote common data elements and uniform data collection to accurately capture the population with cognitive impairments eligible for or served by California’s publicly funded aging and disability programs.
3. Reinstate data collection activities that have been eliminated as a result of budget cuts, e.g., California Alzheimer’s Disease Centers and the Family Caregiver Alliance.
4. Use available data to assist in program refinement, grant submissions and implementation of California’s Alzheimer’s Disease State Plan.



FINANCING THE STATE PLAN: RECOMMENDATIONS, CHALLENGES, AND OPPORTUNITIES

Given California's ongoing budget crisis, the Alzheimer's Disease State Plan addresses financing as a stand-alone topic. Funding is the underlying issue that generally drives policy decisions, impacts access to and quality of care, determines care options, and dictates choices regarding care setting. Recognizing the importance of this single subject, sixteen state and national experts were invited to contribute their insights and ideas.

In a series of phone interviews, experts shared their frustrations with "siloed" government funding streams, categorical programs, discriminatory eligibility requirements, under-funding of home and community-based programs and services, and the need for more personal responsibility to share in the cost of long-term care in the future. The interviewees identified three common themes:



"In public policy, we know that things get done when powerful constituencies are behind them; we need to help drive that demand."
—*financing expert*

1. In terms of cost-containment, avoiding or forestalling acute and long-term institutionalization is the highest priority.
2. Accessing disparate community-based services is problematic and time-consuming; improving communication and financial integration among the services would benefit caregivers immeasurably.
3. Providing sufficient training and support of family caregivers is vital. The ability of family members and friends to care for their loved one and adequately handle the challenges involved is the single most important element for avoidance of premature or inappropriate institutional placement.

Areas of Exploration

In addition, the group identified five areas for further exploration by California policy makers:

1. Utilize public funding more efficiently

Many of those interviewed propose that a carefully designed, financially integrated, coordinated care program would improve the services provided to patients and their caregivers, with the important goal of reducing unwarranted and expensive acute care. Several states have Medicaid waiver programs allowing them to combine all their long-term care dollars, tighten standards for nursing home placement and expand community-based services starting with the most frail population subgroups. A strongly held sentiment is the need to implement programs that build and wrap services around the client as opposed to programs that simply reduce payments to institutional providers.

Inefficiency in public sector programs is not limited to Medicare. In California, there is little connection between the county-designated services, resulting in much duplication of databases and expensive administrative functions. To improve services and efficiency, strong state leadership is needed.

Many interviewees applaud PACE (Program of All-Inclusive Care for the Elderly) as an excellent model for coordinating services with efficient use of Medicare and Medicaid dollars.

Yet even PACE—with its highly regulated structure—does not allow the flexibility or economies of scale that are needed to expand services and increase utilization. The concept of PACE's integrated services and funding are sound. But this needs to move a step further where a bundled payment can be applied to all services that are specific to the unique needs of Alzheimer's families. Programs serving people with developmental disabilities are lauded for their ability to individualize the funding/support needs of each person, eliminating the cookie-cutter approach to service delivery.

All interviewees concur that the best service models keep people with Alzheimer's disease out of nursing homes and avoid hospitalizations by providing affordable, high quality in-home supportive services and caregiver training. There are a variety of randomized trials being conducted in different states, augmenting care coordination and studying the impact on patients, caregivers and acute and skilled nursing facility use; several have proven to be cost neutral or demonstrated a cost benefit.





“Passage of the CLASS Act was a key milestone and important recognition of the need for personal financial planning for long-term care.”

—financing expert

2. Take advantage of national emphasis on innovation

Passage of the federal health care reform in 2010 opened many doors for funding innovation. The new health care law offers funding opportunities for developing and evaluating models of service delivery, financing and staffing. There is particular emphasis on developing effective and efficient ways of managing chronic illnesses such as Alzheimer’s disease, for which a major portion of healthcare dollars are spent; the Centers for Innovation under the Centers for Medicaid and Medicare Services (CMS) will sponsor a variety of projects. Among the suggestions:

- Add Alzheimer’s disease to chronic disease self-management programs now being studied through initiatives under national Comparative Effectiveness Research grants.
- Test fee bundling arrangements with Alzheimer’s disease patients when they are hospitalized for other medical problems, thus expanding coordination of the necessary follow-up care.
- Use bundled payments based in the physician’s office that include diagnosis and four months of assistance for the person and family to help connect them to community services.
- Take advantage of the resurgence of managed care (and introduction of Accountable Care Organizations) to reinforce a coordinated approach to meeting medical and social service needs.
- Combine Medicare Advantage plans with a private pay component to boost the services available in an integrated service model.
- Develop a national model similar to hospice, where multiple service components—medical, psychosocial, nursing, attendant care—are included in one package.
- Push for a greater role for advance practice nurses. Alzheimer’s disease continues to be under-diagnosed and there are insufficient numbers of geriatricians and primary care providers.



3. Advance personal investment strategies

Some interviewees are skeptical that even creative public funding would be sufficient. The current economic environment coupled with the bleak financial forecast for Medicare does not bode well for funding the types of non-medical services required by people living with Alzheimer's disease and their family caregivers. Strategies that focus on individual investment may be the most realistic.

The Community Living Assistance and Supportive Services Act (CLASS Act), a new federal public-private partnership for employer-based long-term care insurance is viewed by most as a very promising way of encouraging personal investment to meet the future long-term care needs of those with cognitive or physical disabilities. The biggest concern is that it is voluntary, requiring employers to offer it and a meaningful percent of employees to participate for there to be a significant impact. Nevertheless, most are hopeful and excited about the potential for helping people living with Alzheimer's disease stay in their home as long as possible.

Long-term care insurance has been around for decades; California's Partnership for Long-Term Care brought the public and private sectors together to create a program, but enrollment continues to be minimal. Lack of public understanding about government assistance for support services and medical care impacts decisions about long-term care insurance. Most mistakenly believe that federal entitlement programs cover the cost of care late in life.

Reverse home mortgages offer the ability to use a person's home equity to contribute meaningfully to financing in-home support services or other needed assistance. Participation has been low in California, and more effort needs to be applied to make it affordable and appealing. Closing costs are a major expense; if Medicaid helped to cover those costs, this investment would pay off with those who can avoid reliance on state and federal coffers.

Other ways to encourage individual savings include using tax credits or pre-tax dollars for caregiver support services. Most people are unaware that an employer's 125 cafeteria plan can be used for dependent care as well as child care.



“Employers have taken notice of ‘presenteeism,’ the term that describes employees distracted by caregiving responsibilities outside of the workplace.”
—financing expert

4. Rally private sector support

The State Plan was made possible by private and philanthropic support. Naturally, implementation of the plan and its goals, recommendations and strategies will require the support of the broader community as government alone cannot address or solve the myriad issues related to dementia.

Those interviewed had a variety of suggestions for using the private sector—corporate philanthropy, foundations, large employers—to augment Alzheimer’s services. For example, faith-based and local non-profits can establish new caregiver training programs and organize volunteers to help provide direct services. Many may need financial assistance to do so and private sector funders might ‘adopt’ such programs. Public sector programs, as well, are often unable to function at the needed capacity and supplementing public dollars with private funds is one approach to increasing services.

Underwriting community programs is not new, but it takes targeted lobbying efforts to promote this. In California, all non-profit hospitals have a community benefits obligation, in which they provide funding each year to help support non-profit or public programs that meet an identified

community need. While it is at the discretion of the hospitals to determine which needs are paramount, supporting Alzheimer’s programs would certainly qualify as a community benefit.

Large and small corporations with a strong connection to their communities are also likely candidates for underwriting local programs. Significant corporate or foundation funding is difficult to maintain over a long period. This funding is particularly useful for short-term intense efforts like public awareness campaigns or to launch pilot projects. Projects that emphasize an evidence-based approach hold great appeal.

Some of those interviewed are optimistic that large employers would step up and provide employee benefits that help with the challenges of Alzheimer’s caregiving. The newly coined term “presenteeism”—when employees are working but distracted by the pressures of caregiving—will become a more significant issue as the boomers age. These employee benefits need not be elaborate: even something as simple as a care coordination counselor and referral services through an Employee Assistance Program could be helpful.



5. Establish dedicated Alzheimer's funding

This is a stand-alone category because it is a strategic designation for funding that could apply to all funding sources. The public prefers earmarking contributions for a very specific purpose, such as Alzheimer's disease research. This could be voluntary as is the case on California's state tax form or through payroll deduction, or involuntary such as an excise tax on particular consumer products (e.g., sodas and other sin taxes).

Other Financing Alternatives Also Under Consideration

In addition to the financing experts interviewed for this report, other thought leaders are exploring creative uses of Medicaid and Medicare dollars as well as advantageous formulas for California. Of note is the report *Home and Community Based Long-Term Care Recommendations to Improve Access for Californians*, in which Robert Mollica, Ed.D., and Leslie Hendrickson, Ph.D., enumerate many options for California policymakers to pursue, including:

- Using the Medicaid Section 1115 waiver renewal to strengthen care coordination and management so as to reduce the use of institutional services and increase use of home and community-based services.
- Exploring how to expand home and community-based Medicaid waivers.
- Creating a unified long-term care budget.
- Considering nursing home reimbursement changes such as adopting a case-mix reimbursement system and a facility occupancy provision.
- Reinvesting savings from institutional care in home and community-based programs.
- Expanding the use of provider fees for community-based programs in order to draw down more federal funds.
- Developing a long-term care data base to support funding efforts.

MEASURES OF SUCCESS



Thousands of Californians are invested in the success of the State Plan, and they are committed to implementing policies and making systems changes that minimize societal stigma and improve detection, diagnosis, treatment and care for individuals and families impacted by the disease. Full implementation of the Alzheimer's Disease State Plan—including next steps, action, advocacy and policy changes—will depend on a collaborative effort among many interested stakeholders.



By statute (Senate Bill 491; Chapter 339), the California Health and Human Services Agency's Alzheimer's Disease and Related Disorders Advisory Committee holds responsibility for oversight and monitoring of the plan. This multi-disciplinary group is charged with tracking progress and periodically updating California's plan. In the spirit of SB 491 and in light of the current budget climate, it is expected that the Advisory Committee will continue to partner with the private sector and seek greater collaboration within state government to achieve the goals, recommendations and strategies outlined in California's plan.

Going forward, the Alzheimer's Disease and Related Disorders Advisory Committee will request the cooperation and participation of the California Council of the Alzheimer's Association and other interested partners in developing an initial two-year action plan that will be the basis for operationalizing immediate strategies to implement

the Alzheimer's Disease State Plan. Over the next 10 years, a total of five, two-year action plans will be developed and will be used as the basis for monitoring annual progress in implementing the Plan, as well as updating it to keep abreast of changes in the health and long-term care, political and scientific landscapes.

California's plan was envisioned, developed, produced and disseminated as a public-private partnership. Therefore, full implementation and timely execution of the plan will depend on the participation and contributions of a broad constituency under the leadership of the Alzheimer's Disease and Related Disorders Advisory Committee in partnership with the Alzheimer's Association.



REFERENCES

California's Alzheimer's Disease State Plan Task Force relied heavily upon and frequently referenced data, charts and figures from *Alzheimer's Disease Facts and Figures in California: Current Status and Future Projections* (2008). A precursor to the State Plan, the report was produced by the Alzheimer's Association and authored by Leslie Ross, Christine Brennan, Jennifer Nazareno and Pat Fox. The research team's methodology is described in the full report available at www.caalz.org.

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2. Bynum, J. (2009). *Characteristics, Costs, and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries* (Lebanon, N.H.: Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research).
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4. Senate Bill No. 491 (Chapter 339) An act to amend sections 1568.15 and 1568.17 of the Health and Safety Code relating to public health. www.leginfo.ca.gov, chaptered 09/26/2008.
5. *Physician Orders for Life-Sustaining Treatment (POLST)* approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST task force, www.capolst.org.
6. Senate Bill No. 697 (Chapter 812, Statutes of 1994) An act to amend Health and Safety Code sections 127340-127365 related to hospitals: community benefits.

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APPENDICES



Overview of Alzheimer's Disease and Other Dementias

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:

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

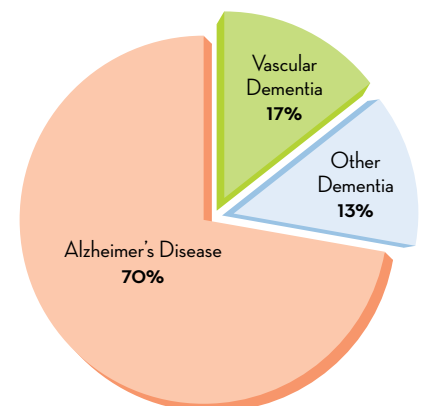


Causes of Dementia*

Alzheimer's disease is the most common type of dementia. Nationally, Alzheimer's accounts for 70% of all cases of dementia in Americans age 71 and over. Vascular dementia accounts for 17% 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%.

* Portions of this report contain information reprinted with permission from Alzheimer's Association, 2008 Alzheimer's Disease Facts and Figures, p. 13.2

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.

Related Dementias

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain. Alzheimer's disease is the most common form of dementia, accounting for 60 to 80 percent of cases. Other causes of dementia may include:

- Mild Cognitive Impairment
- Vascular Dementia
- Mixed Dementia
- Dementia with Lewy Bodies
- Parkinson's Disease
- Frontotemporal Dementia
- Creutzfeldt-Jakob Disease
- Normal Pressure Hydrocephalus
- Huntington's Disease
- Wernicke-Korsakoff Syndrome

10 Signs of Alzheimer's

Memory loss that disrupts daily life is not a typical part of aging. It may be a symptom of Alzheimer's disease, a fatal brain disease that causes a slow decline in memory, thinking and reasoning skills. Individuals who notice these symptoms should see a doctor.

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, work or leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood or personality

Risk Factors for Alzheimer's

Scientists have identified factors that increase the risk of Alzheimer's. While the greatest risk factor is advancing age, many who advance even into their nineties do not have Alzheimer's disease. While family history and associated genetic influences are important predictors, many family members of those with Alzheimer's will not develop this condition. Thus, identifying other disease modifying factors is critically important.

Research is now beginning to reveal clues about other risk factors we may be able to influence through general lifestyle and wellness choices and effective management of other health conditions.

- Head trauma
- Heart-head connection
- Associated health and environmental conditions for Latinos and African-Americans who are at greater risk

The Healthy Brain Initiative: A National Public Health Roadmap to Maintaining Cognitive Health, produced jointly by the Alzheimer's Association and the Centers for Disease Control, is available at www.alz.org.



Resources for Families 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. 237
Los Angeles, CA 90063
(323) 881-0574

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

Inland Empire
9213 Archibald Ave.
Rancho Cucamonga, CA 91730
(909) 944-9680

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

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
80 Nathwood Road, Ste. 302
Camarillo, Ca 93010
(805) 484-6028

ORANGE COUNTY

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

SAN DIEGO/IMPERIAL

6632 Convoy Court
San Diego, CA 92111
(858) 492-4400

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

NATIONAL HEADQUARTERS

Alzheimer's Association
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601
website: 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

California Alzheimer's Disease Centers (CADCs)

Resources for Diagnosis, Treatment, Training, Support and Research Opportunities

NORTHERN CALIFORNIA CENTERS:

Fresno CADC

UC San Francisco/Fresno Alzheimer's and Memory Center
3313 North Hilliard Lane, Fresno, California 93726
(559) 227-4810
Email: alz@fresno.ucsf.edu
<http://fserve.fresno.ucsf.edu/alzheimer/>

Sacramento CADC

UC Davis/Sacramento
4860 Y Street, Suite 3900, Sacramento, CA 95817
(916) 734-5496
<http://alzheimer.ucdavis.edu/>

Martinez CADC

UC Davis/Martinez
150 Muir Road (127A), Martinez, CA 94553
(925) 372-2485
<http://alzheimer.ucdavis.edu/>

San Francisco CADC

UC San Francisco
350 Parnassus Avenue, Suite 905
San Francisco, CA 94143
(415) 476-6880
<http://www.memory.ucsf.edu/>

Palo Alto CADC

Stanford University
SU/VA Alzheimer's Center (116F-PAD)
3801 Miranda Avenue, Palo Alto, CA 94304
(650) 858-3915 (Clinic)
<http://CADC.stanford.edu/>

SOUTHERN CALIFORNIA CENTERS:

CADC General Information Contact:

Department of Health: (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 CADC

UC Irvine Institute for Memory Impairments and Neurological Disorders
1100 Gotschalk Medical Plaza, Irvine, CA 92697
(949) 824-2382
<http://www.alz.uci.edu/>

USC/LA CADC

1510 San Pablo Street, HCC 600
Los Angeles, California 90033
(323) 442-7600
Email: gsc@usc.edu
http://www.usc.edu/schools/medicine/departments/psychiatry_behavioralsciences/research/gsc/

Los Angeles/UCLA CADC

Los Angeles/San Fernando Valley
Reed Neurological Research Building
10911 Weyburn Avenue, 2nd Floor
Los Angeles, CA 90095-7226
General information: (310) 794-3665
UCLA appointments: (310) 794-1195
Cintinela Freeman: (323) 563-5915
Olive View/UCLA Center: (818) 364-1555
Email: adc@ucla.edu
<http://www.adc.ucla.edu/>

San Diego CADC

UC San Diego
SOCARE/UCSD CADC
9500 Gilman Drive - 0948
La Jolla, CA 92093-0948
(858) 622-5800

Caregiver Resource Centers (CRCs)

Family Education, Support, Respite and Legal Referrals

Bay Area Caregiver Resource Center/

Family Caregiver Alliance

Statewide Resources Consultant
180 Montgomery Street, Suite 1100
San Francisco, California 94104
(415) 434-3388 or (800) 445-8106
www.caregiver.org • 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
(714) 870-3530 or (800) 543-8312
www.caregiveroc.org • ocrc@sjf.stjoe.org
Orange County

Coast Caregiver Resource Center

1528 Chapala Street, Suite 302
Santa Barbara, CA 93101
(805) 962-3600 or (800) 443-1236
www.coastcrc.org • info@coastcrc.org
San Luis Obispo, Santa Barbara & Ventura Counties

Del Mar Caregiver Resource Center

736 Chestnut Street, Suite F
Santa Cruz, California 95060
(831) 459-6639 or (800) 624-8304
www.delmarcaregiver.org • info@delmarcaregiver.org
Monterey, San Benito & Santa Cruz Counties

Del Oro Caregiver Resource Center

5723A Marconi Avenue
Carmichael, California 95608
(916) 971-0893 or (800) 635-0220
www.deloro.org • crc@deloro.org
Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Sutter, Yolo & Yuba Counties

Inland Caregiver Resource Center

1420 East Cooley Drive, Suite 100
Colton, California 92324
(909) 514-1404 or (800) 675-6694
www.inlandcaregivers.com
info@inlandcaregivers.org
Inyo, Mono, Riverside & San Bernardino Counties

Los Angeles Caregiver Resource Center

3715 McClintock Avenue
Los Angeles, California 90089-0191
(213) 821-7777 or (800) 540-4442
www.losangelescrc.org • lacrc@usc.edu
Los Angeles County

Mountain Caregiver Resource Center

2491 Carmichael Drive, Suite 400
Chico, California 95928
(530) 898-5925 or (800) 995-0878
www.caregiverresources.org/MCRC_home
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
(707) 542-0282 or (800) 834-1636
www.redwoodcrc.org • 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
(858) 268-4432 or (800) 827-1008
www.scrcc.signonsandiego.com
scrcc@caregivercenter.org
San Diego & Imperial Counties

Valley Caregiver Resource Center

3845 North Clark Street, Suite 201
Fresno, California 93726
(559) 224-9154 or (800) 541-8614
www.valleycrc.org • info@valleycrc.org
Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare & Tuolumne Counties

Historical Context and Recent Efforts

In 1987, California's leaders produced a groundbreaking report that led to policy changes, new state programs, and investments in research. The original plan built upon a strong foundation; California was already home to several flagship programs, including:

- A.** Alzheimer's Day Care Resource Centers (ADCRC)
- B.** Alzheimer's Disease Program (California's 10 university-based Alzheimer's Disease Centers)
- C.** Caregiver Resource Centers (CRC) and Family Caregiver Alliance (FCA) [formerly the Family Survival Project]

For decades, California was heralded as a national model for Alzheimer's care and service delivery due to the presence of the aforementioned programs as well as other pioneering work such as:

- Dementia-specific training requirements for Certified Nurse Aides (CNAs)
- Development of the first evidence-based *Guidelines for Alzheimer's Disease Management*
- Program for All-Inclusive Care for the Elderly (PACE)
- Training and supervision standards for Alzheimer's Special Care Units in residential care and skilled nursing facilities



- Statewide consumer education campaign: Partnering With Your Doctor
- State Agency-level Alzheimer's Disease and Related Disorders Advisory Committee
- State tax check-off program for Alzheimer's disease research

In recent years, many of these programs and services—the very ones that have helped people living with Alzheimer's remain at home with community supports—have been reduced, eroded or eliminated due to state budget actions. As California prepares for the “silver tsunami” and a doubling in the number of people living with Alzheimer's disease, the need for a comprehensive strategic plan to consider the needs of people living with Alzheimer's, many of whom suffer from multiple chronic conditions, compelled policy leaders and key stakeholders to act.

State Plan Development Provided Widespread Opportunities for Community Involvement

Foundation support enabled California to embark on a robust, year-long planning process unmatched by any other state. Unique to California's planning process was the diligence with which the State Plan Task Force reached out to and included people living with Alzheimer's disease and their caregivers. Over the course of the year, more than 2,500 individuals contributed to the dialogue that led to final goals, recommendations and strategies for the future.

Community involvement included:

- Fifteen community meetings convened by the Alzheimer's Association from Eureka to San Diego in which more than 830 family and professional caregivers participated.
- Eight small-group, facilitated conversations with 90 people in the early stages of Alzheimer's disease.
- Three community meetings, attended by nearly 200 family and professional caregivers, hosted at local program sites providing services to ethnically and culturally diverse populations, including African American, Asian-Pacific Islander and Latino.

- An end-of-life forum attended by 50 individuals and jointly sponsored by the Alzheimer's Association and the California Coalition for Compassionate Care, included an expert panel and facilitated caregiver discussion to address advance care planning, hospice and palliative care, and the new Physicians Order for Life Sustaining Treatment (POLST) form.
- An on-line caregiver survey in English, Spanish, Korean, Vietnamese and Chinese had 1,320 respondents, 800 of whom added written comments at the end of the survey.
- Finally, State Plan representatives joined the California Commission on Aging at their regularly scheduled meetings to provide updates and solicit input into issues and the planning process.

Due to the protracted state budget crisis, developing and considering creative long-term care financing strategies was a high priority for the Task Force. Input was gathered from sixteen state and national leaders through one-on-one interviews. Individuals offered their personal perspectives and expert opinions related to funding Alzheimer's care.

Emerging Themes From Statewide Community Forums

California's Alzheimer's community informed the Alzheimer's State Plan Task Force in four key areas that permeate the entire Plan and influenced the final goals, recommendations and strategies.

1. The role of an Alzheimer's caregiver is overwhelming, exhausting, frustrating and expensive, irrespective of socioeconomic status, geographic location, gender, culture or ethnicity.
2. People living with the disease and their family members entrust their care to primary care physicians who often lack Alzheimer's expertise or who fail to effectively communicate a diagnosis or offer treatment, education and support options to the patient and caregiver.
3. Because there is no cure, Alzheimer's disease runs a long, progressive course which carries a stigma that debilitates and isolates individuals and families. Education and support are proven to be effective interventions though the majority of affected individuals and families are reluctant to seek the help they need because of societal stigmas.
4. Families are unprepared and ill-equipped to manage the cost of Alzheimer's care. The complexities of this disease require a full spectrum of medical and supportive services over many years' time. Many effective Alzheimer's programs and services are not covered by Medicare, Medi-Cal or private insurance. In addition, middle-income families are squeezed out of the long-term care marketplace because they do not qualify for public assistance but cannot afford private placement in a licensed facility.

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 PCR.

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.

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 health-care 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 or from the State Department of Public Health website: www.cdph.ca.gov/programs/alzheimers

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.

Glossary of Terms

Assisted Living

Assisted living is a licensed residential setting that provides 24-hour care and supervision to seniors who need assistance, but do not require around the clock nursing care. Assisted living communities provide assistance with Activities of Daily Living (ADLs), medication management, social activities, housekeeping, meals, transportation, and may offer dementia care programs or health-related services.

Caregiver

The term caregiver refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help: a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a father with Alzheimer's disease; a son with traumatic brain injury; a partner with AIDS. **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, full time or part time, and can live with the person being cared for or live separately.

CLASS Act

The CLASS Act (Community Living Assistance Services and Support) is a voluntary, federally administered, consumer-financed insurance plan. It became law when President Obama signed the Patient Protection and Affordable Care Act (federal health care reform law) on March 23, 2010. The CLASS plan provides those who participate with cash to help pay for needed assistance, if they become functionally limited, in a place they call home—from independent living to a nursing facility—if they choose.

Dementia Care Networks

A series of programs funded by U.S. Administration on Aging grants to the State of California and the Alzheimer's Association to create community-based social and support services for underserved populations in targeted locations. The model partners Alzheimer's Association Chapters and ethnically-focused agencies to develop culturally competent services.

Hospice Care

Designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home—in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient's emotional, social, and spiritual needs as well as medical symptoms as part of treating the whole person.

In Home Supportive Services (IHSS)

The IHSS Program will help pay for services provided to you so that you can remain safely in your own home. To be eligible, you must be over 65 years of age, or disabled, or blind. Disabled children are also eligible for IHSS. IHSS is considered an alternative to out-of-home care, such as nursing homes or board and care facilities. The types of services which can be authorized through IHSS are housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision for the mentally impaired.

Long-term care

A variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Long-term care can be provided at home, in the community, in assisted living or in nursing homes. It is important to remember that you may need long-term care at any age. A study by the U.S. Department of Health and Human Services says that people who reach age 65 will likely have a 40 percent chance of entering a nursing home. About 10 percent of the people who enter a nursing home will stay there five years or more.

Medical Home

The American Academy of Pediatrics (AAP) introduced the medical home concept in 1967, initially referring to a central location for archiving a child's medical record. In its 2002 policy statement, the AAP expanded the medical home concept to include these operational characteristics: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care. The American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) have since developed their own models for improving patient care called the "medical home" (AAFP, 2004) or "advanced medical home" (ACP, 2006).

The Patient Centered Medical Home (PCMH) is an approach to providing comprehensive primary care for children, youth and adults. The PCMH is a health care setting that facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient's family.

Medicaid

Medicaid (Medi-Cal in California) is health insurance available to certain people and families who have limited income and resources. Eligibility may also depend on how old you are and whether you are pregnant, whether you are blind or have other disabilities, and whether you are a U.S. citizen or a lawfully admitted immigrant. People with Medicaid may also get coverage for services such as nursing home care.

Medicare

Medicare is the federal health insurance for people age 65 or older, under age 65 with certain disabilities, and any age with permanent kidney failure. You must have entered the United States lawfully and have lived here for 5 years to be eligible for Medicare. Medicare has two parts: Medicare Part A (Hospital Insurance) helps pay for inpatient care you get in a hospital; Medicare Part B (Medical Insurance) helps pay for medically-necessary doctors' services and other outpatient care.

Palliative Care

Palliative care is the medical specialty focused on improving the quality of life of people facing serious illness. Emphasis is placed on pain and symptom management, communication and coordinated care. Palliative care is appropriate from the time of diagnosis and can be provided along with curative treatment.

Patient-Centered Care

In the setting of primary care, and specifically family practice, patient-centered concepts incorporate six interactive components. The first component is the physician's exploration of both the patients' disease and four dimensions of the illness experience including: their feelings about being ill, their ideas about what is wrong with them, the impact of the problem on their daily functioning, and their expectations of what should be done. The second

component is the physician's understanding of the whole person. The third component is the patient and physician finding common ground regarding management. In the fourth component the physician incorporates prevention and health promotion into the visit. The fifth component is the enhancement of the patient-physician relationship. Finally, the sixth component requires that patient-centered practice be realistic. Being patient centered does not mean that physicians abdicate control to the patients but rather that they find common ground in understanding the patients and more fully respond to their unique needs.

Person-Centered Care

Person-centered care is a key concept guiding efforts to improve long-term care. Elements of person-centered care include personhood, knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and a supportive physical and organizational environment. An example is allowing the resident in a facility to have a daily bath at a time that is appropriate for her.

Residential Care Facility for the Elderly (RCFE)

RCFEs provide care, supervision and assistance with activities of daily living, such as bathing and grooming. They may also provide incidental medical services under special care plans. The facilities provide services to persons 60 years of age and over and persons under 60 with compatible needs. RCFEs may also be known as assisted living facilities, retirement homes and board and care homes. The facilities can range in size from six beds or less to over 100 beds. The residents in these facilities require varying levels of personal care and protective supervision. Because of the wide range of services offered by RCFEs, consumers should look closely at the programs of each facility to see if the services will meet their needs.

Skilled Nursing Facility

Skilled nursing facilities (also known as nursing homes) provide housing, meals, skilled and intensive medical care, personal care, social services, and social activities to people who have physical or behavioral conditions that prevent them from living alone. Medicare and private insurance typically cover short-term nursing home stays for skilled care needs, but they do not cover long-term stays. Cost of care in one of California's 1,300 nursing facilities averages \$6,700 per month. Indigent care programs such as Medi-Cal pay for much of this care.

Care in these facilities ranges from personal assistance and limited nursing care for ambulatory residents to 24-hour skilled medical care to accommodate the seriously ill, either based in a hospital or independently operated facility. Nursing homes with this type of intensive care are often the best option for people with debilitating illnesses or physical or mental limitations that require monitoring and care from medical experts.

Supplemental Social Security Income

The SSI Program is a federally funded program which provides income support to you if you are aged 65 or older, blind or disabled. SSI benefits are also available to qualified blind or disabled children. The SSP Program is the state program which augments SSI. Both SSI and SSP benefits are administered by the Social Security Administration (SSA). Eligibility for both programs is determined by SSA using Federal criteria. If you qualify for SSI, you qualify for SSP. The benefits are in the form of cash assistance.



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