

**The Alzheimer's Disease Program  
REPORT TO THE LEGISLATURE**

*Updates and Recommendations*

**As required by Senate Bill 613  
(Allen, Chapter 577, Statutes of 2015)**



**California Department of Public Health  
Center for Chronic Disease Prevention and Health Promotion  
Chronic Disease Control Branch**

**March 2018**

To obtain a copy of the, “Alzheimer’s Disease Program Report to the Legislature: Updates and Recommendations,” or if you have any questions, please contact the Alzheimer’s Disease Program staff at:

Terence Kelley, M.S. HCA  
Program Lead, Alzheimer’s Disease Program  
California Department of Public Health (CDPH)  
PO Box 997377, MS 7210  
Sacramento, CA 95899-7377  
Phone (916) 552-9952  
Email: [Terence.kelley@cdph.ca.gov](mailto:Terence.kelley@cdph.ca.gov)

The content included in this report may be reproduced with the following citation:  
Nunez De Ybarra J, Kelley T, Robinson S (2017). Alzheimer’s Disease Program Report to the Legislature: Updates and Recommendations on the Guideline for Alzheimer’s Disease Management. Sacramento, California: Chronic Disease Control Branch, California Department of Public Health, 2017.

Internet Address: [CDPH Alzheimer's Disease Program](https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/AlzheimersDiseaseProgram.aspx)  
(<https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/AlzheimersDiseaseProgram.aspx>)

## TABLE OF CONTENTS

<b>EXECUTIVE SUMMARY .....</b>	<b>4</b>
<b>1. PURPOSE AND LEGISLATIVE REQUIREMENT.....</b>	<b>5</b>
<b>2. WORKING GROUP MEETINGS.....</b>	<b>5</b>
<b>3. 2017 UPDATE: GUIDELINE FOR ALZHEIMER'S DISEASE MANAGEMENT .....</b>	<b>5</b>
<b>4. GUIDELINE WORKING GROUP RECOMMENDATIONS.....</b>	<b>7</b>
<b>5. CONCLUSION .....</b>	<b>7</b>
<b>6. RESOURCES FOR THE PUBLIC .....</b>	<b>8</b>
<b>7. LIST OF ACRONYMS AND GLOSSARY OF TERMS .....</b>	<b>8</b>
<b>8. REFERENCES.....</b>	<b>8</b>

## EXECUTIVE SUMMARY

---

***Alzheimer's disease is a degenerative brain disease and the most common cause of dementia (Wilson et al., 2012).***

---

In 1984, the State of California established the Alzheimer's Disease Program (ADP) through legislation that sought to relieve the human burden and economic cost associated with Alzheimer's disease and related dementias, and to assist in ultimately discovering the cause, treatment, and prevention of these diseases.

ADP, located in the Chronic Disease Control Branch (CDCB) of the California Department of Public Health (CDPH), was established pursuant to Assembly Bill 2225 (Felando, Chapter 1601, Statutes of 1984) and was expanded pursuant to Senate Bill (SB) 139 (Mello, Chapter 303, Statutes of 1988). The mission of ADP is to reduce the human burden and economic costs associated with Alzheimer's disease (AD) and related dementias, and ultimately, to assist in discovering the cause and treatment of this disease. A primary intent of this legislation was to establish a network of diagnostic and treatment centers at university medical centers throughout California. Since 1984, the California Alzheimer's Disease Centers (CADCs) have effectively improved dementia health care delivery, provided specialized training and education to health care professionals, and advanced the diagnosis and treatment of AD. California has been a national leader in Alzheimer's disease research, and since 1985, the state has invested more than \$90.7 million in the CADCs, which have leveraged the funds to raise more than \$544.5 million in federal and private research money (California State Plan for Alzheimer's Disease, 2011).

SB 613 (Allen, Chapter 577, Statutes of 2015) required CDPH to convene a multidisciplinary workgroup to update the 2008 Guideline for Alzheimer's Disease Management (Guideline) in California, and to submit a report from the workgroup to the Legislature, on or before March 1, 2017. Additionally, SB 613 permitted the workgroup to draw on evidence-based, peer-reviewed research and lessons learned from demonstration and pilot projects in updating the Guideline. The workgroup consisted of experts in AD detection, diagnosis, treatment, and support. The updated Guideline was approved by California Health and Human Services Agency on March 15, 2017, and has been posted on the CDPH/ADP website here: [2017 Guideline for Alzheimer's Disease Management in CA \(https://www.cdph.ca.gov/Programs/CCDC/DCDC/CDCB/CDPH%20Document%20Library/Non-ADA%20Compliant%20Docs%20%206%20Month%20Extension/Alzheimer's%20Disease%20Guidelines.pdf\)](https://www.cdph.ca.gov/Programs/CCDC/DCDC/CDCB/CDPH%20Document%20Library/Non-ADA%20Compliant%20Docs%20%206%20Month%20Extension/Alzheimer's%20Disease%20Guidelines.pdf).

The required legislative report includes an overview of the workgroup meetings that were held, the website link to the current 2017 Guideline, and recommendations from the working group that developed the Guideline. The current 2017 Guideline aligns with current legislation prescribed by SB 613 and is designed to improve AD management. The Guideline will assist primary care physicians (PCPs) with AD patients under their care, and offer resources for other forms of dementia including mild cognitive impairment. An update to the Guideline equips California PCPs with up-to date information and resources to better serve their patients with dementia. More people with AD live in California than in any other state (California State Plan for Alzheimer's Disease, 2011).

## 1. Purpose and Legislative Requirement

Chapter 577, Statutes 2015, SB 613 requires CDPH to convene a multidisciplinary workgroup to update the *2008 Guideline for Alzheimer's Disease Management in California* to address changes in the health care system, and to submit a report:

*“The department shall submit a report of the updates and recommendations from the working group to the Legislature on or before March 1, 2017. This report shall be submitted in compliance with Section 9795 of the Government Code.”*

## 2. Working Group Meetings

ADP, in partnership with stakeholders, conducted the working group comprised of stakeholder experts in AD, medical and clinical specialties and health system administration. Two working group meetings occurred, one on Monday, June 20, 2016, from 10:30 am – 3:30 pm located at the American Association of Retired Persons California State Office in Sacramento, California and one meeting on Wednesday, June 29, 2016, from 10 am – 3 pm at The California Endowment in Los Angeles, California. During the working group meeting, representatives from multiple interest groups attended, and the ADP solicited information from all working group representatives regarding any issues, concerns, or comments they had with respect to the new requirements. The working group was comprised of industry experts that included but was not limited to: gerontology specialists, neurology specialists, psychiatrists, psychologists, principle investigators from the CADCs, Office of the Patient Advocate Director, the Alzheimer's Association, and Alzheimer's Greater Los Angeles to revise the Guideline. The working group also consisted of affiliates from a variety of public and private health plans including, Inland Empire Health Plan, and State Departments, such as Department of Health Care Services and Department of Managed Health Care. Affiliates from non-profit organizations, such as the RAND Corporation were in attendance as well. ADP intends to continue collaboration and discussion with stakeholders on future Guideline updates.

## 3. 2017 Update: Guideline for Alzheimer's Disease Management

Since the 2008 Guidelines were released, significant changes have occurred in the State and national landscape. The 2017 update addresses changes in scientific evidence, clinical practice, and state and federal law. The working group<sup>1</sup> reviewed the 2008 Guideline and joined consensus on a number of changes. The new Guideline refers to changes in Medicare reimbursement such as the Medicare Annual Wellness Visit, references to the Centers for Disease Control and Prevention strategy for state and national partnerships through [The Healthy Brain Initiative](#), which emphasizes proven public health strategies such as monitoring and evaluation, education and training, policy development, and workforce competencies

Peer-reviewed articles in leading publications, such as the Journal of the American Medical Association (JAMA), describe the positive results of randomized, controlled trials in California, Indiana, and Ohio. The American Academy of Neurology, the American Geriatrics Society, and the American Association of Geriatric Psychiatry have endorsed the concept of dementia care management as documented in the following peer-reviewed journals: *the American Journal of Managed Care, Aging & Mental Health, The Gerontologist, Annals of Internal Medicine, and*

---

<sup>1</sup> Required by Senate Bill 613

*JAMA*. Among the outcomes described in these articles are reductions in behavioral and psychological symptoms of dementia, lower reported rates of caregiver distress and depression, higher social support and caregiver confidence, increased use of cholinesterase inhibitors to slow the progression of AD, and possible decreased use of higher cost medical services such as nursing homes, hospitals and emergency rooms. The 2017 Guideline contains four primary topic areas: assessment, care plan, education and support, as well as important considerations detailed below.

**1) *Assessment***

Focuses on addressing the patient's comorbid medical conditions, functional status, cognitive status, and behavioral symptoms, including possible psychotic symptoms and depression. The assessment should also address the patient's support system and decision-making capacity, and identify the primary caregiver who, in addition to other family members, is a critically important source for integrating medical care with education and support. Upon sudden changes or significant decline, and at least annually, conduct and document comorbid medical conditions, which may present with sudden worsening in cognition and function or changes in behavior, and could complicate management of dementia among other changes.

**2) *Care Plan***

Addresses areas such as disease management to discuss the progression and stages of the disease, and evaluate and manage comorbidities in context of dementia and prognosis. Care planning can also consist of promoting and referring the patient to social services and community support with the goals in mind to treat emotional, behavioral, and/or mood symptoms.

**3) *Education and Support***

Addresses the need for consultations involving the patient directly in care planning, treatment decisions and referrals to community resources. As the disease progresses, suggests appropriate home and community-based programs and services. Additionally, recommends linking the patient and caregiver to support organizations for culturally appropriate educational materials and referrals to community and government resources.

**4) *Important Considerations***

Discusses advance planning, which includes the importance of basic legal and financial planning as part of the care plan, and referrals for assistance. Includes capacity evaluations to assess the patient's decision-making skills and determines whether a legal surrogate has been or can be identified. In addition, monitors for evidence of and reports all suspicions of abuse (physical, financial, sexual, neglect, isolation, abandonment and/or abduction) to Adult Protective Services, Long-Term Care Ombudsman or the local police department, as required by law.

PCPs should be able to provide or recommend a wide variety of services beyond medical management of AD and comorbid conditions, including recommendations regarding psychosocial issues, assistance to families and caregivers, and referral to legal and financial

resources in the community. Many specialized services are available to help patients and families manage these aspects of AD, such as adult day services, respite care, and skilled nursing care, as well as helplines and outreach services operated by the Alzheimer's Association, Area Agencies on Aging, Councils on Aging, and Caregiver Resource Centers. However, it is important to recognize that the needs of people with AD and their families extend far beyond the realm of medical treatment, and that PCPs will be called upon to provide a wide spectrum of information and resources to assist them in dealing with this challenging, sometimes overwhelming condition.

ADP distributed the Guideline to the California Conference of Local Health Officers, which is an organization of the 61 legally appointed physician Health Officers in California, one from each of the 58 counties and three cities of Berkeley, Long Beach and Pasadena. Additionally, ADP distributed the Guideline to the Alzheimer's Association, which led dissemination efforts across the State to the California Primary Care Association, the California Academy of Family Physicians Foundation, and other professional trade associations. The CADCs will also use this Guideline for their PCP training and residency programs to help PCPs in offering comprehensive care to patients with AD and those who care for them over the course of their illness.

#### **4. Guideline Working Group Recommendations**

The overall consensus from the working group was that the 2017 Guideline should be user friendly with concise, relevant information. The working group adopted the following recommendations which included, but were not limited to, revising the Guideline to focus on earlier intervention, including information on new Medicare reimbursement of cognitive and functional assessments and a general philosophy around person-centered, team-based care. Also, clarifying that therapeutic interventions are helpful and PCPs should promote the use of cholinesterase inhibitors, the N-methyl-D-aspartate receptor (NMDA) antagonist and other medications, if clinically indicated, to treat cognitive decline. The working group noted that many health care practitioners incorporate elements of AD management, but evidence suggests the patient and family experience of comprehensive, coordinated dementia care is rare. Other adopted recommendations for the Guideline included that at least every six months the PCP conduct and document the patient's ability to manage finances and medications, as well as daily functioning, including feeding, bathing, dressing, mobility, toileting and continence.

In addition, the Guideline references specific cognitive screening tests designed to assist PCPs in detecting AD and related dementias and advises that PCPs should monitor changes in cognitive status using these screening tests e.g., MoCA (Montreal Cognitive Assessment), and the AD8 (Ascertian Dementia 8). The Guideline educates PCPs on the importance of linkages and referrals to community-based organizations and advising the patient and family of opportunities to participate in research through the Alzheimer's Association TrialMatch®. These updates are a critical step for CDPH in addressing the burden of AD in California and thus, the above-mentioned recommendations were adopted and included in the Guideline. This Guideline can assist policymakers, health care providers, community service organizations, and family caregivers to understand how to improve screening measures, diagnosis, and access to care for those with this disease.

#### **5. Conclusion**

As an innovative leader in the management of AD, it is vital that California maintain and build upon its accomplishments by supporting this valuable and unique network of CADCs. Additionally, it is important to incorporate public health approaches to prepare for significant growth in AD. Expanding upon existing resources, such as the data collected by CDPH/ADP, can further assist in program refinement, grant submissions and implementation of the California's Alzheimer's Disease State Plan. ADP aims to set the stage for action and inclusiveness, and help improve delivery and efficacy of treatment through informing caregivers about how to seek optimal care, while expanding education and community outreach to underserved communities. The ADP will continue to develop and provide culturally sensitive diagnostic tools to meet the needs of California's diverse seniors, in collaboration with stakeholders.

## 6. Resources for the Public

### Alzheimer's Disease Program Website

Our website contains information on the services and locations of the CADCs, Resources for Families and Health Professionals, Research Grants and AD Data, Statistics, and Reports. We also include links to our partners such as:

- [Alzheimer's Association](#),
- [Alzheimer's Greater Los Angeles](#),
- [Alzheimer's Orange County](#).
- [Alzheimer's San Diego](#) and the
- [California Caregiver Resource Centers](#).

For more information, please check out our CDPH/ADP website located here:

[CDPH Alzheimer's Disease Program](#)

(<https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/AlzheimersDiseaseProgram.aspx>)

### Evaluation and Surveillance

The ADP provides comprehensive evaluation and surveillance of the CADCs, which includes clinical care information and professional and caregiver training and education activities, to obtain this information please contact us at [alzheimersD@cdph.ca.gov](mailto:alzheimersD@cdph.ca.gov).

## 7. List of Acronyms and Glossary of Terms

AD	Alzheimer's Disease
ADP	Alzheimer's Disease Program
CADCs	California Alzheimer's Disease Centers
CDCB	Chronic Disease Control Branch
CDPH	California Department of Public Health
Guideline	Guideline for Alzheimer's Disease Management
PCPs	Primary Care Physicians
SB	Senate Bill

## 8. References

*California State Plan for Alzheimer's Disease: An Action Plan for 2011-2021* (pp. 1-44, Rep.). (2011). Sacramento, CA: California Health and Human Services Agency Alzheimer's Disease and Related Disorders Advisory Committee.

## **Appendix**

2017 Guideline for Alzheimer's Disease Management