

# Alzheimer's Disease and Its Impact

## **Alzheimer's Disease is the Most Common Form of Dementia and it Disproportionately Impacts Many Californians.**

Dementia is a general term for memory loss and other impairments serious enough to interfere with daily life. Alzheimer's accounts for 60 to 80 percent of dementia cases and currently impacts an estimated 610,000 Californians, a number projected to grow to 840,000 by 2025. Alzheimer's is the 5th leading cause of death in California and the only condition in the top 10 without a known cause, cure, or prevention.

More **women** than men have Alzheimer's disease and other dementias such as vascular dementia and dementia with Lewy bodies, among others. Almost two-thirds of Americans with Alzheimer's are women, as are the majority of family caregivers. Older **African Americans** and **Hispanics** are more likely than older whites to have Alzheimer's disease and other dementias with African Americans at twice the prevalence rate and Hispanics one and one-half times the rate.

**This 2017 Update Reflects New Evidence, Improved Practice and Changes in Law** — This is the 4th edition of the California Alzheimer's Clinical Care Guideline, first published in 1998 and revised in 2002 and 2008. The 2017 update specified in statute (SB 613, Chapter 577, 2015) addresses changes in scientific evidence, clinical practice, and state and federal law. Changes include:

## **NEW GOVERNMENT POLICIES**

**Medicare Reimbursement** — The Centers for Medicare & Medicaid Services (CMS) now reimburses physicians for annual wellness visits every 12 months and includes payment for a Health Risk Assessment, including reimbursement for a cognitive screen. Medicare will pay for cognitive and functional assessments and care planning for patients with Alzheimer's disease and other cognitive impairments.

**Adoption of Physician Order for Life Sustaining Treatment (POLST)** — The POLST form gives patients more control over their end-of-life care, including medical treatment, extraordinary measures (such as a ventilator or feeding tube) and Cardiopulmonary resuscitation. POLST can prevent unwanted treatments, reduce patient and family suffering, and ensure a patient's wishes are honored.

**Social Security Grants Compassionate Allowance Benefit for Early-Onset Individuals** — Individuals under age 65 diagnosed with Alzheimer's disease are eligible for the Social Security Administration's compassionate allowance benefit with minimal objective medical information provided by a physician.

**Healthy Brain Initiative** — The Centers for Disease Control and Prevention has mapped out a strategy for state and national partnerships through [The Healthy Brain Initiative](#) emphasizing proven public health strategies such as monitoring and evaluation, education and training, policy development, and workforce competencies.

## **EMERGING PRACTICE TRENDS**

**Emphasis on Early Detection, Early Diagnosis and Mild Cognitive Impairment** — Mild cognitive impairment can cause serious cognitive changes noticed by those individuals who experience changes or by other people, but not severe enough to interfere with daily life or independent function. As with other chronic diseases, public health experts are focusing on possible early interventions to delay the onset and slow the progression of Alzheimer's disease.

**New Evidence About Antipsychotic Medications and FDA Black Box Warning Labels** — In April 2005, the U.S. Food and Drug Administration (FDA) notified health care professionals that both conventional and atypical antipsychotics are associated with an increased risk of mortality in elderly patients treated for dementia-related psychosis. The FDA notified health care professionals that patients with dementia-related psychosis treated with atypical antipsychotic drugs are at an increased risk of death. Since issuing that notification, the FDA has reviewed additional information that indicates the risk also is associated with conventional antipsychotics.

**Gaps in Disclosure and Documentation** — Scientists who studied patient surveys and Medicare claims data discovered only 45 percent of those billed for Alzheimer's-related care were told by their doctors of their disease. Overlooking or avoiding diagnosis impedes care and denies access to needed services. In an era of electronic health records, documenting the diagnosis is critically important in order to deliver person-centered care.

**Lifestyle Modifications** — Some risk factors for dementia, such as age and genetics, cannot be changed, but the brain can be protected by some of the same strategies that guard against cardiovascular risk, including smoking cessation; keeping blood pressure, cholesterol and blood sugar within recommended limits; and, maintaining a healthy weight. Regular physical exercise may help lower dementia risk. Diet may impact brain health through its effect on heart health. Evidence suggests heart-healthy eating patterns, such as the Mediterranean diet, which emphasizes eating foods like fish, fruits, vegetables, beans, high-fiber breads and whole grains, nuts, and olive oil may help protect the brain.

# Alzheimer's\* Clinical Care Guideline

## ASSESSMENT

### Understand (or Know) the Patient

#### Address the Patient Directly

- Confirm, disclose and document the diagnosis in the patient record.
- Identify the patient's culture, values, primary language, literacy level, and decision-making process.
- Identify the primary caregiver and assess the adequacy of family and other support systems, paying attention to the caregiver's own mental and physical health.

#### Monitor and Reassess Changes

Upon sudden changes or significant decline, and at least annually, conduct and document the following:

- Ability to manage finances and medications, as well as daily functions, including feeding, bathing, dressing, mobility, toileting and continence;
- Cognitive status, using a valid and reliable instrument, e.g., [MoCA](#) (Montreal Cognitive Assessment), AD8 (Ascertain Dementia 8) or other tool;

- Comorbid medical conditions, which may present with sudden worsening in cognition and function or changes in behavior, and could complicate management of dementia;
- Emotional, behavioral and/or mood symptoms;
- Medications, both prescription and non-prescription, for appropriate use and contraindications; and
- Adequacy of home environment, including safety, care needs, and [abuse and/or neglect](#).

## CARE PLAN

### Beneficial Interventions

#### Disease Management

- Discuss the progression and stages of the disease.
- Evaluate and manage comorbidities in context of dementia and prognosis.
- Consider use of cholinesterase inhibitors, N-Methyl-D-aspartate antagonist, and other medications, if clinically indicated, to slow cognitive decline.
- Promote and refer to social services and community support.

#### Treat Emotional, Behavioral and/or Mood Symptoms

- First consider non-pharmacologic approaches such as counseling, environmental modification, task simplification, activities, etc.

- Consult with or refer to mental health professionals as needed.
- IF non-pharmacological approaches prove unsuccessful, THEN use medications targeted to specific emotions, behaviors or moods, if clinically indicated. Note, many medications carry an FDA black box warning and side effects may be serious, significant or fatal.

#### Evaluate Safety Issues

- Discuss driving, wandering, firearms, fire hazards, etc. Recommend [medical identification](#) for patients who wander.

#### Document Goals of Care

- Explore preferred intensity of care to include palliative care and end-of-life options such as hospice.
- Provide information and education on advance health care directives, Do Not Resuscitate Orders, [Physicians Orders for Life Sustaining Treatment](#), Durable Power of Attorney and other documents.

#### Promote Healthy Living

- Discuss evidence in support of modifiable risk factors, e.g., regular physical activity and diet/nutrition.

#### Refer to Clinical Studies

- If interested, advise patient and family of opportunities to participate in [research](#).

## EDUCATION AND SUPPORT

### Engage with the Community

#### Connect with Social and Community Support

- Involve the patient directly in care planning, treatment decisions and referrals to community resources.
- As the disease progresses, suggest appropriate home and community-based programs and services.
- Link the patient and caregiver to support organizations for culturally appropriate educational materials and referrals to community and government resources.

For statewide patient and family resources, link to: **California Department of Public Health, Alzheimer's Disease Program** (916) 552-9900

[www.cdph.ca.gov/programs/Alzheimers/Pages/default.aspx](http://www.cdph.ca.gov/programs/Alzheimers/Pages/default.aspx)

Check for local services in your area.

## IMPORTANT CONSIDERATIONS

### Time Sensitive Issues

#### Advance Planning

- Discuss the importance of basic legal and financial planning as part of the care plan and refer to [assistance](#).

#### Capacity Evaluations

- Assess the patient's decision-making capacity and determine whether a legal surrogate has been or can be identified.
- Consider literacy, language and culture in assessing capacity.

#### Elder Abuse

- Monitor for evidence of and report 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.

#### Driving

- [Report the diagnosis](#) of Alzheimer's disease in accordance with California law.

#### Eligibility for Benefits

- Patients diagnosed with early-onset Alzheimer's disease may be eligible for [Social Security compassionate allowance](#).
- Other benefits may include Department of Veterans Affairs or long-term care insurance coverage under existing policies.