

Guideline for Alzheimer's Disease Management

ASSESSMENT

Monitor Changes

Conduct and document an assessment and monitor changes in:

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

Reassess Frequently

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

Identify Support

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

Assess Capacity

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

Identify Culture & Values

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

TREATMENT

Develop Treatment Plan

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

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

Treat Behavioral Symptoms

Treat behavioral symptoms and mood disorders using:

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

Non-Pharmacological Treatment First

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

Treat Co-Morbid Conditions

Provide appropriate treatment for comorbid medical conditions.

Provide End-of-Life Care

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

PATIENT & FAMILY EDUCATION & SUPPORT

Integrate Medical Care & Support

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

Organizations include:

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

Discuss Diagnosis & Treatment

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

Involve Early-Stage Patients

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

Discuss Stages

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

Discuss End-of-Life Decisions

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

LEGAL CONSIDERATIONS

Planning

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

Capacity Evaluations

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

Elder Abuse

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

Driving

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

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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.

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