

Guidelines for Managing Alzheimer's Disease: Part I. Assessment

JEFFREY L. CUMMINGS, M.D., and JANET C. FRANK, DR.P.H., University of California, Los Angeles, School of Medicine, Los Angeles, California

DEBRA CHERRY, PH.D., Alzheimer's Association, Los Angeles, California

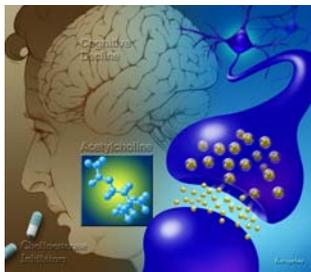
NEAL D. KOHATSU, M.D., M.P.H., California Department of Health Services, Sacramento, California

BRYAN KEMP, PH.D., University of Southern California Rancho Los Amigos National Rehabilitation Center, Los Angeles, California

LINDA HEWETT, PSY.D., University of California, San Francisco, School of Medicine, San Francisco, California

BRIAN MITTMAN, PH.D., Veterans Administration Healthcare System, Los Angeles, California

Family physicians play a key role in assessing and managing patients with Alzheimer's disease and in linking the families of these patients to supportive services within the community. As part of comprehensive management, the family physician may be responsible for coordinating assessments of patient function, cognition, comorbid medical conditions, disorders of mood and emotion, and caregiver status. Suggestions for easily administered and scored assessment tools are provided, and practical tips are given for supporting primary caregivers, thereby increasing efficiency and quality of care for patients with Alzheimer's disease. (Am Fam Physician 2002;65:2263-72. Copyright© 2002 American Academy of Family Physicians.)



This is part I of a two-part article on Alzheimer's disease. Part II, "Treatment," will appear in the next issue.

Alzheimer's disease is the most common cause of cognitive impairment in elderly persons, with an incidence that doubles every five years after the age of 60 years. This disease afflicts approximately 4 million Americans¹ and is estimated to cost the U.S. economy \$60 billion annually.²

Advances have been made in the clinical diagnosis and treatment of Alzheimer's disease. Using the criteria established by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association,³ autopsy results support the clinical diagnosis in 86 to 90 percent of cases.⁴ Advances in therapy include the introduction of cholinesterase inhibitors⁵ and the use of antioxidants.⁶

Several professional organizations and work groups have developed consensus statements and guidelines for the diagnosis and treatment of Alzheimer's disease from the perspective of subspecialty care.⁷⁻⁹ To date, however, user-friendly, practical guidelines have not been available for busy family physicians. Recent studies have shown that many family

physicians have relatively limited knowledge of dementia.¹⁰

The growth of managed care as the principal means of health care delivery in the United States has increased demands on family physicians. In addition, the growth of managed Medicare has increased the number of elderly persons receiving medical care from family physicians. This article offers practical guidance and tools to help family physicians provide a comprehensive management program for patients with Alzheimer's disease.

The management guidelines discussed in this two-part article and summarized in *Table 1* are intended to be used in directing the care of patients and their caregivers after the diagnosis of Alzheimer's disease has been made. They are most relevant to the management of community-dwelling patients being cared for by family members. The guidelines do not address the initial identification, evaluation, or differential diagnosis of memory complaints in elderly patients; these issues are covered in other guidelines. Part I of this two-part article focuses on assessment, and part II reviews treatment.

TABLE 1

Guidelines for the Management of Alzheimer's Disease**Assessment**

Conduct and document assessments of the following:

- Daily function, including feeding, bathing, dressing, mobility, toileting, continence, and ability to manage finances and medications
- Cognitive status, using a reliable and valid instrument such as the Mini-Mental State Examination
- Other medical conditions
- Behavioral problems, psychotic symptoms, and depression

Reassess the patient every 6 months or more frequently if indicated.

Identify the primary caregiver and assess the adequacy of family and other support systems.

Assess the culture, values, primary language, and decision-making process of the patient and family.

Treatment

Develop and implement an ongoing treatment plan, with defined goals that include the following:

- Use of cholinesterase inhibitors, if clinically indicated, to treat cognitive decline
- Referral for appropriate structured activities such as exercise, recreation, and adult day care
- Appropriate treatment of comorbid medical conditions

Treat behavioral problems and mood disorders using the following:

- Nonpharmacologic approaches such as environmental modification, task simplification, and appropriate activities
- Referral to social service agencies or support organizations, including the Alzheimer's Association Safe Return Program for people who wander
- Medications, if clinically indicated

Patient and caregiver education and support

Discuss the diagnosis and progression of Alzheimer's disease with the patient and family in a manner consistent with their values and preferences, as well as the patient's abilities.

Refer the patient and family to organizations that can provide educational materials on community resources, support groups, legal and financial issues, respite care, and future care needs and options. Sources of information and support include the following:

Local social services department

Alzheimer's Association: national telephone: 800-272-3900; Web site: www.alz.org

Family Caregiver Alliance: national telephone: 800-445-8106; Web site: www.caregiver.org

Alzheimer's Disease Education and Referral Center: national telephone: 800-438-4380; Web site: www.alzheimers.org/adear

Discuss the patient's need to have advance directives and to identify surrogates for medical and legal decision-making.

Reporting requirements

Monitor for evidence of abuse. Report all instances of abuse to the local police department and/or social services department as required by local law.

Report the diagnosis of Alzheimer's disease to the appropriate motor vehicle or other department in accordance with local law.

Assessment

The five areas that require assessment (and periodic reassessment) in the patient with Alzheimer's disease are daily function, cognition, comorbid medical conditions, disorders of mood and emotion, and caregiver status.

DAILY FUNCTION

An assessment of daily function is critical to an understanding of the degree of the patient's disability and dependence on the caregiver. Basic activities of daily living (ADL), such as feeding and toileting, can be assessed with an interview or by using a tool such as the ADL scale (*Figure 1*).¹¹ The results of the assessment enable realistic planning for necessary supportive interventions.

The ADL assessment form is used to evalu-

ate the degree of assistance received by the patient during a set period (e.g., the previous week) for each of six activities: bathing, dressing, toileting, transfer, continence, and feeding. The family physician or an assigned rater (nurse, caregiver, etc.) records the actual assistance given, not the capability of the patient.

Data recorded on the ADL evaluation form are converted to an ADL point scale ranging from zero (complete independence in all six categories) to 6 (complete dependence in all six functions). Intermediate scores of 1 to 5 indicate various degrees of independence. For a patient to be considered dependent, the third column of the ADL form must be checked. The ADL instrument can be repeated to determine changing needs for assistance.

Instrumental activities of daily living (IADLs), such as shopping, cooking, and

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Figure 1.

The Mini-Mental State Examination can be used to serially quantify changes in cognitive functioning, although there is a "floor effect" late in the course of Alzheimer's disease.

managing finances and medications, can also be assessed using formal instruments or informal questioning of the primary caregiver. The IADL scale is most frequently used. This instrument measures seven areas of more complex activities required for optimal independent functioning (Figure 2).¹² The scoring indicates whether the patient is completely independent, requires assistance, or is dependent for the performance of each activity. As with the ADL scale, the IADL instrument may be repeated periodically to determine the need for more support.

An in-home assessment may identify environmental supports needed to maximize the patient's function, ensure the patient's safety, and minimize the primary caregiver's distress.

COGNITION

Cognitive status should be reassessed periodically during the course of Alzheimer's disease. The timing of reassessments depends on the stage of the illness and the monitoring required for comorbid medical conditions. Based on consensus discussions during the development of the guidelines presented in this article, reassessment every six months is recommended as a general rule.

Optimal management requires an understanding of disturbances of memory, language, and visuospatial skills. Although brief cognitive tests are available for assessing dementia, one survey¹³ found that approximately 40 percent of physicians did not use formal mental status testing in elderly patients.

The annotated Mini-Mental State Examination (MMSE) is the brief instrument most commonly used to assess cognitive changes in patients with dementia.¹⁴ The MMSE covers six areas: (1) orientation, (2) registration,

(3) attention and calculation, (4) recall, (5) language, and (6) ability to copy a figure. This easily administered 30-item instrument screens for cognitive deficits, aids in the diagnosis of dementia, and can be used serially to quantify changes in cognitive function. The MMSE has been translated into many languages and, with modest adjustments, can be used in a variety of cultural settings.

A perfect score on the MMSE is 30 points. A total score of 23 or less suggests dementia. However, MMSE scores indicative of cognitive impairment vary by age and education; normative values are available for these adjustments.¹⁵

The MMSE has limitations. The instrument is not sensitive in detecting mild dementia; abnormalities are not specific for Alzheimer's disease or dementia. Furthermore, late in the course of Alzheimer's disease, the test has a "floor effect" (with patients scoring at the bottom of the range despite worsening dementia). On average, the MMSE score changes at a rate of approximately three or four points per year in patients with Alzheimer's disease. More marked worsening should trigger a search for complicating comorbid illness or another dementing illness.

A one-time referral for formal neuropsychologic testing may be helpful in distinguishing Alzheimer's disease from the normal effects of aging and in characterizing the deficits present on initial assessment.

COMORBID MEDICAL CONDITIONS

Patients with Alzheimer's disease frequently have comorbid medical conditions such as cardiovascular disease, infection, pulmonary disease, renal insufficiency, arthritis, and diminution of vision and hearing. Appropriate treatment of these conditions can optimize patient function and minimize excess disability.

The approach to managing comorbid medical conditions must take into account the stage of dementia and its effects on care planning, communication methods, benefits and risks of treatments, and adherence to treat-

Instrumental Activities of Daily Living

Name of patient: _____ Date: _____

This form may help you assess the functional capabilities of your older patients. The data can be collected by a nurse from the patient or from an informant such as a family member or other caregiver. (I = independent; A = assistance required; D = dependent)

<i>Obtained from:</i>		<i>Activity</i>	<i>Guidelines for assessment</i>
<i>Patient</i>	<i>Informant</i>		
I A D	I A D	Using telephone	I = Able to look up numbers, dial telephone, and receive and make calls without help A = Able to answer telephone or dial operator in an emergency, but needs special telephone or help in getting numbers and/or dialing D = Unable to use telephone
I A D	I A D	Traveling	I = Able to drive own car or to travel alone on buses or in taxis A = Able to travel, but needs someone to travel with D = Unable to travel
I A D	I A D	Shopping	I = Able to take care of all food and clothes shopping with transportation provided A = Able to shop, but needs someone to shop with D = Unable to shop
I A D	I A D	Preparing meals	I = Able to plan and cook full meals A = Able to prepare light foods, but unable to cook full meals alone D = Unable to prepare any meals
I A D	I A D	Housework	I = Able to do heavy housework (i.e., scrub floors) A = Able to do light housework, but needs help with heavy tasks D = Unable to do any housework
I A D	I A D	Taking medicine	I = Able to prepare and take medications in the right dose at the right time A = Able to take medications, but needs reminding or someone to prepare them D = Unable to take medications
I A D	I A D	Managing money	I = Able to manage buying needs (i.e., write checks, pay bills) A = Able to manage daily buying needs, but needs help managing checkbook and/or paying bills D = Unable to handle money

FIGURE 2. Instrumental Activities of Daily Living scale. This instrument evaluates the patient's ability to perform the more complex activities that are necessary for optimal independent functioning.

Adapted with permission from Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 1969;9:179-86.

ment. The family physician must evaluate the patient's capacity to participate in treatment decisions and, as necessary, involve the caregiver in helping make informed choices.

In the early stage of Alzheimer's disease, the patient may be lucid. During each medical visit, however, the patient's capacity to under-

stand and communicate must be reassessed before information and instructions are provided. Written instructions and reminders are helpful in increasing adherence to and correct implementation of the physician's recommendations. The caregiver can be a valuable ally in ensuring that medications are taken

Patients with Alzheimer's disease should be assessed periodically for agitation, depression, and psychotic symptoms, because behavioral problems become common as the disease progresses.

and other treatment activities are accomplished correctly. Potential problems may be identified earlier if the caregiver is coached to watch for behavioral changes that may indicate adverse treatment effects.

The primary caregiver and other family members may assess treatment options differently when a patient is in the late stage of Alzheimer's disease, because of diminished treatment benefit in the context of dementia and quality-of-life issues. In the patient with advanced disease, management is directed at infectious illnesses, nutritional and feeding difficulties, bowel and urinary disorders, mobility-associated problems, and pressure ulcerations.¹⁶

The Authors

JEFFREY L. CUMMINGS, M.D., is professor of neurology and psychiatry at the University of California, Los Angeles (UCLA), School of Medicine, where he also serves as director of the Alzheimer's Disease Center.

JANET C. FRANK, DR.P.H., is assistant director of academic programs for the UCLA multicampus program in geriatric medicine and gerontology. She also directs the education core of the UCLA Alzheimer's Disease Center.

DEBRA CHERRY, PH.D., is associate executive director of the Alzheimer's Association of Los Angeles.

NEAL D. KOHATSU, M.D., M.P.H., is medical director of the Medical Board of California, California Department of Health Services, Sacramento.

BRYAN KEMP, Ph.D., is codirector of the Alzheimer's Disease Research Center of California at the University of Southern California Rancho Los Amigos National Rehabilitation Center, Los Angeles.

LINDA HEWETT, PSY.D., is executive director of the California Alzheimer's Disease Research Center at the University of California, San Francisco, School of Medicine.

BRIAN MITTMAN, PH.D., is a health services researcher at the Veterans Administration Healthcare System, Los Angeles.

Address correspondence to Jeffrey L. Cummings, M.D., Alzheimer's Disease Center, Department of Neurology, UCLA School of Medicine, 710 Westwood Plaza, Los Angeles, CA 90095-1769 (e-mail: cummings@ucla.edu). Reprints are not available from the authors.

DISORDERS OF MOOD AND EMOTION

The patient with Alzheimer's disease should be assessed periodically for behavioral problems, psychotic symptoms, and depression. Behavioral problems eventually occur in nearly all patients with the disease.¹⁷ These problems are a major cause of caregiver distress and one of the principal determinants of institutionalization. Behavioral disturbances may be directly observed by the physician but are more often reported by the primary caregiver.

The patient should be evaluated for drug toxicity and medical, psychiatric, psychosocial, or environmental problems that may underlie behavioral changes. In general, reassessment every six months is necessary because new behaviors emerge over the course of Alzheimer's disease. The care plan should include potentially useful nonpharmacologic interventions as well as adequate precautions to reduce the risk of harm to the patient and others, to minimize excess disability associated with treatable behavioral or mood disturbances, and to reduce the risk of residential placement.

Agitation. This behavioral disturbance is common in patients with Alzheimer's disease.¹⁷ Agitation can have a number of triggers, including pain, medications, and psychosocial stressors. A thorough assessment is essential to rule out iatrogenesis and treatable contributing causes.

Psychosis. Psychotic symptoms are less common than agitation but increase in frequency as Alzheimer's disease progresses.¹⁷ Several rating scales are available to assess agitation, psychosis, and other types of behavioral disturbances.

The Neuropsychiatric Inventory Questionnaire (NPI-Q) is a rapidly administered instrument that provides a reliable assessment of behaviors commonly observed in patients with dementia (*Figure 3*).¹⁸ The NPI-Q may be a useful tool for family physicians because it assesses the severity of the symptom in the patient and the distress the symptom causes in the caregiver.

Neuropsychiatric Inventory Questionnaire

Name of patient: _____ Date: _____

Informant: Spouse: _____ Child: _____ Other: _____

Please answer the following questions based on *changes* that have occurred since the patient first began to experience memory problems. Circle "yes" only if the symptom has been present in the *past month*. Otherwise, circle "no".

For each item marked "yes":

Rate the *severity* of the symptom (how it affects the patient):

- 1 = Mild (noticeable, but not a significant change)
- 2 = Moderate (significant, but not a dramatic change)
- 3 = Severe (very marked or prominent; a dramatic change)

Rate the *distress* you experience because of that symptom (how it affects you):

- 0 = Not distressing at all
- 1 = Minimal (slightly distressing, not a problem to cope with)
- 2 = Mild (not very distressing, generally easy to cope with)
- 3 = Moderate (fairly distressing, not always easy to cope with)
- 4 = Severe (very distressing, difficult to cope with)
- 5 = Extreme or very severe (extremely distressing, unable to cope with)

Please answer each question honestly and carefully. Ask for assistance if you are not sure how to answer any question.

Delusions	Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Hallucinations	Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Agitation or aggression	Is the patient stubborn and resistive to help from others?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Depression or dysphoria	Does the patient act as if he or she is sad or in low spirits? Does he or she cry?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Anxiety	Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Elation or euphoria	Does the patient appear to feel too good or act excessively happy?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Apathy or indifference	Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Disinhibition	Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Irritability or lability	Is the patient impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Motor disturbance	Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Nighttime behaviors	Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Appetite and eating	Has the patient lost or gained weight, or had a change in the food he or she likes?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			

FIGURE 3. Neuropsychiatric Inventory Questionnaire. This tool provides a reliable assessment of behaviors commonly observed in patients with dementia.

Adapted with permission from Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry Clin Neurosci 2000;12:233-9. Copyright© J.L. Cummings, 1994.

Caregiver Burden Scale

Caregiver's name: _____ Date: _____

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0	1	2	3	4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score: _____

SCORING KEY:

0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

FIGURE 4. Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the "experience of burden."

Adapted with permission from Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980;20:649-55.

Depression. Although depressive symptoms are present in approximately 40 percent of patients with Alzheimer's disease,¹⁷ they are often overlooked. These symptoms are treatable in most patients.⁸

The Geriatric Depression Scale (GDS) is a 30-item, self-rated or observer-rated screening instrument for use in cognitively intact older adults.¹⁹ A score between zero and 10 is considered to be in the normal range; a score of 11 or higher may indicate the presence of depression and warrants a more thorough evaluation. GDS scores may underreport depression in patients with mild to moderate Alzheimer's disease.²⁰

CAREGIVER STATUS

The physical and emotional health of the primary caregiver is critical to optimal care of the patient with Alzheimer's disease. Caregivers suffer from increased rates of depression and physical illness and are prescribed medications at a higher rate than persons not required to be in a care-giving role.²¹

Assessment of caregiver status can lead to the implementation of measures that minimize patient-caregiver stress and defer institutionalization of the patient. The family physician should conduct the assessment or refer the caregiver to a psychologist, social worker, or other member of the health care delivery team.

Various tools have been developed to provide information about the activities and concerns of persons who care for patients with Alzheimer's disease. One of the earliest and most widely used tool is the Caregiver Burden Scale, a self-administered 22-item questionnaire with a five-item response set ranging from "never" to "nearly always" (Figure 4).²² The numbers for the responses are added to obtain the total score, with higher scores indicating greater caregiver distress.

Special Factors in Caregivers and Patients. Members of ethnic minority groups have different care-giving patterns than persons in the majority culture, and they may place dif-

ferent interpretations on memory and behavioral problems. Black and Hispanic families, for example, distribute care among multiple family members, rather than having one primary caregiver as occurs in most white families. In addition, decision-making processes vary among families; sensitivity to the nuances of family decision-making is required to establish an effective working relationship with family caregivers.

Reassessment

Regular reassessments are critical to all aspects of the management of patients with Alzheimer's disease. The frequency of reassessment depends on the acuity of the needs of the patient and caregiver. It is generally necessary to see the patient every six months during the course of the illness, and more frequently when complex or potentially dangerous symptoms emerge or when new drug therapies are being introduced. These regular visits also allow reassessment of the caregiver, identification of caregiver burnout, referral of the caregiver to support groups, and the initiation of other appropriate interventions.

The authors indicate that they do not have any conflicts of interest. Sources of funding: Dr. Cummings has served as a consultant and conducted research for AstraZeneca L.P., Bayer Corporation, Janssen Pharmaceutica Products, L.P., Eli Lilly and Company, Novartis Pharmaceuticals Corporation, Parke-Davis, and Pfizer Inc. Dr. Frank has served as a consultant for Novartis Pharmaceuticals. This manuscript is based on work initiated by the Ad Hoc Standards of Care Committee of the Alzheimer's Disease Diagnostic and Treatment Centers of California and continued by the California Workgroup on Guidelines for Alzheimer's Disease Management Project. The work was supported in part by California's Department of Health Services under contract nos. 95-23557 and 00-91317, and by grant no. CSH000149-5 from the Federal Health Resources and Services Administration's Bureau of Primary Health Care and Administration on Aging, and the Los Angeles chapter of the Alzheimer's Association. The California Geriatric Education Center and the Center for the Study of Healthcare Provider Behavior have received subcontracts to assist the Alzheimer's Association. Members of the California Workgroup on Guidelines for Alzheimer's Disease Management Pro-

ject have donated their time and expenses to improve the quality of care for patients with Alzheimer's disease and their families. Support was made available from the Alzheimer's Disease Center at the University of California, Los Angeles, under grant no. AG 16570 and from the Sidell-Kagan Foundation.

The authors acknowledge the members of the California Workgroup on Guidelines for Alzheimer's Disease Management, including members of the workgroup's executive committee (names in bold): Maria P. Aranda, Ph.D., Judy Canterbury, M.S.N., **Debra Cherry, Ph.D.**, Michael Cushing, M.D., Richard Della Penna, M.D., Cordula Dick-Muehlke, Ph.D., Edith S. Eddleman-Robinson, L.C.S.W., Elizabeth Edgerly, Ph.D., Lynn Friss Feinberg, M.S.W., **Janet Frank, Dr.P.H.**, Vicki Hart, L.C.S.W., Linda Hewett, Psy.D., Robert Hierholzer, M.D., James T. Howard, M.S., Roland Jacobs, M.D., **Bryan Kemp, Ph.D.**, **Neal Kohatsu, M.D.**, **M.P.H.**, **Kit Lackey**, Daniel A. Lang, M.D., Kathryn Lowell, Joan Mengelkoch, M.A., Lydia Missaelides, M.H.A., **Brian Mittman, Ph.D.**, Janet Morris, J.D., Laura Mosqueda, M.D., Kate O'Malley, R.N., Cheryl Phillips-Harris, M.D., Ann Quinones, M.P.A., R.N., Christine Rozance, M.D., Debra Saliba, M.D., M.P.H., Dan Schroepfer, Lynda Shelton, M.P.A., Steven Sproger, L.C.S.W., Ph.D., Dodie Tyrell, M.A., Barbara Vickrey, M.D., M.P.H., and Sharron Watts, M.P.A., as well as Kathryn Duke, Gene Giber-son, Kara Kennedy, M.S.W., and Katie Maslow, M.S.W.

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