

# Guideline for Alzheimer's Disease Management

**California Workgroup on Guidelines  
for Alzheimer's Disease Management**

**FINAL REPORT  
2008**

Supported by the State of California,  
Department of Public Health

CALIFORNIA VERSION © April 2008

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### ***Acknowledgments***

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# PREFACE

This report updates and expands the Guidelines for Alzheimer’s Disease Management (California Workgroup on Guidelines for Alzheimer’s Disease Management, 2002), which itself was a revision of the California Workgroup’s original Guideline published in 1998. All of these documents were based upon work begun by the Ad Hoc Standards of Care Committee of the Alzheimer’s Disease Diagnostic and Treatment Centers (ADDDTCs) of California (Hewett, Bass, Hart, & Butrum, 1995) and were supported in part by the State of California, Department of Health Services, and the Alzheimer’s Association, California Southland Chapter.

## **Purpose and Scope of This Report**

More than 5 million Americans now have Alzheimer’s Disease (Alzheimer’s Association, 2008), an increase of 25% since the previous version of this Guideline was published. Alzheimer’s Disease destroys brain cells, causing problems with memory, thinking, and behavior severe enough to affect work, family and social relationships, and, eventually, the most basic activities of daily living. Alzheimer’s Disease gets worse over time, it is incurable, and it is fatal. Today it is the seventh leading cause of death in the United States, and the fifth leading cause for individuals 65 and older (Alzheimer’s Association).

Since the 2002 revision was completed, there has been an explosion of research in the field, generating new insights into the progression, treatment, and management of Alzheimer’s Disease. The revised Guideline and this report are based in large part on a review of journal articles and meta-analyses published after 2001, incorporating the results of this tremendous body of new work.

Most older adults—including those with Alzheimer’s Disease—receive their medical care from Primary Care Practitioners (PCPs) (Callahan et al., 2006), who may lack the information and other resources they need to treat this growing and demanding population (Reuben, Roth, Kamberg, & Wenger, 2003). Nevertheless, PCPs should be able to provide or recommend a wide variety of services beyond medical management of Alzheimer’s Disease 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. This Guideline is intended to provide assistance to PCPs in offering comprehensive care to patients with Alzheimer’s Disease and those who care for them over the course of their illness.

Because the Guideline is intended for use by PCPs who will encounter Alzheimer’s Disease in the course of their work, we use the word “patients” throughout this report. However, it is important to recognize that the needs of people with Alzheimer’s Disease 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.

## **New Information**

The 2002 Guideline was written prior to the development and testing of some new pharmacological agents, as well as numerous non-pharmacological interventions designed to improve disease management and quality of life for both Alzheimer's Disease patients and their caregivers. Although some of these treatment methods were already in use, few were supported by evidence of efficacy from well-designed clinical trials. In many cases, this evidence now exists, and it is discussed in the current revision.

A notable advance in pharmacological treatment of Alzheimer's Disease was the introduction of memantine (Namenda) in October 2003, a year after release of the previous version of this Guideline. The first drug approved by the U.S. Food and Drug Administration (FDA) for treatment of moderate to severe Alzheimer's Disease, memantine has become an important component of treatment for many patients. The Treatment section includes two tables devoted to its use.

In the ensuing 6 years, additional emphasis on other topics relevant to the treatment of Alzheimer's Disease, along with the needs of patients and their families, has become apparent. These topics include, among others:

- the importance of cultural and linguistic factors in Alzheimer's Disease treatment;
- the conduct of legal capacity evaluations; and
- the special needs of early-stage and late-stage patients and their families

The revised report includes much new material regarding these critically important subjects, as well as updated references for many points discussed in previous versions.

## **New Format**

This version of the report also has been reformatted for convenience and ease of use, with appendices containing copies of many of the assessment instruments and forms cited in the text. Websites containing valuable resources for both PCPs and patients are included, and the online version of the report contains links to many of these resources.

As with the previous versions, the Guideline's recommendations themselves were designed to fit on one page for handy reference and organized by major care issues (assessment, treatment, patient and family education and support, and legal considerations). The revised and expanded report has been organized to conform to this layout. Each section deals with one of the four care issues and provides an overview of the issue, followed by the care recommendations and a review of the literature supporting them. The language used throughout the report reflects the strength of the supporting evidence, either "strong" (e.g., randomized clinical trial) or "moderate." In some instances, recommendations that are not evidence-based are nevertheless supported by expert opinion and Workgroup consensus, and are labeled as such.

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# 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](http://www.alz.org)
- **Caregiver Resource Centers**  
(800) 445-8106 [www.caregiver.org](http://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](http://www.caalz.org).

Prepared by the  
California Workgroup on Guidelines  
for Alzheimer's Disease Management  
April 2008

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.

# ASSESSMENT

## Overview

Appropriate treatment goals and plans that meet all of the patient's needs can only be developed through comprehensive assessment of the patient, the family, and the home environment. This assessment should address 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 of information. The Primary Care Practitioner (PCP) should solicit and consider caregiver and family input in post-diagnostic treatment planning.

### Recommendations

- 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
- 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 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 the patient's decision-making capacity and determine whether a surrogate has been identified.
- Identify the patient's and family's culture, values, primary language, literacy level, and decision-making process.

## Assessment: Daily Functioning

Careful and competent functional assessment enables the PCP and family to determine how best to maximize patients' independence (Ensberg & Gerstenlauer, 2005; Holmes & Adler, 2005; Kane, Ouslander, & Abrass, 1994). Functional assessment includes evaluation of physical, psychological, and socioeconomic domains. Physical functioning may focus on basic activities of daily living (ADLs) that include feeding, bathing, dressing, mobility, and toileting (Kane et al.; Katz, 1983). Assessment of instrumental (or intermediate) activities of daily living (IADLs) addresses more advanced self-care activities, such as shopping, cooking, and managing finances and medications. Standardized assessment instruments such as the Barthel (Mahoney & Barthel, 1965) or Katz (Katz, Down, Cash, & Grotz, 1970) indices (see Appendix A) can provide information on the patient's capacity for self-care and independent living. Proxies or patient surrogates can complete a number of these instruments when necessary (Bucks, Ashworth, Wilcock, & Siegfried, 1996; Byrni, Wilson, Bucks, Hughes, & Wilcock, 2000).

The cognitive changes commonly associated with Alzheimer's Disease first impact both the instrumental and eventually, the basic activities of daily living (Fitz & Teri, 1994; Monllau et al., 2007; Park, Pavlik, Rountree, Darby, & Doody, 2007). The initial assessment of functional abilities is important to determine a baseline to which future functional deficits may be compared. Assessment of a patient's living environment can identify environmental supports that may be needed to maximize function, ensure safety, and minimize caregiver stress. It will also provide realistic goal setting and treatment planning information and allow early supportive interventions to be initiated (Ham, 1997).

*Recommendation: 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.*

## Assessment: Cognitive Status

Cognitive status should be reassessed periodically to identify sudden changes, as well as to monitor the potential beneficial or harmful effects of environmental changes, specific medications, or other interventions. Proper assessment requires the use of a standardized, objective instrument that is relatively easy to use, reliable (with less variability between different assessors), and valid (results that would be similar to gold-standard evaluations). A number of brief assessment instruments have been developed, enabling PCPs to adopt instruments that are appropriate to their practices and patient populations.

The Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) has become the most commonly used tool for cognitive assessment. However, it has been criticized for the influence of education and language on an individual's performance (Escobar et al., 1986; Grigoletto,

Zappala, Anderson, & Lebowitz, 1999; Mulgrew et al., 1999; Mungas, 1996). Moreover, the MMSE is a proprietary instrument. The added cost of administration may lead to the increasing familiarity and use of other cognitive screening instruments. Alternatives useful for clinical practice include: (a) Blessed Orientation-Memory-Concentration Test (BOMC; also called Blessed Information-Memory-Concentration Test, or BIMC) (Blessed, Tomlinson, & Roth, 1968); (b) Mini-Cog (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000); (c) Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005); (d) Cognitive Assessment Screening Instrument (CASI) (Teng et al., 1994), and (e) St. Louis University Mental Status Examination (SLUMS) (Tariq, Tumosa, Chibnall, Perry, & Morley, 2006). (see Table A1 below; the Blessed Test, Mini-Cog, MoCA, and SLUMS are included in Appendix B.) All of these instruments have been validated and some are available in languages other than English (e.g., Spanish, Tagalog, Cantonese). Expected annual rates of cognitive decline and the influence of education and language on respondent scores vary among cognitive screening tests. Regardless of the instrument used, the PCP needs to consider the effect that literacy level and language may have on cognitive screening test scores. (See “Language, Culture, and Literacy” later in this section for a more detailed discussion of this issue.)

Neuropsychological testing is also helpful, particularly in the early stages of dementia (Jacova, Kertesz, Blair, Fisk, & Feldman, 2007), for differentiating cognitive deficits of Alzheimer's Disease from other dementias as well as deficits associated with other neurological and psychological disorders (Cammermeyer & Prendergast, 1997; Griffith et al., 2006; Ritchie, 1997).

**Recommendation:** *Conduct and document an assessment and monitor changes in cognitive status using a reliable and valid instrument.*

### Assessment: Comorbid Medical Conditions

Approximately one-fourth of people with Alzheimer's Disease also have other chronic illnesses such as heart failure, chronic obstructive pulmonary disease, osteoarthritis, and/or diabetes (Maslow, Selstad, & Denman, 2002). The PCP should diagnose comorbid diseases and treat them promptly and efficiently (Doraiswamy, Leon, Cummings, Marin, & Newmann, 2002; Ham, 1997). It is tempting to attribute changes in function to the dementing illness, but one must be vigilant for the presence of new medical conditions such as thyroid disease (which may present as weight loss or gain) and known medical conditions such as poorly compensated heart failure, which may declare itself with a change in behavior.

Assessment of the patient's medical condition should include obtaining information about the person through structured patient and caregiver interviews (American Psychiatric Association, 2007). The involvement of family members and other caregivers in gathering a history and completing an evaluation to identify co-morbid medical conditions is essential, and the use of other health and social service professionals (psychologists, social workers, or care managers) or an interdisciplinary care team is critical to determine the extent of appropriate care and to develop the therapeutic plan. The family is an excellent source of information regarding a patient's baseline level of functioning. This will assist the PCP in determining whether there is an acute medical condition in addition to Alzheimer's Disease. The PCP should request

**Table A1: Brief Cognitive Assessment Instruments**

Name of Instrument	Number of Items; Time Required Maximum Score	Cognitive Functions Assessed
<b>BOMC</b> (Blessed Orientation-Memory-Concentration Test)	6 items; 3 minutes Maximum Score = 28	Orientation; concentration; short-term verbal recall
<b>CASI</b> (Cognitive Assessment Screening Instrument)	25 items; 15-20 minutes Maximum Score = 100	Attention; mental manipulation; orientation; long-term memory; short-term memory; language; visual construction; word list fluency; abstraction and judgment
<b>MiniCOG</b>	2 items; 3 minutes Maximum Score = 5	Visuospatial, executive functioning, short term recall (Note: Includes clock drawing)
<b>MMSE</b> (Mini-Mental State Exam)	19 items; 10 minutes Maximum Score = 30	Orientation; registration; attention and calculation; short-term verbal recall; naming; repetition; 3-step command; reading; writing; visuospatial
<b>MoCA</b> (Montreal Cognitive Assessment)	12 items; 10 minute Maximum Score = 30	Visuospatial/executive functioning; naming; attention; repetition; verbal fluency; abstraction; short-term verbal recall; orientation (Note: Includes clock drawing)
<b>SLUMS</b> (St. Louis University Mental Status Examination)	11 items; 7 minutes Maximum Score = 30	Orientation; verbal recall, calculation, naming, attention, executive function (Note: Includes clock drawing)

information from the caregiver about any other medical care received. Attention must be given to current medications both prescribed and non-prescribed, which may worsen cognitive, behavioral, or psychiatric behaviors associated with Alzheimer's Disease. Other medical conditions and medications should be identified, recorded in the patient's record, and incorporated into appropriate care plans.

Delirium, or an acute confusional state, is more common in individuals diagnosed with Alzheimer's Disease and other dementias than in non-demented older adults (McCusker, Cole, Dendukuri, Han, & Belzile, 2003). It is an urgent medical condition because it is often a sign of a serious underlying medical illness, requiring comprehensive evaluation to identify the underlying cause so that prompt corrective action can be taken (McCusker et al.). Delirium in patients with Alzheimer's Disease may present with agitation or other behavior changes. The PCP should be alert to such acute behavior changes as a trigger for further medical evaluation (Fillit et al., 2006).

It is important to monitor for signs and symptoms that may indicate the presence of other comorbid disease states. Reversible causes must be sought when a patient demonstrates rapid cognitive deterioration (Fillit et al., 2006). For example, if the caregiver reports anorexia or weight loss exceeding 2 kg or 5% of the person's body weight over the past 3-6 months, this should trigger a nutritional assessment. The Mini Nutritional Assessment (MNA) (Belmin et al., 2007; Vellas et al., 2006), which is also available in a shortened form (Rubenstein, Harker, Salvà, Guigoz, & Vellas, 2001) (see Appendix C), and a measurement of the plasma albumin are methods to assess the need for intervention. The patient should be examined for new medical problems, such as thyroid disorders and colon cancer, as well as depression and medication adverse effects. A generic symptom such as excess drowsiness may be an indicator of medication effect or infection, as well as the result of dementia-related disruption of the normal sleep-wake cycle.

**Recommendation:** *Conduct and document an assessment and monitor changes in comorbid medical conditions, which may present with sudden worsening in cognition, function, or as change in behavior.*

### **Assessment: Behavioral Symptoms, Psychotic Symptoms, and Depression**

**Behavioral Symptoms.** More than 80% of Alzheimer's Disease patients experience some form of behavioral symptoms such as anxiety, agitation, and apathy during the course of the disease (Craig, Mirakbur, Hart, McIlroy, & Passmore, 2005; Steffens, Maytan, Helms, & Plassman, 2005; Lyketsos & Lee, 2004). Behavioral symptoms become problematic when they are the cause of significant distress (for patient and/or caregiver), loss of functional capacity, or risk of harm to the patient or others (American Psychiatric Association, 2007; Friedman & Newburger, 1993; Harwood, Barker, Ownby, &

Duara, 2000). These symptoms present the most challenging aspect of caregiving, and often precipitate institutionalization; however, careful evaluation and management may delay the need for institutionalization (Mittelman, Haley, Clay, & Roth, 2006; Mittelman, Roth, Coon, & Haley, 2004).

Patients and families will present to their PCPs with a range of behavioral symptoms that often fluctuate over time and there is a wide range of abilities to tolerate or cope with these behaviors. The management of behavioral symptoms requires developing early, appropriate, and individualized care goals and plans that should be re-evaluated regularly (Allen-Burge, Stevens, & Burgio, 1999; Boucher, 1999; Logsdon, McCurry, & Teri, 2007) (see Treatment section). Sudden onset of behavioral symptoms requires evaluation for medical causes, including pain, medication effects, infection, and cardiopulmonary disease. Once these potential issues are addressed, assessment should focus on the frequency, severity, and duration of particular behaviors as well as caregiver stress and coping strategies. This will allow accurate identification of significant or dangerous behaviors and their triggers, appropriate prioritization of interventions, and development of targeted support and educational strategies for caregivers.

Behavioral symptoms tend to cluster into four subsyndromes: hyperactive (agitated) behaviors, psychosis, affective behaviors and apathy (Aalten et al., 2007). Agitation and aggression have been shown to be associated with pain in patients with dementia (Howard et al., 2001).

Standardized tools can be used by PCPs or clinic staff to gather information on behavioral symptoms from the caregiver and evaluate effectiveness of interventions over time. These are usually brief and easy to administer and include the (a) Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992), (b) Neuropsychiatric Inventory Questionnaire (NPI-Q) (Cummings et al., 1994; Kaufer et al., 2000), (c) Cohen-Mansfield Agitation Inventory (CMA-I) (Cohen-Mansfield, 1986; Cohen-Mansfield & Billig, 1986; Finkel, Lyons, & Anderson, 1992), (d) Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) (DeDeyn & Wirshing, 2001; Reisberg et al., 1987), and (e) Ryden Aggression Scale (Ryden, 1988). See Table A2 for more information; a form for administering the RMBPC is provided in Appendix D. Caregivers may be able to assist at home by keeping a log of troubling behaviors that includes the times they occur, as well as strategies that are successful in modifying or curtailing these symptoms.

**Psychotic Symptoms.** Although psychotic symptoms are less common than the behavioral disturbances discussed above, a recent meta-analysis of 55 studies published between 1990 and 2003 (Ropacki & Jeste, 2005) found a prevalence of approximately 41% in Alzheimer's Disease patients, with delusions of theft predominating. Evidence suggests an increased prevalence of psychotic symptoms as the disease progresses (Ropacki & Jeste). Delusions (especially paranoid-type) and

**Table A2: Brief Behavioral Assessment Instruments**

Name of Instrument	Description	Advantages	Disadvantages
BEHAVE-AD	Assessment of 25 behavioral symptoms and a global rating	Includes psychotic symptoms	Minimal assessment of disruptive behaviors
Cohen-Mansfield Agitation Inventory (CMAI)	Rates frequency of 29 agitated behaviors on 7 point scale	Very detailed information about agitation	Only assesses agitation
Neuropsychiatric Inventory Questionnaire (NPI-Q)	Rates frequency, severity of 12 behavioral symptoms as well as caregiver distress associated with symptoms	Several versions; can adapt to setting/time limits; provides information about caregiver stress	Long version may be time-consuming to administer
Revised Memory and Behavior Problem Checklist (RMBPC)	Rates frequency of 24 specific behaviors over past week and degree of distress to caregiver caused by each	Self-administered caregiver-report tool requires less than 10 minutes to complete; allows clinical/empirical assessment of potentially modifiable behavior problems	Dependent on caregiver's reading and interpretation (as are all self-report measures)
Ryden Aggression Scale (RAS)	Assessment of frequency of 25 aggressive behaviors	Very detailed information on aggression	Limited to aggressive behaviors

hallucinations are the most common form of psychotic symptoms in Alzheimer's Disease (Jeste & Finkel, 2000; Mintzer & Targum, 2003), and are of great concern because these symptoms are often linked to aggressive behaviors (Aarsland, Cummings, Yenner, & Miller, 1996; Gilley, Wilson, Becket, & Evans, 1997; Koltra, Chacko, Harper, & Doody, 1995). Psychotic behaviors reported by family or other caregivers should be documented in the patient's medical record; however, many families may be unwilling to report these behaviors due to cultural norms that stigmatize dementia as shameful to the family (Valle, 1998; Yeo & Gallagher-Thompson, 2006). The Neuropsychiatric Inventory Questionnaire (NPI-Q) (Cummings et al., 1994; Kaufer et al., 2000), mentioned above, is a brief, reliable, informant-based assessment of neuropsychiatric symptoms and associated caregiver distress and is appropriate for use in a general clinical practice (Kaufer et al.). Another assessment instrument, the Columbia University Scale for Psychopathology in Alzheimer's Disease, is brief and effective in assessing psychotic symptoms, but is not appropriate for assessing changes in severity of symptoms (Devanand, 1997; Devanand et al., 1992).

**Depression.** It is important for health care professionals to be sensitive to symptoms of affective disorders associated with Alzheimer's Disease and to facilitate early intervention (Bolger, Carpenter, & Strauss, 1994), as depression affects as many as 50% of Alzheimer's Disease patients living in the community (Lyketsos & Lee, 2004). Adverse outcomes related to depression include earlier nursing home placement (Steele, Rovner, Chase, & Folstein, 1990), greater physical aggression towards caregivers (Lyketsos et al.,

1999), increased caregiver depression and burden (González-Salvador, Arango, Lyketsos, & Barba, 1999), and higher mortality (Bassuk, Berkman, & Wypiy, 1998). Consultation with and/or referral to a specialist (e.g., psychiatrist) is warranted if the presentation or history of depression is atypical or complex (Lyketsos & Lee). Since administering assessment tests for depression to Alzheimer's Disease patients is often challenging (Warshaw, Gwyther, Phillips, & Koff, 1995) and patients may be unable to describe their symptoms to the PCP, gathering data from family members becomes especially important (Jones & Reifler, 1994; Rosenberg et al., 2005).

Symptoms of depression in Alzheimer's Disease may overlap with symptoms of delirium, apathy, and psychosis (Jeste & Finkel, 2000). Mood symptoms, which may wax and wane, may include irritability, anxiety, and further functional decline (Lyketsos & Lee, 2004). Fear, suspiciousness, and delusions may be found in a third of Alzheimer's Disease patients with depression. Therefore, it is important for the provider to consider depression in the differential diagnosis when these behavioral symptoms present (Zubenko et al., 2003).

Effective diagnosis and treatment of depression in Alzheimer's Disease requires awareness of the relationship between the patient's depression, function, and cognition. A decline in function but not in cognition usually precedes the first episode of depression (Holtzer et al., 2005). Major changes in the patient's environment may trigger depression, but the patient may be unable to articulate the disturbance due to cognitive loss. One potential trigger is elder abuse in which the patient cannot verbally articulate the details of the abuse, but the resulting behavior manifests as depression (Vandeweerd, Paveza, & Fulmer, 2006).

As Alzheimer's Disease progresses, collateral information from the caregiver becomes essential to diagnose, treat and track the course of patients' depressive symptoms, and to monitor patients' suicidal potential. The Cornell Scale for Depression in Dementia (Alexopoulos, n.d ; Alexopoulos, Abrams, Young, & Shamoian, 1988.) is a useful tool for providers because it captures both patient and caregiver input (see Appendix E).

**Recommendation:** *Conduct and document an assessment and monitor changes in behavioral symptoms, psychotic symptoms, or depression.*

### **Assessment: Medications**

Medications that are improperly prescribed or administered are a significant source of morbidity and mortality in older adults (Budnitz, Shehab, Kegler, & Richards, 2007; Gallagher, Barry, Ryan, Hartigan, & O'Mahony, 2008). It is thus important for the PCP to ask who is monitoring the medication usage, who has access to medications, and who makes decisions about "prn" (as needed) medications. All medications used by the patient, both prescription and non-prescription (including herbals, supplements, and over-the-counter) should be brought to the medical office on every visit. This allows the PCP to do a review with the following six key issues in mind:

1. Is this medication achieving its intended effect?
2. Is this medication causing an adverse effect that is annoying or severe enough to warrant discontinuation?
3. Is this medication interacting with other medications in a dangerous way?
4. Is this medication still necessary?
5. Can the dose of the medication be decreased?
6. Can use of this medication be safely discontinued?

The use of certain classes of medications should be avoided in patients with Alzheimer's Disease. Those that cause increased confusion, such as sedative-hypnotics and barbiturates, should be avoided, as should anticholinergics, particularly in those patients prescribed an acetylcholinesterase inhibitor agent (Fick et al., 2003; Gill et al., 2005). A thorough assessment will determine whether any of these medications has been prescribed for the patient, and if so, whether the risks associated with their use may outweigh their benefits.

**Recommendation:** *Conduct and document an assessment and monitor changes in medications, both prescription and non-prescription (at every visit).*

### **Assessment: Living Arrangements, Safety, Care Needs, Abuse, and Neglect**

Assessment of a patient's living environment may help identify retained abilities and things the individual is able to do within a familiar setting. It can also aid in identifying environmental supports that may be needed to maximize function, ensure safety, and minimize caregiver stress.

Safety issues such as driving, fall risk, medication management, environmental hazards, wandering, and access to firearms need to be discussed periodically with the patient and caregiver. Safety concerns typically focus on three risks in particular: falling (the leading cause of injury deaths, non-fatal injuries, and hospital admissions for trauma among older adults) (Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, 2006), wandering, and driving (Maslow et al., 2002). A home safety evaluation is an ideal way to accomplish this. Use of a safety checklist (see Appendix F) can assist the patient, family, and PCP in identification of potential safety hazards. There is a tension between the patient's right to autonomy and the caregiver's duty to protect. The PCP should assess and assist with the need for balancing these concerns with respect to such decisions as determining the time to stop driving. People with early Alzheimer's Disease may be at risk and put others at risk if they continue to drive (Uc, Rizzo, Anderson, Shi, & Dawson, 2004). California law (California Health & Safety Code §103900; California Code of Regulations, Title 17 §§2800-2812) mandates that the PCP report the diagnosis of Alzheimer's Disease, which triggers evaluation of the patient's driving ability by the Department of Motor Vehicles (see Legal Considerations section and Appendix G).

**Abuse and Neglect.** Another California law (Welfare and Institutions Code §15610.17) requires that any health-care provider who has a reasonable suspicion of elder abuse must make a report to local law enforcement authorities (see Legal Considerations section and Appendix G). Abuse can go both ways: the patient may be abusive toward the caregiver, or the caregiver may be abusive toward the patient (Coyne, Reichman, & Berbig, 1993; Paveza et al., 1992). With respect to the patient, simple questions such as: "Are you afraid of anyone? Is anyone stealing from you? Has anyone hurt you?" are easy ways to screen for abuse (Aravanis et al., 1993). Depression (Vandeweerdt et al., 2006), behavioral symptoms including social isolation and withdrawal, and physical signs such as dehydration, broken bones and bruises, or poor basic and oral hygiene (Joshi & Flaherty, 2005; Shugarman, Fries, Wolf, & Morris, 2003) may be signs that an Alzheimer's Disease patient has been the victim of abuse or neglect. See Table A3 for characteristics of caregivers and their elderly dependents that have been identified as risk factors for abuse of care recipients by their caregivers (Reay & Browne, 2002).

In addition, the most important care recipient characteristics to look for in assessing for potential abuse are:

- Problems with short-term memory;
- Psychiatric diagnosis;
- Alcohol abuse;
- Difficulty interacting with others;
- Self-reported conflict with family members and friends;

- Feelings of loneliness; and
- Inadequate or unreliable support system (Shugarman et al., 2003).

It is recommended that patients exhibiting three of the seven predictors of potential abuse be targeted for further investigation, although fewer “triggers” also may signal a strong need for preventive measures such as additional support services (Shugarman et al.).

Because timely referrals to support services may help mitigate or eliminate circumstances associated with abuse and neglect (see Treatment section and Patient and Family Education and Support section), thorough assessment and monitoring by the PCP is essential to the safety of both patient and caregiver.

**Recommendation:** *Conduct and document an assessment and monitor changes in living arrangements, safety, care needs, and abuse and/or neglect.*

### Assessment: Palliative and End-of-life Care

As patients progress from mild to moderate and eventually severe Alzheimer's Disease, the goals of assessment often change, as do the goals of treatment. Palliative care requires individualizing a patient's care plan to reflect needs that may differ substantially from that of an otherwise healthy individual. The American College of Physicians recently recommended that PCPs assess patients regularly for pain, dyspnea, and depression (Qaseem et al., 2008). Because patients with severe dementia are likely to be unable to communicate verbally, assessment of symptoms in late-stage Alzheimer's Disease may be especially difficult (Aminoff & Adunsky, 2006) and requires careful attention to nonverbal cues. Several pain assessment instruments are available for this purpose (van Herk, van Dijk, Baar, Tibboel, & de Wit, 2007).

Although predicting the end of life for a patient with severe Alzheimer's Disease is difficult, obtaining hospice care

requires a prognosis of mortality within six months (Mitchell et al., 2004), and instruments have been developed for this purpose (e.g., Mini Suffering State Examination [Aminoff, Purits, Noy, & Adunsky, 2004]). Factors likely to herald a poor outcome include dependence on others for all activities of daily living, weight loss, recurrent infections, loss of mobility, multiple pressure ulcers, and recent hip fracture (Sachs, Shega, & Cox-Haylet, 2004), as well as cardiovascular disease, diabetes mellitus, need for oxygen therapy, and excessive sleep (Mitchell et al.). Under these circumstances, referral to hospice should be considered (Aminoff & Adunsky, 2006).

**Recommendation:** *Conduct and document an assessment and monitor changes in the need for palliative and/or end-of-life care planning.*

### Assessment: Regular Reassessments

Longitudinal monitoring of disease progression and therapy, along with regular health maintenance checkups, are considered essential (American Psychiatric Association, 2007; Hogan et al., 2007). Ongoing primary care should include medication review, treatment and monitoring of other medical conditions, treatment of dementia by available medications if appropriate, monitoring of disease progression, referral to specialists as needed, and referral to clinical drug trials and other research studies when appropriate. (General information regarding clinical trials, including the benefits and risks of participating in them, is available on the Internet at <http://www.nihseniorhealth.gov>, and information about planned and ongoing clinical trials may be found at <http://www.clinicaltrials.gov>.) Workgroup consensus suggests reassessments should be conducted using the same instruments in order to effectively monitor changes and progression of the disease over time.

Frequency of visits will be determined by a number of factors including the patient's clinical status, likely rate of

**Table A3: Risk Factors for Abuse of Elderly Care Recipients**

Caregiver Characteristics	Care Recipient Characteristics
Responsibility for dependent over 75 years of age	Physical or mental dependence on caregiver
Lives constantly with dependent	Poor communication abilities
Inexperienced or unwilling to provide care	Demanding and/or aggressive
Has overly high expectations of dependent	Has abused caregiver in the past
Acts hostile, threatening, and/or aggressive	Shows potentially provocative behavior
Has other care demands (e.g., spouse, children)	Lives constantly with caregiver
Is subject to high external stressors	Has history of hospitalization, esp. falls
Isolation and lack of community support	Is reluctant or unlikely to report abuse
History of mental health problems (esp. clinical depression or anxiety)	Becomes submissive, withdrawn, or depressed in presence of abuser
Poor physical health	
History of alcohol or drug abuse	
History of childhood abuse or neglect or family violence	

change, current treatment plan, need for any specific monitoring of treatment effects, and reliability and skill of the patient's caregivers (American Psychiatric Association, 2007). Workgroup consensus is that patients with Alzheimer's Disease should be seen at least every six months for reassessment, unless changes in function or behavior, or other intervening conditions warrant more frequent medical contact. Any sudden change or decline in cognition, function, or behavior requires prompt medical evaluation, as this may indicate the presence of an acute medical problem (e.g., delirium) that requires treatment. More frequent visits (once or twice a week) may be required in the short term for patients with complex or potentially dangerous symptoms, or during administration of specific therapies (American Psychiatric Association).

Regular appointments allow the PCP to monitor the patient's cognitive and functional status, as well as the development and evolution of cognitive and behavioral symptoms of Alzheimer's Disease and their response to intervention. They also provide a forum for health promotion and maintenance activities (Dunkin & Anderson-Hanley, 1998) and an opportunity to assess how well the caregiver is managing.

**Recommendation:** *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.*

### **Assessment: Primary Caregiver and Support System**

Strong evidence suggests that assessment of the caregiver should include the following elements: knowledge base (e.g., expectations of treatment outcomes and local services), social support (both availability and perceived adequacy), psychiatric symptomatology and burden (e.g., depression, anxiety), family conflict (quality of the relationship, elder abuse) (Dunkin & Anderson-Hanley, 1998), and ethnic and cultural issues (e.g., primary language and acculturation). PCPs need to be vigilant with respect to the health of the primary caregiver as well as that of the patient with Alzheimer's Disease, whether or not the caregiver is their patient. A brief self-assessment tool for caregivers is available on the website of the American Medical Association (2008), and a copy is included as Appendix H.

Establishing and maintaining alliances with caregivers is critical for care of the Alzheimer's Disease patient (Bultman & Svarstad, 2000; Family Caregiver Alliance, 2006). Major physician organizations have emphasized the importance of family caregivers by calling on PCPs to form partnerships with families who care for dementia patients (e.g., American Academy of Neurology [Lyketsos et al., 2006], American Association for Geriatric Psychiatry [Doody et al., 2001], American Psychiatric Association [2007]). Family caregivers are central to the PCP's assessment and care of the patient with Alzheimer's Disease (Family Caregiver Alliance; National Institute for Health and Clinical Excellence & Social Care Institute for Excellence [NICE-SCIE], 2006). The PCP

must rely on family members to report relevant information (Doody et al.). Therefore, the PCP should routinely solicit and incorporate family and other caregivers' reports of patients' changes in daily routine, mood, behavior, sleep patterns, weight gain or loss, and gait and mobility.

For patients with moderate to severe Alzheimer's Disease, the real managers of care are family members who implement and monitor treatment (Barrett, Haley, & Powers, 1996; Friss, 1993). The PCP should make sure that the caregiver's contact information is noted and kept up to date in the patient demographics section of the patient's medical record. It is important to note that the individual bringing the patient into the office may not be the primary caregiver. Identification of the primary caregiver of the Alzheimer's Disease patient may be challenging in certain cultures where more than one person may be expected to perform that function (see "Language, Culture, and Literacy" later in this section).

Assessment of the caregiver may occur on two levels: as the provider of care to the Alzheimer's Disease patient, and as a patient him/herself (Family Caregiver Alliance, 2006). Family caregivers face increased risk of serious illness (including circulatory and heart conditions and respiratory disease and hypertension), increased physician visits and use of prescription medications, emotional strain, anxiety, and depression (Bullock, 2004). There is moderate evidence that caregiver strain is an independent contributor to mortality, particularly among elderly spousal caregivers (Schulz & Beach, 1999). The risk of depression is particularly high, with prevalence rates of self-reported depression among community-dwelling caregivers of Alzheimer's Disease patients ranging from 30% to as high as 83% (Eisdorfer et al., 2003). Thus, caregiver assessment should seek to identify any psychological distress as well as the psychological impact upon the caregiver with respect to changes in the cognitive status or behavior of the Alzheimer's Disease patient receiving care.

Signs of caregiver stress may include the following:

- Self-reported stress;
- Increased dependency on alcohol or other drugs;
- Reported weight gain or loss; and
- Sleep disturbance.

Caregivers should continue to be assessed even if the decision for long-term placement (e.g., nursing home) has been made because there is strong evidence that many caregivers continue to provide care after placement, and the effects of caregiver strain and burden may still be present (Family Caregiver Alliance, 2006; Gwyther, 2001; Maas et al., 2004; NICE-SCIE, 2006). See Table A4 (Family Caregiver Alliance, 2006) and the Patient and Caregiver Education and Support section for more information on caregiver assessment.

**Recommendation:** *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.*

**Table A4: Fundamental Principles of Caregiver Assessment****Caregiver assessment should:**

Recognize, respect, assess, and address their needs

Embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver

Result in a plan of care, developed collaboratively with the caregiver, that identifies services to be provided and intended measurable outcomes

Be multidimensional, reflect culturally competent practice, and be updated periodically

**Assessment: Capacity Determination and Surrogate Identification**

“Capacity” refers to one’s ability to make decisions about specific actions, which can be a complex cognitive process. Some experts distinguish this from “competency,” which is typically used as a legal term. Capacity assessment is decision-specific, with more complex decisions requiring higher cognitive function than simpler decisions (Karlawish, 2008; Moye et al., 2007). A key factor in capacity determination is an assessment of whether an individual can appreciate the risks, benefits, and alternatives to a particular decision. It is more likely that a cognitively impaired individual will be able to demonstrate capacity to understand and make the choice of a health care proxy, for example, rather than a decision about whether or not to have cardiac surgery. Determining capacity may be made more difficult and time-consuming if the patient has impaired ability to communicate.

Research indicates that a patient’s level of cognitive function, as determined by objective testing, is indicative of ability for decision-making about medical treatment (Karlawish, Casarett, James, Xie, & Kim, 2005; Moye et al., 2007). The following questions may help guide clinical assessment of the critical decision-making abilities: understanding, appreciation, choice, and reasoning (Karlawish, 2008):

1. Can the patient make and express personal preferences at all?
2. Can the patient give reasons for the alternative selected?
3. Are supporting reasons rational?
4. Can the patient comprehend the risks and benefits of the particular decision in question?
5. Does the patient comprehend the implications of the decision?

In early-stage dementia, patients typically retain much of their decision-making capacity and their ability to appoint a surrogate (Braun, Pietsch, & Blanchette, 2000; Zgola, 1999). However, as the disease progresses, this capacity will diminish and eventually be lost. Moreover, decisional capacity can change from day to day. Research has shown that even indi-

viduals with mild to moderate Alzheimer’s Disease may retain the capacity to make some treatment decisions, and that the capacity to make each decision has to be specifically assessed each time the need arises (Karlawish, 2008; Kim & Appelbaum, 2006).

The PCP should determine decision-making capacity at the initial assessment and should ask the patient and family whether a surrogate decision-maker has been identified by the patient. The patient who has the capacity to identify a surrogate should be encouraged to do so as soon as possible for the sake of improving the quality of care over the course of the illness (Braun et al., 2000; Post, Blustein, & Dubler, 1999; Karlawish, 2008; Potkins et al., 2000; Silveira, DiPiero, Gerrity, & Feudtner, 2000) (see Legal Considerations section).

*Recommendation: Assess the patient’s decision-making capacity and determine whether a surrogate has been identified.*

**Assessment: Language, Culture, and Literacy**

It has long been recognized that cultural values and norms govern familial relationships and care of elderly people (Chui & Gatz, 2005; Cox & Monk, 1993; Dilworth-Anderson & Gibson, 2002). Thus, the PCP must be culturally competent for appropriate and most effective evaluation and treatment of Alzheimer’s Disease. With that said, cultural groups are internally heterogeneous, with greater differences within groups than between them, and no one case reflects the total primary culture to which the patient belongs. Moreover, in a multicultural society such as that of the United States, acculturation factors are ever present, even in ostensibly monocultural individuals or groups (Valle & Lee, 2002).

There are three main ingredients of a cultural assessment within the clinical evaluation process for Alzheimer’s Disease. First, PCPs need to be sensitive to the preferred language of the patient and family, which may determine service linkage and adherence outcomes (Folsom et al., 2007). In ethnically diverse populations, bilingual families may have quite different service engagement outcomes than monolinguals.

Second, PCPs must be able to understand the patient’s and family’s customary ways of relating to others within their own group and with persons in authority, being aware that internal decision-making processes may vary both among and within different cultural groups. For example, the PCP may be seen as the sole person in authority, with the expectation that he or she will be making detailed caregiving decisions. PCPs must ascertain as early as possible in the assessment process how a family makes decisions and identify its primary decision-maker, who may not be the person doing most of the “hands-on” caregiving (Valle, 2001).

Third, PCPs need to tap into underlying belief systems regarding Alzheimer’s Disease and other comorbid conditions. This underlying world view and accompanying normative expectations are often expressed in terms of “folk understandings” which may influence the way in which people

from diverse cultures receive and act on the information and directions provided by the PCP (Henderson & Traphagan, 2005; Hinton, Franz, Yeo, & Levkoff, 2005). The PCP should consult with the primary caregiver to identify beliefs about health and aging, learn about cultural taboos (e.g., direct eye contact), determine the language or dialect spoken by the patient and the patient's family, and utilize bilingual, bicultural health care providers as appropriate (Cherry, 1997; Yeo & Gallagher-Thompson, 2006). In some office settings, the PCP may be able to assign a staff person to obtain information about the family's beliefs regarding the cause of the illness, their expectations for treatment outcomes, the nature and extent of the support network surrounding the patient and the family, and how decisions are made in the family (Valle, 2001), with the goal of using this information in patient care planning and treatment.

**Basic Literacy.** Low literacy may directly and negatively affect patient performance on assessment instruments and treatment follow-through, and may also have an effect on caregivers and significant others involved in the situation (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association [AMA], 1999). According to the National Literacy Act of 1991 (20 U.S.C. §1201), basic literacy means the ability not only to read and write, but also to “compute and solve problems at levels of proficiency necessary to function on the job and in society to achieve one's goals, and develop one's knowledge and potential.”

PCPs should be aware that paper and pencil tests and forms may not work well with the diverse populations they treat, if basic literacy is not present, even when such forms are in the persons' (or groups') native language. Therefore, PCPs should consider both culturally as well as literacy-appropriate assessment tools. Cognitive testing in Alzheimer's Disease is especially sensitive to language and literacy level (Teng, 2002; Teng & Manly, 2005). Cognitive screening tools such as the Cognitive Abilities Screening Instrument (CASI) (Teng et al., 1994), which are relatively unaffected by cross-cultural bias and education level, may be administered to persons of both high and low education and are especially useful when working with ethnically diverse populations (Davis et al., 2006) (see Table A1 in this section). Some experts suggest that patients be tested only on what they reasonably may be expected to know (Teng & Manly). A person with little schooling may not know how to do the serial sevens on the MMSE, but may be capable of an accurate application of subtraction in handling simple monetary transactions.

The same concerns extend to printed information about Alzheimer's Disease that may be provided to patients and their families. The content may require a literacy level that is too high for the persons receiving it; thus alternatives, such as more pictorially presented materials, may need to be considered (Davis et al., 2006).

**Health Literacy.** Assessment of health literacy is equally important, as even literate persons may have trouble understanding medical language. Health literacy is defined as the ability to understand medical terminology and instructions, including prescription labels, appointment slips, and other health-related materials, whether presented in written or verbal form. Health literacy is a major health-related problem (AMA, 1999) as it affects an individual's ability to understand and care for his/her medical problem and may result in ineffective care due to inability to understand the PCP's instructions (Baker, Parker, Williams, Clark, & Nurss, 1997; Gazmararian et al., 1999; Valle & Lee, 2002; Williams, Baker, & Parker, 1998; Williams, Davis, Parker, & Weiss, 2002). With respect to Alzheimer's Disease management, assessment of health literacy should focus on both the patient (in the early stages) and the primary caregiver (in all disease stages). Caregiver health literacy is especially critical as patient care responsibilities shift from the patient to the caregiver with disease progression.

The following questions provide a framework for conducting the cultural assessment recommended in this section:

1. What is the patient's and family's preferred (i.e., most comfortable) language for communicating with the PCP? If not English, is there a bilingual person available to assist?
2. How “acculturated” are the patient and family? How well equipped are they to manage clinical and other service referrals that the PCP may suggest?
3. How do members of the patient's cultural group relate to each other, to those in authority (e.g., PCPs and staff members), or to strangers?
4. What sources of cultural information are available to help the PCP make this assessment (e.g., patient self-report, reports of family members or other caregivers, other service providers, direct observation by the PCP)?
5. What other, non-cultural elements may skew the PCP's understanding of cultural factors influencing treatment outcomes (e.g., stereotyping)?

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



# TREATMENT

## Overview

Ongoing regular medical management of general health (including other medical conditions and their prevention), in addition to monitoring of cognitive deficits, is essential. Management goals and interventions should be based on a solid alliance with the patient and family and on thorough psychiatric, neurological, and general medical evaluations of the nature and cause of cognitive deficits and associated non-cognitive symptoms. Effective treatment requires development and implementation of a plan with defined goals for the patient. Goals should be developed in consultation with the patient (if capable) and with the patient's family, using an individualized approach to their needs, values, and preferences, and should be modified as the disease progresses. Early discussion of future care options with the patient and family will provide guidance to the Primary Care Practitioner (PCP) in modifying patient care goals over time in ways that is acceptable to patients with Alzheimer's Disease and their family members.

## Recommendations

- 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; and
  - Referral to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation.
  - Treat behavioral symptoms and mood disorders using:
  - Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc.; and
  - Referral to social service agencies or support organizations, including the Alzheimer's Association's MedicAlert® + Safe Return® program for patients who may wander.
- 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.
- Provide appropriate treatment for comorbid medical conditions.
- Provide appropriate end-of-life care, including palliative care as needed.

## Treatment: Developing a Treatment Plan (Therapies for Cognition)

There currently are three cholinesterase inhibitors (ChEIs) and one N-methyl-D-aspartate (NMDA) antagonist that are FDA-approved and actively marketed (see Table T1 and Table T3 in this section). The agents are approved for monotherapy as well as combination therapy to improve cognitive function or delay decline in patients with mild, moderate, or severe dementia. PCPs should counsel patients with Alzheimer's Disease and their families about realistic expectations of treatment outcomes with these agents, which are likely to be small (Kaduszkiewicz, Zimmermann, Beck-Bornholdt, & van den Bussche, 2005). Evidence of a beneficial response, temporary stabilization, or modification of deterioration following administration of a ChEI or NMDA antagonist can be gathered using a clinician's global assessment, caregiver report, neuropsychological assessment, and/or mental status questionnaire, as well as from evidence of behavioral or functional changes (see Assessment section). Widely used brief mental status tests are inadequate to measure the cognitive effects of ChEIs (Bowie, Branton, & Holmes, 1999) or NMDA antagonist; a substantial observation period of 6 to 12 months is required to assess changes in cognition and rate of cognitive decline, as well as functional benefits of, or behavioral response to, these agents.

### Cholinesterase Inhibitors

A large number of clinical trials have been conducted to evaluate the effect of ChEIs on the symptoms and course of Alzheimer's Disease. Several meta-analyses of both individual agents and the class as a whole have provided insight into the clinical effect of these agents. A review of donepezil studies (Birks & Harvey, 2006) indicated that both 5 mg and 10 mg doses of donepezil, given for up to 52 weeks, produced small but statistically significant benefits in cognition, activities of daily living, and behavior. A systematic review of trials of rivastigmine performed in 2000 (Birks, Grimley Evans, Iakovidou, & Tsolaki, 2000) demonstrated improvements in cognition, activities of daily living, and dementia severity at daily doses of 6 to 12 mg. An updated review (Birks & Harvey) came to the same conclusions and recommended additional research into dosing and administration in order to reduce the frequency and severity of adverse effects. Oral and patch forms of rivastigmine are available; there are fewer side effects with transdermal administration (Winblad et al., 2007). A recent meta-analysis of galantamine treatment studies (Loy & Schneider, 2006) found that patients who received at least 16 mg/day over 3-6 months of treatment had stabilized or improved cognition. A meta-analysis of clinical trials lasting at least 6 months of all ChEIs other than tacrine (Birks, 2006) also found mild effects on cognitive function, activities of daily living, and behavior with all agents, and a study investigating the effect of ChEI treatment on the risk of nursing facility placement found a reduction of more than 20% at 25 months of treatment (Becker, Andel, Rohrer, & Banks, 2006).

**Table T1: Cholinesterase Inhibitors (for Treatment of Mild, Moderate and Severe Alzheimer's Disease)**

Agent	Suggested dosage	Side Effects	Comments and Cautions
Donepezil hydrochloride (Aricept®) Oral; FDA-approved for mild, moderate, and severe Alzheimer's Disease	Start: 5 mg daily Escalation: 10 mg daily after 4-6 weeks if tolerated	Nausea, vomiting, and diarrhea (sometimes can be reduced when taken with food, reducing dose, slower titration, or dividing the dose to twice daily) Muscle cramps Urinary incontinence Syncope Bradycardia (doses >10 mg/day) Fatigue	5 mg dose is effective Caution when using in people with cardiac conduction conditions such as symptomatic bradycardia, or with a history of falls or syncope (may want to avoid or seek cardiac consult)
Galantamine (Razadyne®, Razadyne ER®) Oral; approved for mild and moderate Alzheimer's Disease only	<i>Immediate Release:</i> Start: 4 mg twice daily Escalation: 8 mg twice daily after 4 weeks. May increase to 16 mg twice daily after an additional 4 weeks. Max: 24 mg/day <i>Extended Release:</i> Note: Razadyne ER is once daily Start: 8 mg daily or 4 mg twice daily. Escalation: 16 mg daily after 4 weeks or 8 mg twice daily after 4 weeks. May increase to 24 mg per day (32 mg per day not more effective in Alzheimer's Disease)	Same as for donepezil	Starting dose is not therapeutic. Maximum dose 16 mg per day if renal impairment Other cautions same as donepezil
Rivastigmine tartrate (Exelon®) Oral; approved for mild and moderate Alzheimer's Disease only	Start: 1.5 mg twice daily Escalation: 3 mg twice daily after 4 weeks. May increase to 4.5 mg twice daily after an additional 4 weeks. May increase to 6 mg twice daily after an additional 4 weeks.	Nausea, vomiting, and diarrhea (must be taken with food) More nausea and vomiting than with other ChEIs Anorexia Maybe less muscle cramping than with other ChEIs-Bradycardia (rare at therapeutic doses) Other side effects the same as other ChEIs	Starting dose is not therapeutic Cautions same as for donepezil and galantamine
Rivastigmine (Exelon®) Transdermal; approved for mild to moderate Alzheimer's Disease only	Start: 4.6 mg/24 hour patch daily. Escalation: 9.5 mg/24 hour patch daily after 1 month <i>When switching from oral to the patch:</i> For a total daily dose of less than 6 mg oral rivastigmine switch to 4.6 mg/24 hour patch (first check medication adherence); For a total daily dose between 6-12 mg of oral rivastigmine switch to 9.5 mg/24 hour patch Apply the first patch on the day following the last oral dose	Nausea, vomiting, at 4.6 mg/24 hr patch same as with placebo Other side effects the same as donepezil and galantamine	Starting dose is not therapeutic. Caution same as for donepezil and galantamine

Table adapted from FDA approved package inserts

**Table T2: Principles for Prescribing ChEIs**

Prescribe	Evaluate	Discontinue	Switch	Co-Administer
As initial treatment	After 2-4 weeks (for adverse effects)	Prior to surgery	If poor tolerance	With memantine, if indicated
Upon diagnosis of probable or possible Alzheimer's Disease (NINCDS/ADRDA criteria)	After 3-6 months (for effect on cognition and function)		If, after 6 months, there is continued deterioration at pre-treatment rate	
Upon duration of Alzheimer's Disease symptoms for more than 6 months	After 6 months, and at least every 6 months thereafter (for effect on disease symptom progression)			

Table adapted from Hogan et al., 2007

Nausea, vomiting, and diarrhea are the most common adverse effects in patients treated with ChEIs. Patients with bradycardia or bradyarrhythmias, especially if symptomatic, should be carefully assessed and monitored if treatment with ChEIs is being considered because they have elevated risk for syncope or dizziness (Birks, 2006).

### NMDA Antagonist

Few randomized, placebo-controlled, double-blind studies have been published investigating the effect of memantine, the only available NMDA antagonist, as a treatment for Alzheimer's Disease. Two recent studies investigating its effect in moderate to severe Alzheimer's Disease reported a small effect on cognition, activities of daily living, and behavior at six months, but a review of three unpublished trials conducted in patients with mild to moderate Alzheimer's Disease found no effect on behavior or activities of daily living and only a minimal effect on cognition (although agitation was slightly less likely to develop in patients receiving memantine) (McShane, Areosa Sastre, & Minakaran, 2006). Cummings and associates (2006) noted improved behaviors in patients with moderate to severe Alzheimer's Disease who were treated with memantine as an adjunct therapy to donepezil.

**Table T3: Memantine (N-Methyl-D-Aspartate [NMDA] Receptor Antagonist) for Treatment of Moderate to Severe Alzheimer's Disease**

Oral Agent: Memantine (Namenda®)

#### Suggested Dosage

Start: 5 mg daily for 1 week  
Escalation: 5 mg twice daily for 1 week, then 5 mg and 10 mg in separate doses for 1 week, then 10 mg twice daily  
Reduce dose in people with renal impairment  
(see "Cautions and Comments")

#### Side Effects

Headache  
Dizziness  
Sedation  
Agitation  
Constipation

#### Cautions and Comments

Target dose of 5 mg BID is recommended in patients with severe renal impairment (creatinine clearance of 5-29 mL/min based on the Cockcroft-Gault equation)

Note: Merz (Germany) recommends that for patients with moderate renal impairment (creatinine clearance 40-60 mL/min/1.73 m<sup>2</sup>), daily dose should be reduced to 10 mg per day. No data are available for patients with severely reduced kidney function  
(see sections 4.4 and 5.2)

Table adapted from FDA approved package inserts

**Table T4: Principles for Prescribing Memantine**

Prescribe	Evaluate	Discontinue	Switch	Co-Administer
As monotherapy or adjunct treatment	After 2-4 weeks (for adverse effects)	Prior to surgery	If poor tolerance	With ChEIs, if indicated
Upon diagnosis of probable or possible Alzheimer's Disease (NINCDS/ADRDA criteria)	After 3-6 months (for effect on cognition and function)		If, after 6 months, there is continued deterioration at pre-treatment rate	
Upon duration of Alzheimer's Disease symptoms for more than 6 months	After 6 months, and at least every 6 months thereafter (for effect on disease symptom progression)			

Table adapted from Hogan et al., 2007

### Other Pharmacotherapeutic Agents

There is insufficient evidence to recommend other pharmacological treatments for Alzheimer's Disease patients in general. Patients and their families should participate fully in the decision-making process, and individual decisions should be based on clear understanding of the probable benefits and risks of therapy and personal patient preferences.

Antioxidant therapy with vitamin E was reported in one trial to postpone functional decline (Sano et al., 1997) and delay institutionalization, but it does not appear to improve cognition (Doody et al., 2001). There is conflicting evidence whether dosages greater than 400 I.U. per day increase mortality risk and should be avoided (Miller et al., 2005). Although early studies suggested that estrogen or hormone replacement therapy may delay the onset of Alzheimer's Disease, more recent trials have shown no clear benefit (Hogervorst, Yaffe, Richards, & Huppert, 2002), and may indicate an increased risk of cognitive decline (Shumaker et al., 2003). Results of trials using ginkgo biloba have been negative or equivocal (Birks & Grimley Evans, 2007). Early studies indicated that nonsteroidal anti-inflammatory drugs may reduce neuronal damage and cognitive decline (Ham, 1997), but more recent investigations have shown negative results (Tabet & Feldman, 2003) (using ibuprofen) as well as serious adverse effects (Tabet & Feldman, 2002) (using indomethacin).

*Recommendations: Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family the use of cholinesterase inhibitors, NMDA antagonist, and other medications, if clinically indicated, to treat cognitive decline.*

### Treatment: Referral to Community-Based Services

The PCP is in a unique and influential position to direct the Alzheimer's Disease patient and family to available resources that may assist in care provision and improve the quality of life of both patient and caregiver (Lyketos et al., 2006; Post & Whitehouse, 1995; Winslow, 2003). To successfully navigate the challenging and unpredictable course of Alzheimer's Disease, patients and their families need a variety of community-based and long-term care resources as a complement to PCP care. Such services range from legal and financial planning early in the disease to skilled nursing care and hospice at the end of life, as detailed in Table T5 in this section.

A recent review of charts for 240 managed care patients aged 75 and over with dementia (Boise, Neal, & Kaye, 2004) found so few references to non-pharmacological management or referrals to community services that the researchers chose not to report these data. Given the wide range of services needed and the variety of community-based and institutional care settings, PCPs often fail to make referrals due to a lack of sufficient knowledge about resources (Hinton et al.,

2007; Reuben, Roth, Kamberg, & Wenger, 2003). Availability of a knowledgeable care manager in the primary care setting can ease the burden on the PCP and ensure follow-through on the part of the family (Callahan et al., 2006; Cherry et al., 2004; Vickrey et al., 2006).

Patients in the early stages of Alzheimer's Disease may derive significant benefits from use of community-based services focusing on their needs. In a study carried out at an interdisciplinary center for older adults in Florida that offered education, therapy, and psychosocial support for both individuals with memory loss and their family members, researchers found positive effects on cognition, affect, health, self-esteem, and stress (Buettner, 2006; Buettner & Fitzsimmons, 2006). A recent review of the literature and consensus report on the needs of early-stage patients (Alzheimer's Association, 2007a) found strong enough evidence in favor of such programs to support a recommendation that development of community-based early dementia programs be considered a "National Healthcare Priority."

Given the increasing structure, support, and personal assistance needed by a person with Alzheimer's Disease as cognitive impairment worsens, adult day care is one of the best care settings for the mid-stage individual living in the community. As compared to non-users, caregivers of Alzheimer's Disease patients using adult day services report (a) fewer difficult-to-manage care recipient behaviors and less time spent managing these symptoms (Gaugler et al., 2003a); (b) fewer hours managing memory difficulties and impairments in activities of daily living and, consequently, less burden, worry, and strain (Gaugler et al., 2003b); (c) fewer recreational restrictions and conflicts between caregiving and other responsibilities (e.g., job requirements, family needs) (Schacke & Zank, 2006); (d) a better relationship with the affected individual (Dziegielewski & Ricks, 2000); and (e) lower levels of depression, anger, and perceived overload and strain (Zarit, Stephens, Townsend, & Greene, 1998). To achieve benefits, it is recommended that the Alzheimer's Disease patient attend adult day services at least two days per week for an extended period of at least three months, as this dose has been found to result in significantly less caregiver burden (Zarit et al.). Finally, sustained use of adult day services can delay nursing home placement, particularly when started early (Zarit et al.). When nursing home placement does occur, previous use of adult day services may attenuate the cognitive decline associated with institutionalization (Wilson, McCann, Li, Aggarwal, Gilley, & Evans, 2007).

In the adult day services setting, Alzheimer's Disease patients have access to activities which have been shown to benefit these individuals. Such activities include music therapy, which can improve social and emotional skills, decrease behavioral symptoms, and aid recall (Ziv, Granot, Hai, Dassa, & Haimov, 2007); reminiscence, which can promote interpersonal connections (Kasl-Godley & Gatz,

2000); and walking and other forms of physical exercise, which can improve cognition, mood, sleep, and functional ability (Eggermont, van Heuvelen, van Keeken, Hollander, & Scherder, 2006; Williams & Tappen, 2007).

In making referrals to adult day services or any other community-based services, it is essential that recommendations be individualized to the particular patient's and/or family's needs. It is particularly important that PCPs attend to cultural and language issues (see Assessment section). Referrals must be made to services that are consistent with cultural values and to organizations that can accommodate the needs (e.g., language) of individuals from different ethnic backgrounds. For example, referral to an adult day services center or other organization that does not have any staff members who speak the patient's and/or caregiver's primary language may be more confusing and distressing than use of other community-based services that are linguistically equipped to assess and address the needs of the family. Several state-wide and national organizations, such as the Alzheimer's Association and the California Caregiver Resource Centers, serve as clearinghouses for community services and offer services themselves, such as helplines, information, advice, assessment, referral, and support groups (Friss, 1993). Social workers and "care managers" can offer counseling and link patients and family with needed community resources in a culturally appropriate environment (Lyketsos et al., 2006).

Use the contact information in Table T5 to obtain referrals and information regarding:

- Adult day services
- Assisted living
- Caregiver and patient education programs
- Caregiver-physician communication education programs
- Continuing care retirement communities
- Early Stage programs
- Exercise programs
- Home health care

- Homemaker/ companion services
- Hospice
- Home-delivered meals
- Legal services
- Nursing homes
- Residential care (board & care)
- Respite care
- Support groups

*Recommendations: Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family referrals to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation.*

### **Treatment: Behavioral Symptoms and Mood Disorders**

Behavioral symptoms and mood disorders are among the most difficult aspects of Alzheimer's Disease for both patients and caregivers, and the most common, affecting up to 90% of people with Alzheimer's Disease at some point in their illness (De Deyn et al., 2005). They are major causes of excess disability, patient distress, caregiver burden, and institutionalization (Conn & Thorpe, 2007; De Deyn et al.). These symptoms encompass a spectrum of behaviors including apathy, wandering, agitation, verbal and physical aggression, and psychotic symptoms, and may range from annoying or disruptive to threatening and dangerous. Except for emergency situations, non-pharmacological strategies are the preferred first-line treatment approach for behavioral problems. Medications should be used only as a last resort, if non-pharmacological approaches prove unsuccessful and they are clinically indicated.

A sudden onset of, or acute change in, behavioral symptoms requires that the PCP rule out any medical explanations, including pain, infection, or medication-related causes. Often, behavioral symptoms represent the only ways in which peo-

**Table T5: Support Organizations and Resources for Alzheimer's Disease Patients and Caregivers**

Organization	Telephone	Website
Alzheimer's Association	(800) 272-3900	www.alz.org
Alzheimer's Disease Education and Referral (ADEAR) Center	(800) 438-4380	www.niapublications.org/adear
Alzheimer's Disease Research Centers of California	(916) 552-8995	www.dhs.ca.gov/alzheimers
Area Agencies on Aging	(800) 510-2020	www.c4aging.org
Family Caregiver Alliance (Caregiver Resource Centers)	(800) 445-8106	www.caregiver.org
Eldercare Locator for Continuum of Services	(800) 677-1116	—

*Table adapted from Hogan et al., 2007*

ple with severe Alzheimer's Disease can communicate such problems to their caregivers (Smith & Buckwalter, 2005). Once other medical problems have been ruled out, a behavioral assessment should be conducted (see Assessment section) and non-pharmacological strategies for management of the behavioral symptoms should be implemented. To accurately and appropriately target interventions, this assessment should include frequency, severity, timing, and precipitating factors as well as possible consequences of the symptoms. Immediate protection of the patient or caregiver may be necessary or, at the least, education and support should be made available to an overwhelmed caregiver (see Patient and Family section). This education and support is available through the Alzheimer's Association and other community organizations.

Expert opinion and Workgroup consensus suggest that successful management of behavioral symptoms requires the PCP to develop early, appropriate, and individualized care plans which must be re-evaluated regularly (Allen-Burge, Stevens, & Burgio, 1999; Boucher, 1999; Cohen-Mansfield, 2000; Cohen-Mansfield & Werner, 1998; Colling, 1999; Lee, Strauss, & Dawson, 2000; Logsdon, McCurry, & Teri, 2007; Sink, Holden, & Yaffe, 2005; Zgola, 1999). Not every behavioral symptom is a problem or requires intervention. In general, steps to managing challenging behaviors include identifying the behavior, understanding its cause, and adapting the treatment plan to remedy the situation (Cherry, 1997; Woods & Roth, 1996). Interventions should begin with the least restrictive alternative and should focus on ensuring safety; assisting the caregiver to understand the underlying cause of the behavior; simplifying the environment and routines; and distracting, rather than confronting, arguing, or disagreeing with the patient (Teri, Logsdon, & McCurry, 2002).

Pharmacological interventions should target one or more of the specific behavioral syndromes associated with Alzheimer's Disease, which have been identified as aggression, non-aggressive agitation, psychosis, and mood disorders (Ballard, Waite, & Birks, 2006). Atypical antipsychotics such as risperidone and olanzapine may be useful in the treatment of aggression and psychosis in Alzheimer's Disease patients, but the potential for serious adverse effects including increased risk of stroke, extrapyramidal disorders, and mortality (Recupero & Rainey, 2007), as well as limited evidence of their effectiveness (Schneider et al., 2006; Sink et al., 2005), argue against the use of these medications in the majority of cases.

### **Non-pharmacological Approaches for Behavioral Symptoms**

Recent meta-analyses do not provide strong evidence for the effectiveness of many specific non-pharmacological approaches for the treatment of behavioral symptoms (Ayalon, Gum, Feliciano, & Areán, 2006; Livingston, Johnston, Katona, Paton, & Lyketsos, 2005; Verkaik, van Weert, & Francke, 2005). However, non-pharmacological strategies

often better address the underlying reason for the behavior, avoid both the risks and limitations of pharmacological interventions, and prevent medicating away adaptive or helpful behaviors (Cohen-Mansfield, 2001). There is also evidence that they may delay the need for institutionalization and reduce caregiver burden (Logsdon et al., 2007). The literature consists primarily of case studies and limited trials of such non-pharmacological interventions as Snoezelen (Chung & Lai, 2002), music (Vink, Birks, Bruinsma, & Scholten, 2003), aromatherapy (Ballard, O'Brien, Reichelt, & Perry, 2002), bright lights (Forbes, Morgan, Bangma, Peacock, & Adamson, 2004), massage and touch (Viggo Hansen, Jørgensen, & Ørtenblad, 2006), validation (Neal & Barton Wright, 2003; Tondi, Ribani, Bottazzi, Viscomi, & Vulcano, 2007), and reminiscence (Woods, Spector, Jones, Orrell, & Davies, 2005). Although many have reported positive findings, rigorous reviews have shown them to be inconclusive (Chung & Lai; Neal & Barton Wright; Woods et al.); however, this may indicate a need for further study rather than ineffectiveness (Hermans, Htay, & McShane, 2007; Hogan et al., 2007; Logsdon et al.). Several specialty organizations strongly recommend that non-pharmacological interventions be employed as the first line of treatment for behavioral symptoms (e.g., the American Academy of Neurology [Doody et al., 2001], American Association for Geriatric Psychiatry [Lyketsos et al., 2006], and American Psychiatric Association [2007]).

As noted above, non-pharmacologic interventions may begin with a modification of the patient's environment and routine (see Table T6 in this section). Special attention should be paid to the triggers of the problem behavior to select effective, individualized interventions. The goal is often reduction or modification of the behavior rather than total elimination. The PCP should encourage the establishment of an exercise routine for the patient, to maintain ambulation and improve patient behavior and mood (Lyketsos et al., 2006; Teri et al., 2003). Although evidence for the latter effect is mixed (Livingston et al., 2005), a recent study involving 90 nursing home residents with mostly moderate-to-severe Alzheimer's Disease found that participation in a comprehensive group exercise program resulted in significantly greater improvement in affect and mood than either supervised walking or non-therapeutic conversation groups (Williams & Tappen, 2007). There is strong evidence in support of non-pharmacologic measures for management of Alzheimer's Disease-related behavioral symptoms in general (Livingston et al.; Logsdon et al., 2007), including:

- Intervene early to prevent escalation;
- Remain calm, using a gentle, reassuring voice, and maintain eye contact;
- Provide the patient with a structured, predictable routine (exercise, meals, and bedtime should be routine and punctual);
- Use visual cues or barriers to discourage wandering and direct the patient away from unsafe areas;

**Table T6: Non-pharmacological Approaches for Common Behavioral Symptoms and Mood Disorders**

Behavioral Symptom	Non-Pharmacological Interventions
Apathy	Stimulation/activities Simple tasks
Sleep disturbances	Sleep hygiene practices Stimulation during the day (esp. adult day services) Reduction of excessive stimulation/noise in the evening
Irritability/agitation	Breakdown of tasks into simple steps Redirection
Wandering	Visual cues Exercise Safe places to wander Enrollment in MedicAlert® + Safe Return®
Mood disorders	Exercise
Psychotic symptoms	Reassurance Distraction rather than confrontation Removal of potential sources of confusion (e.g., mirrors)
Eating/appetite disorders	Offering simple, finger foods Removal of distractions from dining area Soothing music

*Table adapted from Teri et al., 2002; Teri et al., 2003*

- Explain all procedures and activities slowly and in simple, straightforward terms;
- Simplify tasks by breaking them down into easy, manageable steps;
- Allow patients to dress in their own clothing and maintain possessions;
- Use calendars, clocks, labels, or newspapers for orientation to time;
- Reduce excess stimulation, including noise from TV and household clutter;
- Avoid glare from windows and mirrors;
- Provide a safe environment free of sharp-edged furniture, slippery floors or throw rugs, and obtrusive electric cords;
- Equip doors and gates with safety locks;
- Install grab bars by the toilet and in the shower;
- Use lighting to reduce confusion and restlessness at night;
- Use distraction and redirection of activities; and
- Provide music of the patient's choosing, especially during meals and bathing

Caregivers can be taught techniques for managing behavioral symptoms (Haupt, Karger, & Janner, 2000; Logsdon, McCurry, & Teri, 2002; Mittelman, 2004; Sörensen, Pinquart, & Duberstein, 2002). One well-established approach for caregivers is the ABC (Antecedent-Behavior-Consequence) model of behavioral analysis (Teri, 1990; Teri et al., 2002; Volicer & Hurley, 2003), which seeks to identify the precipitants (antecedents) of a specific behavior and its effects on the patient, caregivers and others (consequences) in order to help caregivers better understand and modify the context in which behavioral symptoms occur. Helping patients to “redirect and refocus” by distracting them from upsetting or dangerous activities in favor of more appropriate ones is another useful approach (Teri et al., 2002). Recent research has shown that training caregivers in these strategies can reduce frequency and severity of behavioral symptoms as well as caregiver depression and burden (Mittelman et al.; Teri, McCurry, Logsdon, & Gibbons, 2005; Volicer & Hurley). Caregiver knowledge of dementia management also has been demonstrated to produce higher quality of care for patients with dementia (Chodosh et al., 2007). Caregiver support groups sponsored by the Alzheimer's Association or Caregiver Resource Centers are an excellent resource for caregivers to learn these and other management strategies.

### Pharmacologic Interventions for Behavioral Symptoms

When non-pharmacological approaches fail to treat agitation or other behavioral symptoms, psychotropic medications may be used in the management of some symptoms, but must be used with caution due to potential drug interactions and side effects. Symptoms or behaviors may respond to medication, but treatment is not likely to eliminate them completely. When prescribing pharmaceutical agents, side effects should be closely monitored (American Psychiatric Association, 2007; Doody et al., 2001; Ham, 1997; Lyketsos et al., 2006).

There are several key factors that are influential in medication prescription. These include awareness of potential drug-drug and drug-disease interactions and side effects (e.g., worsening of cognitive impairment, increased susceptibility to falls); always using low starting doses and small increases; and avoiding non-essential medications. Table T7 below in this section includes a description of pharmacologic agents, recommended use, cautions in use, and potential side effects.

Behavior-controlling drugs should be used cautiously and only for narrowly specified, predetermined goals, which must be monitored (Gambert, 1997; Lyketsos et al., 2006; Post & Whitehouse, 1995). PCPs should take the extra time to explain possible benefits and side effects and establish criteria on which to base a decision for continuation. It is also recommended that clinicians begin with low doses (American Psychiatric Association, 2007), which may be increased slowly until the behavior has improved, or adverse effects emerge.

The use of psychotropic medications with Alzheimer's Disease patients remains controversial, and no agents are approved by the U.S. Food & Drug Administration (FDA) for use in people with Alzheimer's Disease. A number of recent clinical trials have examined their use in treating behavioral symptoms of Alzheimer's Disease:

#### ***Benzodiazepines***

Benzodiazepines and similar agents that may be used for anxiety, insomnia, and agitated behaviors increase the risk for falls, cause confusion, worsen memory impairment, and may (in rare cases) lead to a paradoxical disinhibition (Grossberg & Desai, 2003; Sink et al., 2005).

#### ***Antidepressants***

A recent systematic review of controlled clinical trials of antidepressant use in patients with dementia experiencing depressive symptoms (Bains, Birks, & Denning, 2002) concluded that the evidence for use was weak. The weakness of evidence could be due in large part to the fact that only a few small studies have been published.

#### ***Atypical Antipsychotic Agents***

Evidence exists to support the use of select atypical antipsychotic agents for the management of psychotic and aggressive behaviors. A recent meta-analysis of randomized, placebo-controlled trials of atypical antipsychotics (Ballard et al., 2006) found that risperidone and olanzapine reduced aggression, and risperidone reduced psychosis. Their use, however, was accompanied by a significantly increased risk for cerebrovascular events. Reviews conducted by the FDA and others (Carson, McDonagh, & Peterson, 2006; Schneider, Dagerman, & Insel, 2005) also identified an increased risk for mortality among dementia patients, and the FDA has issued a "black box" warning with respect to the use of atypical antipsychotics in the treatment of behavioral symptoms of Alzheimer's Disease (American Academy for Geriatric Psychiatry, 2005a; Lyketsos et al., 2006). In addition, Alzheimer's Disease patients in one study treated with atypical antipsychotics scored significantly worse on a recent autobiographical memory measure than did patients who were not taking antipsychotics (Harrison & Therrien, 2007). In some cases, however, there may be no better option than atypical antipsychotics for treating Alzheimer's Disease patients with serious behavioral symptoms (American Academy for Geriatric Psychiatry, 2005b; Madhusoodanan, Shah, Brenner, & Gupta, 2007).

#### ***Typical Antipsychotic Agents***

A meta-analysis of older, typical antipsychotic agents suggests that the increased risk for serious adverse events, such as stroke, heart attack, and pulmonary infections, is about the same as for atypical antipsychotics (Wang et al., 2005). However, the risk for developing tardive dyskinesia is much lower with the atypical agents.

#### ***Anticonvulsants***

Recent studies of the use of anticonvulsants for the management of behavioral and psychological symptoms in patients with Alzheimer's Disease have yielded conflicting results: only two (carbamazepine and valproate) have been the subjects of randomized, controlled, double-blind clinical trials. Although carbamazepine demonstrated significant improvement of symptoms, it should be used with caution due to possible drug interactions and negative side effects; valproate was not shown to be more effective than placebo (Herrmann, Lanctôt, Rothenburg, & Eryavec, 2007; Konovalov, Muralee, & Tampi, 2008).

Two studies have noted that patients' responses to medications, including psychotropic medications (e.g., neuroleptics, tricyclic antidepressants, etc.), can be affected by biological differences, eating behaviors, and/or environmental conditions that affect both drug metabolism and distribution in the body (pharmacokinetics) and the body's response to the drug (pharmacodynamics) (Lin, Anderson, & Poland, 1995; Lin, Poland, & Anderson, 1995). The PCP should review the patient's history with a particular medication if taken before, or responses to other medications that might come from the same class as the psychotropic medication in question.

***Recommendations: To summarize specific recommendations with respect to pharmacologic management of behavioral symptoms:***

- ***Prior to initiating treatment with new medication, consider whether the behavior may be caused or exacerbated by a current medication.***
- ***Delirium, pain, or an acute medical condition (e.g., UTI, constipation, pneumonia) should be ruled out as a cause of the behavior.***
- ***Medications used for managing behavioral symptoms should be used cautiously. Little evidence exists to support their efficacy, with the exception of atypical antipsychotics (Schneider et al., 2005).***
- ***Systematic trials of single agents should be tried rather than the use of multiple agents.***
- ***Start with low doses and increase gradually until a therapeutic effect is achieved, which may require a few weeks (Grossberg & Desai, 2003).***
- ***Periodically reduce psychopharmacologic agents after behavioral symptoms have been controlled for 4 to 6 months to determine whether continuing pharmacotherapy is required (American Psychiatric Association, 2007; Cummings & Benson, 1992; Lyketsos et al., 2006).***

**Table T7: Pharmacological Treatment of Behavior and Mood****ANTIPSYCHOTICS**

Recommended Uses: Used to control problematic delusions, hallucinations, severe psychomotor agitation, and combativeness. CAUTION: These are NOT FDA-approved for dementia treatment. Should be reserved for use only when other treatments have failed. PCPs may want to refer patient to a geriatric psychiatric specialist.

**ATYPICAL ANTIPSYCHOTICS (Second Generation Antipsychotics)**

General Cautions: Diminished risk of developing extrapyramidal symptoms (EPS) and tardive dyskinesia relative to typical antipsychotics, but use has been associated with increased risk for stroke. Overall risk for morbidity and mortality = typicals (e.g., haloperidol). Not FDA-approved for dementia treatment.

Agent	Dosage	Comments and Cautions
Aripiprazole (Abilify®)	Initial dose: 5 mg/day (range 5 to 10 mg/day) 2 mg/day = placebo (Mintzer et al., 2007)	Generally classified as non-sedating, weight neutral Dopamine blocker with agonist properties Modest documentation
Clozapine (Clozaril®)	Initial dose: 12.5 mg twice daily- Max: 75-150 mg (in divided doses)	Generally not used as a first line agent Mandatory weekly blood monitoring and patient monitoring registry <i>Black Box Warnings:</i> adverse cardio/respiratory effects (orthostatic hypotension, cardiac and respiratory arrest with benzodiazepines), agranulocytosis, seizures, myocarditis Do not use with bactrim or tegretol (due to increased risk of agranulocytosis), benzodiazepines (due to additive CNS depression), cogentin or benadryl (due to strong anticholinergic effect) Levels substantially increased by fluvoxamine, fluoxetine, ciprofloxacin; decreased by smoking Must monitor HgbA1c, blood sugar (for possible new onset diabetes) and cholesterol every 3 months
Olanzapine (Zyprexa®)	Initial dose: 2.5 mg at bedtime (generally < placebo except for anxiety) Max: 7.5 to 10 mg/day (15 mg /day = placebo)-Injectable: 2.5 to 5 mg IM (De Deyn et al., 2004; Meehan et al., 2002; Street et al., 2000)	Has anticholinergic activity, may impair gait-Must monitor HgbA1c, blood sugar (for possible new onset diabetes) and cholesterol every 3 months Avoid in LBD and PD Worst offender DM, Chol wt gain Modest documentation efficacy in AD (Chengappa et al., 2000; Goetz, Blasucci, Leurgans, & Pappert, 2000)
Quetiapine (Seroquel®)	Initial dose: 12.5 mg twice daily or 25 mg at bedtime. Max: 200 mg twice daily Therapeutic dose in AD not very firm (Rainer, Haushofer, Pfolz, Struhal, & Wick, 2007; Zhong, Tariot, Mintzer, Minkwitz, & Devine, 2007)	More sedating; beware of transient orthostasis Minimal EPS, similar to placebo Limited documentation
Risperidone (Risperdal®)	Initial dose: 0.25 mg at bedtime or 0.25 mg po BID Effective dose 1 mg/day	Current research supports its use in low doses EPS more common at 2 mg Should monitor HgbA1c, blood sugar (for possible new onset diabetes) and cholesterol every 3 months Has best documentation for BSPD use (Brodaty et al., 2003; De Deyn & Buitelaar, 2006; Katz et al., 1999)
Ziprasidone (Geodon®)	Initial dose: 10 mg/day Max: 80 mg/day -Injectable: 20 mg IM (Berkowitz, 2003; Kohen, Preval, Southard, & Francis, 2005)	Requires baseline and periodic EKGs for possible QTc elevation Should be given with food to increase bioavailability Generally classified as non-sedating, weight neutral Documentation: case reports

**Table T7: Pharmacological Treatment of Behavior and Mood, con't.****TYPICAL ANTIPSYCHOTICS**

General Cautions: Current research suggests that these drugs be avoided, if at all possible. They are associated with significant, often severe, side effects involving the cardiovascular, and extrapyramidal systems. There is also the inherent risk of developing irreversible tardive dyskinesia, which can occur in 50% of elderly after two years of continuous use. Not FDA-approved for dementia treatment.

Agent	Dosage	Comments and Cautions
Chlorpromazine (Thorazine®)	Do not use for behavioral psychiatric problems	Significant hypotension, anticholinergic symptoms, and drowsiness limit their usefulness May be used for intractable hiccups, nausea/vomiting, etc.
Haloperidol (Haldol®)	—	Anticipate EPS. If present, lower the dose or switch to another agent Haloperidol parenteral may be useful in acute behavioral issues that require a rapid response
Thioridazine (Mellaril®) Benzotropine mesylate (Cogentin®) Fluphenazine (Prolixin®) Loxapine (Loxitane®) Molindone (Moban®) Perphenazine (Trilafon®) Thiothixene (Navane®) Trihexyphenidyl (Artane®) Trifluoperazine (Stelazine®)	No recommended dose	Thioridazine SHOULD NOT be prescribed for AD patients Avoid other agents listed here in AD psychiatric behavioral conditions as well

**MOOD STABILIZERS (ANTI-AGITATION AGENTS)**

Recommended Uses: Used to control problematic delusions, hallucinations, severe psychomotor agitation, and combativeness. Useful alternatives to antipsychotics for severe agitated, impulsive, repetitive, and combative behaviors. General Cautions: Not FDA-approved for dementia treatment

Agent	Dosage	Comments and Cautions
Carbamazepine (Tegretol®)	Initial dose: 25 mg twice daily;-Titrate to maximum of 300 mg daily in divided doses	Monitor CBC and liver enzymes regularly Drug Interactions Problematic side effects-One controlled study (Tariot et al., 1998)
Valproate (Depakote®)	Initial dose: 125 mg daily Generally Titrate to maximum of 500 mg twice daily, although some may go higher	Monitor liver enzymes; platelets & PT/PTT as indicated Note: added lab tests increase cost and discomfort for the patient <i>Black Box Warnings:</i> pancreatitis, hepatotoxicity Poorly documented efficacy For impaired impulse control, aggressive behavior, etc., consider a SSRI (Konovalov et al., 2008, Lonergan & Luxenberg, 2004)

**Table T7: Pharmacological Treatment of Behavior and Mood, con't.****ANXIOLYTICS—BENZODIAZEPINES**

Recommended Uses: For management of insomnia, anxiety, and acute agitation. The BDZs as a class should be avoided if possible, but can be useful in the short term and in patient specific instances.

General Cautions: High risk for cognitive impairments as well as the risk for falls. Paradoxical agitation possible, but rare. Infrequent, low doses 1/3 to 1/2 the usual adult dose are least problematic. Regular use can lead to tolerance, addiction, depression. Watch for ETOH consumption with BDZ.

Agent	Dosage	Comments and Cautions
Alprazolam (Xanax®)	In general, for all of the BDZs, order one-third to one-half the usual adult starting dose	High potency, intermediate acting Withdrawal symptoms may be problematic
Clonazepam (Klonopin®)	1 mg clonazepam = 1 mg lorazepam	High potency, long acting Can be useful in BDZ withdrawal No active metabolite
Diazepam (Valium®)	—	Low potency, intermediate acting Has active metabolites, resulting in accumulation of the drug in the elderly
Lorazepam (Ativan®)	1 mg of lorazepam = 5 to 10 mg of diazepam oral, sublingual, parenteral	High potency, intermediate acting NOTE: Lorazepam is not short-acting and is not safer than other BDZs The elderly are more sensitive to BDZs than younger patients
Oxazepam (Serax®)	—	Low potency, intermediate acting
Temazepam (Restoril®)	—	Low potency, intermediate acting
Tiazolam (Halcion®)	Generally avoid use (exception: oral sedation for some dental procedures)	High potency, short acting Rebound insomnia

**ANXIOLYTICS—NON-BENZODIAZEPINES**

Agent	Dosage	Comments and Cautions
Buspirone (Buspar®)	Initial dose: 5 mg twice daily Max: 20 mg three times daily	May be useful in mild-moderate agitation only May take 2-4 weeks to become effective Poorly documented efficacy
Zolpidem tartrate (Ambien®)	Non-BDZ sleep med. 5 mg orally at bedtime	Reduced hepatic clearance in the elderly Amnestic syndrome, sleep walking, hallucinations Note: in one study (adults, primary insomnia) trazodone was as effective as zolpidem at one week, slightly less effective at week two (Walsh et al., 1998)

**Table T7: Pharmacological Treatment of Behavior and Mood, con't.****ANTIDEPRESSANTS—TRICYCLICS**

General Cautions: Selection is usually based on previous treatment response, tolerance, and taking advantage of potentially beneficial side effects, e.g., sedation vs. activation. A full therapeutic trial requires at least 4-8 weeks. As a rule, doses are increased using increments of the initial dose every 5-7 days until therapeutic benefits or significant side effects become apparent. After 9 months, reassess need for medications by dose reductions. Discontinuing medication over 10-14 days limits withdrawal symptoms. Note: Depressed patients with psychosis require concomitant antipsychotic treatment.

Agent	Dosage	Comments and Cautions
Desipramine (Norpramin®/Petrofrane®)	Initial dose: 10-25 mg daily Max: 150 mg daily	Tends to be activating, give in AM Lower risk for hypotensive and anticholinergic side effects (anticholinergic activity less than paroxetine) May cause tachycardia
Doxepin (Sinequan®/Adapin®)	Initial dose: 10-25 mg at bedtime Max: 150 mg daily HS-Note: All TCAs have high risk of OD	Significant hypotensive and anticholinergic effects are limiting
Nortriptyline (Aventyl®/Pamelor®)	Initial dose: 10 mg at bedtime Max: 100 mg daily	Tolerance profile similar to desipramine but tends to be more sedating, more anticholinergic Moderate anticholinergic activity Moderate sedation may be useful for agitated depression and insomnia

**ANTIDEPRESSANTS—HETERO- AND NONCYCLICS****SELECTIVE SEROTONERGIC REUPTAKE INHIBITORS (SSRIs)**

General Cautions: These agents may prolong the half-life of other drugs by inhibiting various CYP450 isoenzymes. As a class, typical side effects can include sweating, tremors, nervousness, insomnia/somnolence, dizziness, and various gastrointestinal and sexual disturbances. Withdrawal effects may occur if agents are abruptly discontinued

Agent	Dosage	Comments and Cautions
Citalopram (Celexa®)	Initial dose: 10 mg daily Max: 40 mg daily	Well tolerated; nausea and sleep disturbances in some Demonstrated efficacy for treatment of BPSDs (comparable to risperidol) (Pollock et al., 2007); comparable to perphenazine (Pollock et al., 2002); both significantly more effective than placebo
Escitalopram (Lexapro®)	Initial dose: 10 mg daily Max: 20 mg/day	Well tolerated; nausea and sleep disturbances in some
Fluoxetine (Prozac®)	Initial dose: 10 mg every other day Max 20 mg daily	Activating Very long half life Side effects may not manifest for a few weeks
Fluvoxamine (Luvox®)	Initial dose: 25 mg daily Max: 100 mg twice daily- Reduce by half when using with Coumadin, Xanax, or Halcion	—
Paroxetine (Paxil®)	Initial dose: 10 mg daily Max: 40 mg daily	Less activating but more anticholinergic than fluoxetine
Sertraline (Zoloft®)	Initial dose: 25 mg daily Max: 200 mg daily	Well-tolerated Less effect on metabolism of other medications

**Table T7: Pharmacological Treatment of Behavior and Mood, con't.**

## SEROTONIN/ NOREPINEPHRINE REUPTAKE INHIBITORS (SNRIs)

Agent	Dosage	Comments and Cautions
Duloxetine (Cymbalta®)	Initial dose: 20 mg/day Max: 60 mg/day	Activating Food delays absorption Causes low to no sexual dysfunction Avoid use in patients with liver impairment due to increased risk of liver toxicity
Venlafaxine (Effexor®)	Initial dose: 37.5 mg twice daily Max: 225 mg/day doses less than 150 mg/day only SSRI, need 150 to 225 mg/day for serotonin/noradrenergic activity	Activating Most potent SSRI-plus (also inhibits norepinephrine reuptake in divided doses or once daily as SR) Causes low to no sexual dysfunction Withdrawal symptoms can be severe

## ANTIDEPRESSANTS—TRICYCLICS

General Cautions: Selection is usually based on previous treatment response, tolerance, and taking advantage of potentially beneficial side effects, e.g., sedation vs. activation. A full therapeutic trial requires at least 4-8 weeks. As a rule, doses are increased using increments of the initial dose every 5-7 days until therapeutic benefits or significant side effects become apparent. After 9 months, reassess need for medications by dose reductions. Discontinuing medication over 10-14 days limits withdrawal symptoms. Note: Depressed patients with psychosis require concomitant antipsychotic treatment.

Agent	Dosage	Comments and Cautions
Benzodiazepines	—	Not recommended for use by AD patients; see Comments and Cautions above
Diphenhydramine	—	Not recommended for use by AD patients or elderly, due to anticholinergic properties; see Comments and Cautions above In older hospitalized patients, use is associated with increased risk of cognitive decline and other adverse effects with a dose response relationship (Agostini, Leo-Summers, & Inouye, 2001)
Trazadone (Desyrel)	25-100 mg at bedtime	Useful sedative for sleep at doses well below those required to treat depression. Minimal affect on sleep physiology and no discernible anticholinergic side effects
Zaleplon (Sonata®)	5-10 mg at bedtime	—
Zolpidem (Ambien®)	5-10 mg at bedtime	—

**Table T7: Pharmacological Treatment of Behavior and Mood, con't.****MISCELLANEOUS**

Agent	Dosage	Comments and Cautions
Bupropion (Wellbutrin®)	Initial dose: 37.50 mg daily, then to: Max Immediate Release: 150 mg three times daily Max Sustained Release: 150 mg twice daily Max Extended Release: 450 mg daily Note: when ordering specify "release form"	Activating; possible rapid improvement in energy level To minimize risk of insomnia, give second dose before 3 PM Causes low to no sexual dysfunction Avoid in agitated patients and those with seizure disorders
Lithium	Initial dose: 150 mg daily Blood levels between 0.2-0.6 meq are generally adequate; usually achieved with 150-300 mg twice daily	Anti-cycling agent that may also be used to augment antidepressant medication Elderly are prone to developing neurotoxicity at higher doses Baseline labs: TSH, SCr/BUN, electrolytes, urine specific gravity, EKG
Mirtazapine (Remeron®)	Initial dose: 7.5 mg at bedtime Max: 30 mg at bedtime	Generally well-tolerated-Promotes sleep (at lower doses) May increase appetite, weight gain Causes low to no sexual dysfunction
Nefazodone	Initial dose: 50 mg twice daily Max: 150-300 mg Liver toxicity limits use	Drug interactions 3A4 twice daily of co-administered Xanax/Halcion No sexual dysfunction
Trazodone (Desyrel®)	Initial dose: 25 mg at bedtime Max: 200-400 mg/day (divided doses)	Moderately effective; useful for associated HS and daytime for "agitation" Primarily used for insomnia; also anxiety AM orthostatic hypotension(rare) Administer with caution in patients with PVCs No sexual dysfunction Priapism is a known side effect Documentation fair, mostly clinical experience

**ELECTROCONVULSIVE THERAPY (ECT)**

(for use with patients non-responsive to or unable to tolerate pharmacological therapies)

Recommended Uses: For those at risk of injuring or starving themselves; the severely psychotic; and the patients not responding to, or intolerant of, pharmacologic treatments for depression.

BUT NOTE: There have been no adequate studies of ECT in demented patients to date (Katagai, Yasui-Furukori, Kikuchi, & Kaneko, 2007).

Table adapted from FDA approved package inserts

## Common Alzheimer's Disease-Related Behavioral Symptoms and Their Treatment

### Wandering

To assess wandering, caregivers should try to identify the triggers for wandering behaviors (e.g., boredom). Is there a goal for the wandering? Does the patient appear to be searching for something, or is it aimless wandering? The answers to these questions can help caregivers make behavioral modifications to reduce wandering (Futrell & Melillo, 2002). Daily exercise and redirection have been used successfully for this purpose (Dalsania, 2006); examples of other behavioral modifications include music therapy, bright light therapy, reality orientation, physical therapy, occupational therapy, and therapeutic touch, although their efficacy has yet to be demonstrated in randomized controlled trials (Hermans et al., 2007). Wandering is not likely to respond to pharmacologic intervention (Herrmann, Gauthier, & Lysy, 2007). Caregivers should be advised that wanderers burn extra calories, so additional snacks may need to be provided to decrease the risk of weight loss.

One of the main roles of the PCP is to advise families about the danger of wandering. In order to decrease the hazards, patients who wander should wear identification at all times. They should be given an unrestricted place to wander, such as a fenced yard. Doors and exits can be disguised with curtains or gridlines. Unnecessary clutter should be removed. In-house alarms or chimes may be used to prevent unsupervised wandering. Complex door locks or safety gates may be installed, although the need for easy exit in case of fire or other emergency must be kept in mind (Rowe & Glover, 2001). The Alzheimer's Association's MedicAlert® + Safe Return® program should be recommended to caregivers and families early in the treatment process, as it can help identify, locate, and return wandering or lost patients who have been registered with the program (Lachenmayr, Goldman, & Brand, 2000).

Current consensus is that pharmacologic treatments are not indicated for wandering, unless the wandering is due to anxiety from untreated depression.

### Depression

Depression is common in Alzheimer's Disease, affecting as many as 50% of patients (Lyketsos & Olin, 2002; Zubenko et al., 2003). Recognition of depression in Alzheimer's Disease requires awareness of the overlap in presenting symptoms of delirium, apathy syndrome, and the psychosis of Alzheimer's Disease (Jeste & Finkel, 2000). Health care providers need to be aware of how depression in Alzheimer's Disease manifests differently from that of other types of depression. For instance, the mood symptoms may wax and wane, and may be associated with irritability, anxiety, and further functional decline (Lyketsos & Lee, 2004). There is evidence that the nature of depressive symptoms changes with the severity of dementia, with symptoms of dysphoria being associated with

earlier stages of Alzheimer's Disease and agitation, apathy, and motor slowing being more typical of depressed patients in the later stages of the disease (Lyketsos & Olin; Wright & Persad, 2007). Fear, suspicion, and delusions may be found in a third of Alzheimer's Disease patients with depression; therefore, the PCP must recognize that presence of these behavioral symptoms may indicate an underlying depression (Zubenko et al.).

Collateral information from the caregiver is essential in diagnosing behavioral symptoms such as depression, and the PCP may find the Cornell Depression Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988) (see Appendix E), which includes caregiver input, to be a useful tool in diagnosing and treating major depression and monitoring suicidal potential. Consultation with and/or referral to a psychiatrist is warranted if the Alzheimer's Disease patient with depression has high medical comorbidity or other diagnostic and treatment concerns. Moderate evidence exists for the efficacy of exercise training to reduce depressive symptoms (Teri et al., 2003), as well as pharmacologic treatment (e.g., sertraline hydrochloride) (Lyketsos et al., 2003).

One of the most effective behavioral treatments for depression involves increasing pleasurable activities (Lewinsohn, Sullivan, & Grosscup, 1980), and this strategy has been tested successfully in persons with Alzheimer's Disease (Teri, McKenzie, & LaFazia, 2005). Research has demonstrated that depression in persons with mild-to-moderate Alzheimer's Disease may be reduced by having caregivers plan and carry out pleasant activities with their loved ones (Teri & Uomoto, 1991), a finding replicated through a controlled clinical trial with moderately impaired individuals (Teri, Logsdon, Uomoto, & McCurry, 1997). Recreationally oriented programs (e.g., adult day services and early stage programs) offer another means of increasing pleasurable experiences for the person with Alzheimer's Disease through involvement in art, writing, music, and other meaningful, productive activities.

Depression occurs frequently in individuals with mild or early-stage Alzheimer's Disease (Hogan et al., 2007), and is often among the initial symptoms of the disease (Lyketsos & Olin, 2002). Recommendations for early-stage Alzheimer's Disease should include non-pharmacological as well as pharmacological approaches to reduction of depressive symptoms when present (see Patient and Family Education and Support section). In one recent study, persons with early-stage Alzheimer's Disease who participated in recreational activities designed to stimulate cognitive, physical, and psychosocial well-being were significantly less depressed at both 6- and 12-month follow-ups than their peers who did not participate (Buettner, 2006).

### Agitation

Agitated behavior, a complex and multidimensional issue in terms of both assessment and intervention, is a frequent symptom in Alzheimer's Disease patients (McGonigal-Kenny & Schutte, 2004). Categories of interventions include

modifying the environment, interpersonal strategies, and use of physical or chemical restraints (Roper, Shapira, & Chang, 1991). In accordance with studies conducted in the nursing home environment, the use of restraints is not recommended (Post & Whitehouse, 1995; Warshaw, Gwyther, Phillips, & Koff, 1995), as it has been found to increase mortality (Bredthauer, Becker, Eichner, Koczy, & Nikolaus, 2005; Hamers & Huizing, 2005). With respect to medication, anxiety and agitation that cannot be handled by gentle reassurance may respond to short-acting anxiolytics, such as oxazepam or lorazepam (both of which may have significant adverse effects) (Sink et al., 2005), or citalopram (Herrmann & Lanctôt, 2007; Pollock et al., 2007; Pollock et al., 2002).

### Sleep disorders

Sleep disturbances are common and pharmacologic intervention should be considered only when other non-pharmacologic interventions have failed (American Psychiatric Association, 2007). A study conducted with patients in the moderate stages of Alzheimer's Disease demonstrated that a combination of "sleep hygiene" education for caregivers and daily walking for patients effectively reduced sleep disturbances, such as nighttime awakenings, and depression (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005). Elements of the "sleep hygiene" intervention included the following:

- The sleeping area should be free of distractions and might contain nightlights if helpful to the patient.
- Naps should be limited and kept short.
- Increased exercise or activity should be provided in the morning and early afternoon.
- Patients should be dressed during daytime hours.
- Caffeine and nicotine should be avoided, and nighttime fluids and diuretics should be restricted.

More recently, participation in a high-quality adult day services program by itself was shown to improve nighttime sleep by keeping dementia patients engaged and reducing inactivity during the day (Femia, Zarit, Stephens, & Greene, 2007). In addition, warm milk and tryptophan before sleep may be helpful, as may a tepid bath or light snack high in carbohydrates (Warshaw et al., 1995). However, families typically need assistance in setting up and maintaining such routines; caregiver education alone is often insufficient (McCurry et al., 2005).

Pharmacologic treatment of sleep disorders must take into account whether depressive symptoms, fear, pain, or side effects from other drugs underlie the insomnia (Warshaw et al., 1995). Great caution must be exercised and caregivers warned because of the possibility of reactions to major tranquilizers, which may include incontinence, instability and falls, and agitation. Antidepressants (e.g., Trazadone), minor tranquilizers, or benzodiazepines may suffice in intermittent short-term doses, but should be terminated at the earliest possible time (Warshaw et al.). Use of various dopamine

agonists has been described in case reports, but the efficacy of these drugs has not been demonstrated in controlled studies. Simple remedies, such as use of melatonin, may help insomnia. For stronger sedation, a low dose of antipsychotic is preferable to a longer-acting benzodiazepine, which often has lingering effects. Diphenhydramine hydrochloride (over-the-counter) should be avoided because it may increase confusion due to its anticholinergic effects (Inouye, 1998). Although zolpidem, zaleplon, and ramelteon have been used safely in the elderly (Glass, Lanctôt, Herrmann, Sproule, & Busto, 2005), they have not been studied specifically with respect to the insomnia associated with Alzheimer's Disease. (See Table T7 in this section for more information regarding pharmacological treatment of these symptoms.)

*Recommendations: Treat behavioral symptoms and mood disorders using:*

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

### Treatment: Comorbid Medical Conditions

When treating the Alzheimer's Disease patient's other chronic and acute medical conditions, the PCP must be aware that cognitive impairment will often have an impact on the patient's ability to manage these conditions (e.g., by forgetting to take required medications), and that this impact will increase as Alzheimer's Disease progresses. Regular surveillance is necessary, and expert consensus suggests that health maintenance visits should be scheduled at least every six months, or more frequently if required by the patient's health (see Assessment section). Whenever new treatment plans or interventions are considered, the PCP must assess the patient's (and caregiver's) ability both to understand and to participate in the decision-making process. Routine reassessment requires that the PCP (Larson, 1998):

- Review treatment of existing comorbid conditions, including review of administration and dosage of medications;
- Evaluate acute changes; and
- Expect unreported problems (e.g., urinary tract infection).

Visual and auditory deficits are common in older adults and may further impair the patient's self-care abilities, as well as exacerbate symptoms of cognitive decline. The PCP should ensure that corrections (e.g., glasses, hearing aids) are optimal and are used properly (Grossberg & Desai, 2003; Kane, Ouslander, & Abrass, 1994). Sensory deficits can affect patient performance on assessment and evaluation scales; therefore, it is important to determine whether low scores are due to sensory deficits or to actual cognitive decline.

Routine dental care is essential for the Alzheimer's Disease patient, as individuals with Alzheimer's Disease have an especially high risk of tooth decay even before diagnosis, which increases with the severity of cognitive decline (Ellefsen et al., 2008). Oral diseases can have a negative effect on overall health, nutritional intake, behavioral symptoms, social interactions, and overall quality of life (Chalmers & Pearson, 2005; "Oral health of people with dementia," 2006). Daily oral hygiene can help prevent loss of teeth and keep gums in good repair, reducing the risk of periodontal disease, which often requires complex, invasive, and painful treatments. When routine dental care becomes too challenging for Alzheimer's Disease patients, specialists in geriatric dentistry should be asked to recommend special oral devices and procedures for use by caregivers (Chalmers & Pearson).

**Recommendation:** *Provide appropriate treatment for comorbid medical conditions.*

### **Treatment: Palliative and End-of-Life Care**

In the early stages of Alzheimer's Disease, the treatment goals may be similar to those of otherwise healthy, ambulatory individuals. Such goals should include management of chronic medical diseases, such as diabetes and congestive heart failure, and treatment of newly diagnosed diseases. As the patient's dementia worsens and the ability to understand treatments and participate in medical decision-making declines, the goals of treatment often shift their primary focus to the relief of discomfort (see Patient and Family Education and Support section). The presence of pain or non-pain-related symptoms, and the potential for treatments to relieve these symptoms, may provide guidance in determining appropriate management.

The advisability of routine screening tests, hospitalization, and invasive procedures including artificial nutrition and hydration will depend upon the severity of the dementia. Treating patients with Alzheimer's Disease depends upon integration of patient and family preferences with the clinician's estimation of relative risks and benefits of the treatments under consideration. For example, as a patient progresses from mild to severe dementia, weight loss is likely to occur for a variety of reasons ranging from forgetfulness and distraction to deterioration of motor skills (Amella, Grant, & Mulloy, 2008). It should be noted that current evidence argues against the use of feeding tubes in patients with severe dementia due to uncertainty about whether nutritional intake

has any clinically meaningful outcomes in advanced dementia (Finucane, Christmas, & Leff, 2007; Finucane, Christmas, & Travis, 1999), as well as evidence that tube feeding does not necessarily prolong life or decrease suffering in severely demented patients (Alvarez-Fernández, García-Ordoñez, Martínez-Manzanares, & Gómez-Huelgas, 2005; Gillick, 2000; Hoefler, 2000; Volicer & Hurley, 2003). A particular challenge with respect to tube feeding in patients with severe Alzheimer's Disease is the tendency of confused patients to pull out the feeding tube, often leading to the use of physical restraints, which may result in increased confusion and a decrease in quality of life for the patient with Alzheimer's Disease (Gillick; Hoefler).

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



# PATIENT AND FAMILY EDUCATION AND SUPPORT

## Overview

Education and support services for both patients and families affected by Alzheimer's Disease are critical for effective long-term management of this chronic progressive disease. While education and support services have historically focused on caregivers, who are usually (but not always) members of the patient's family, earlier diagnosis of Alzheimer's Disease and mild cognitive impairment (MCI) is resulting in a growing population of early-stage individuals who need and are able to benefit from education and support interventions. Consequently, this section of the guideline reviews education and support interventions separately for early-stage individuals and patients in the more advanced stages of Alzheimer's Disease. Patient and caregiver education and support are essential components of disease management, and have been shown to reduce depression in both Alzheimer's Disease patients and their caregivers and to delay institutional placement.

## Recommendations

- 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](http://www.alz.org)  
*Caregiver Resource Centers*  
(800) 445-8106, [www.caregiver.org](http://www.caregiver.org)  
or your own social service department.
- 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.
- 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 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 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.

## Patient and Family: Referral to Support Services and Organizations for Caregivers

Family care is the most important source of assistance for people with chronic or disabling conditions who require long-term care. Although policymakers and health care providers frequently associate long-term care with nursing homes, that perception mischaracterizes the reality of where most long-term care is provided and by whom. Over half of all Alzheimer's Disease patients live in home settings (American Geriatrics Society, 2008), and 87% of Alzheimer's Disease patients are cared for primarily by family members (Alzheimer's Association & National Alliance for Caregiving, 2004). Nearly three-quarters of Alzheimer's Disease caregivers are women, with an average age of about 48 (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

A body of research over the past 25 years has found family caregivers to be a vulnerable and at-risk population that the health and long-term care system often neglects (Family Caregiver Alliance, 2006). However, there is increasing evidence that caregiver assessment, education, and community resource referral can all lead to improved well-being and enhancements in quality of life for both caregiver and care receiver (Feil, MacLean, & Sultzer, 2007; Logsdon, McCurry, & Teri, 2007; Sörensen, Pinquart, & Duberstein, 2002). Factors such as the quality of the caregiver/patient relationship, type and frequency of behavioral symptoms exhibited by the person with dementia, availability of a family and/or community support system, and the flexibility of the caregiver in response to lifestyle changes must be considered when evaluating the strengths of a caregiving relationship and the degree of burden likely to be experienced (Family Caregiver Alliance; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Yaffe et al., 2002).

With the heavy burden, stress, and sacrifices involved in caring for someone with dementia, it is no surprise that caregivers express a number of unmet needs for information and support. The burden of caring for an impaired relative has been associated with several risk factors that encompass physical, social, psychological, and financial domains (Ory et al., 1999; Schulz & Williamson, 1997; Schulz et al., 1995). In terms of psychological outcomes, caregivers have been shown to experience elevated levels of depression (Atienza, Collins, & King, 2001; Austrom et al., 2006; Draper, Poulos, Poulos, & Ehrlich, 1996; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Russo, Vitaliano, Brewer, Katon, & Becker, 1995). The emotional toll placed on caregivers is profound and a significant source of caregiver morbidity (Damjanovic et al., 2007; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003; Von Kanel et al., 2006), and most caregivers rate their own physical health as fair to poor (Vitaliano et al.; Schulz et al.).

On the other hand, increased social support has been linked to greater well-being (Atienza et al., 2001; Cohen, Sherrod, & Clark, 1986; Cohen & Wills, 1985), and caregivers who have greater support from their spouses and families have lower risk for depression (Atienza et al.; Hooker,

Monahan, Bowman, Frazier, & Shifren, 1998). A positive attitude toward caregiving also is positively correlated with caregiver health (Cohen, Colantonio, & Vernich, 2002; Cohen, Gold, Shulman, & Zuccherro, 1994; Pearlin, Mullan, Semple, & Skaff, 1990), and caregivers who reported more positive feelings were less likely to report depression (Cohen et al., 1994; Cohen et al., 2002), even following bereavement (Boerner, Schulz, & Horowitz, 2004).

### Caregiver Education

Studies have shown that education and support for caregivers increases the chances of adherence to treatment recommendations for patients (Callahan et al., 2006; Cherry et al., 2004; Fillit et al., 2006; Pinquart & Sørensen, 2005; Vickrey et al., 2006). The PCP should provide information and education about the current stage of the disease process and talk with the patient and family to establish treatment goals (Feil et al., 2007). Based on the agreed-upon goals, a discussion regarding the expected effects (positive and negative) of interventions on cognition, mood, and behavior will ensure that the prescribed treatment strategy is appropriate to family values and culture (American Psychiatric Association, 2007; Callahan et al.; Family Caregiver Alliance, 2006; Toth-Cohen et al., 2001).

### Referral to Support Services

Seamless resource referral and access to critical services for both patients and caregivers are considered essential (Family Caregiver Alliance, 2006; Fillit et al., 2006; Mittleman, 2004; Vickrey et al., 2006). The PCP should encourage the caregiver to participate in educational programs, support groups, respite services, and adult day service programs. The local Alzheimer's Association chapter or other local agency support groups and community resources such as the Caregiver Resources Centers should be recommended (American Psychiatric Association, 2007; Lyketsos et al., 2006) (see Treatment section and Table T5)

The PCP must address caregiver support on an ongoing basis, and assess caregivers' mental and physical health regularly (see Assessment section). Support groups may be helpful, as both research and clinical practice suggest that these interventions may decrease behavioral symptoms, promote compliance with treatment plans, provide a support system for people who often feel isolated from their communities, family, and friends, and improve mood in patients and family members alike (Doody et al., 2001; Fillit et al., 2006; Mittelman, Haley, Clay, & Roth, 2006). Evidence suggests that counseling, support group participation, and the continuous availability of ad hoc telephone support may preserve caregiver health (Mittelman, Roth, Clay, & Haley, 2007) and delay institutionalization of Alzheimer's Disease patients (Doody et al., 2001; Gallagher-Thompson & Coon, 2007; Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996;

**Table P1: Factors Affecting Caregiver Ability to Cope**

The ability to cope with caregiving depends upon:

Quality of the caregiver's relationship with the person with Alzheimer's Disease prior to the onset of the disease

Caregiver's emotional and physical health

Type, frequency, and disruptive effects of behavioral and psychological symptoms exhibited by the patient with Alzheimer's Disease

Caregiver's response to and tolerance for these symptoms

Formal and informal support services available

Caregiver's perception of whether he/she receives sufficient emotional support

Caregiver's ability to make lifestyle adjustments, including taking over household responsibilities and decision-making within the home

*Table adapted from Family Caregiver Alliance, 2006*

Mittleman et al., 2006). Both patients and caregivers also may benefit from the use of technological methods such as computer networks and telephone support programs to provide education and virtual support (Doody et al., 2001).

### Evidence-based Interventions

Given the potentially deleterious psychological and physiological outcomes associated with Alzheimer's Disease caregiving, there is a need for interventions that specifically target the unique problems of these caregivers. The last ten years have seen tremendous growth in the number of high-quality treatment outcome studies (e.g., randomized controlled trials of manualized treatments based on a coherent theory of change, with increased emphasis on treatment fidelity) that have identified intervention strategies meeting criteria for evidence-based psychological treatments (Yon & Scogin, 2007). A recent review of this literature found 19 studies that supported the efficacy of a variety of caregiver interventions, including psychoeducational skill building programs, psychotherapy and counseling, and multi-component interventions (Gallagher-Thompson & Coon, 2007). There is strong evidence for the effectiveness of psychoeducational/skill building programs, psychotherapy, and multi-component interventions that include some or all of these features (Mittelman et al., 2007; Schulz, Martire, & Klinger, 2005). Psychoeducational programs have been shown to be among the most efficacious forms of therapy, with a broad impact beyond knowledge acquisition: participating caregivers have shown consistent improvement on measures of burden, depression, well-being, ability, and relevant knowledge,

with a corresponding reduction in care recipient symptoms (Sørensen et al., 2002). In one study, a treatment program involving psychoeducation and anger management training for caregivers who abused or neglected their elderly dependents significantly reduced strain, depression, and anxiety in both abusers and neglecters, as well as cost of care and, in the case of abusive caregivers, levels of conflict, and these reductions were maintained over a six-month follow-up period (Reay & Browne, 2002).

Interventions with cognitive behavioral therapy (CBT), delivered either individually or in a small-group format, have demonstrated success in reducing caregiver depression (Gallagher-Thompson & Coon, 2007). In general, treatment involves targeting problematic patterns of thinking and working with the caregiver to develop more adaptive, less stress-inducing alternatives, as well as managing symptoms through relaxation, working on problem solving, and encouraging more frequent engagement in pleasant events (Beck, Rush, Shaw, & Emery, 1979). A recent series of large-scale clinical trials incorporating CBT in a multi-component intervention with Hispanic/Latino, African American, and Caucasian caregivers found it to be successful in reducing caregiver burden and depression and improving quality of life (Belle et al., 2003; Belle et al., 2006; Schulz et al., 2003).

Current research shows that caregivers are frequently satisfied with the psychosocial interventions in which they participate, indicating that their own coping skills are improved (Brodaty, Green, & Koschera, 2003) along with their relationships with the recipients of their care (Quayhagen et al., 2000).

### General Legal and Financial Advice

The PCP also plays a critical role in providing guidance to the family regarding the need for financial and legal advice (Ham, 1997; Lyketsos et al., 2006). Efforts should be made to get the patient and family to seek sound professional advice (Overman & Stoudemire, 1988). Recommendations should include consultation with financial advisors and legal counsel and discussion of conservatorship (American Psychiatric Association, 2007) (see Legal Considerations section). In California, a low-cost legal consultation may be obtained through the State's network of Caregiver Resource Centers ([www.caregiver.org](http://www.caregiver.org)).

### Interventions for Culturally Diverse Caregivers

Cultural differences may have strong effects on caregiver stress appraisals and coping responses (Aranda & Knight, 1997; Knight, Silverstein, McCallum, & Fox, 2000), as well as psychological responses to stress and variables associated with utilization of services (Gallagher-Thompson & Coon, 2007). Ethnicity significantly affects how a family member views a disease and approaches the role of providing care for a rela-

tive with dementia (Pinquart & Sørensen, 2005). For instance, members of some ethnic and cultural groups may be more likely than others to view Alzheimer's Disease as a source of shame, possibly retribution for the sins of the family or of one's ancestors (e.g., Chinese Americans [Wang et al., 2006]).

As a result, different interventions have been found to be more or less effective with different ethnic and cultural groups and subgroups (Gallagher-Thompson et al., 2003). For example, Mexican American caregivers often respond better to group-based interventions offering high levels of social support (Talamantes, Trejo, Jimenez, & Gallagher-Thompson, 2006), while Vietnamese Americans typically prefer more private discussions with monks, nuns, or others who can perform folk healing rituals (Tran, Tran, & Hinton, 2006). Familiarity with these and similar aspects of the patient's and family's particular culture may assist the PCP in offering appropriate services and advice to the family caregiver.

A substantial body of literature has developed to provide PCPs with practical guidelines for engaging and assisting these families, based on their cultural preferences and belief systems (e.g., Cuban Americans [Argüelles & Argüelles, 2006]; African Americans [Dilworth-Anderson, Gibson, & Burke, 2006]; Hmong Americans [Gerdner, Xiong, & Yang, 2006]; American Indians [Hendrix & Swift Cloud-Lebeau, 2006]; Japanese Americans [Hikoyeda, Mukoyama, Liou, & Masterson, 2006]; Filipino Americans [McBride, 2006]; Puerto Ricans [Montoro-Rodríguez, Small, & McCallum, 2006]; Korean Americans [Moon, 2006]; Asian Indians [Periyakoil, 2006]; Mexican Americans [Talamantes et al., 2006]; Vietnamese Americans [Tran et al., 2006]; Chinese Americans [Wang et al., 2006]).

**Recommendation:** *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](http://www.alz.org)*
- *Caregiver Resource Centers  
(800) 445-8106  
[www.caregiver.org](http://www.caregiver.org)*
- *or your own social service department.*

## Patient and Family: Disclosure of Diagnosis and Family Conferences

It is important that disclosure of the diagnosis of Alzheimer's Disease be handled in accordance with the wishes of the patient and family. Disclosure is significant in terms of initiating the process of short- and long-term planning for circumstances relating to quality of life and other matters (Bamford et al., 2004; Feil et al., 2007). However, for many clinicians, patients, and caregivers, disclosure is neither inevitable nor straightforward. There is currently wide variability in the process of disclosing a diagnosis of Alzheimer's Disease. Empirical studies of diagnostic disclosure in dementia have largely focused on quantifying attitudes and practice,

with less emphasis on the process and impacts of disclosure (Bamford et al.; Carpenter et al., 2008). While some attitudinal studies have suggested that many caregivers do not support disclosure of the diagnosis to the person with dementia (Pucci, Belardinalli, Borsetti, & Giuliani, 2003), where disclosure has occurred, studies have reported that the majority of caregivers approved the decision (Bachman et al., 2000; Dautzenberg, van Marum, van der Hammen, & Paling, 2003), and that it may relieve both patient and caregiver anxieties (Carpenter et al.). Cultural background may influence family choice regarding disclosure (Pinner & Bouman, 2002). The perspectives of people with Alzheimer's Disease remain under-researched.

The consensus opinion of experts involved with the diagnosis and management of Alzheimer's Disease is that a meeting with the patient and supportive family member(s) should be held when disclosing the diagnosis, allowing enough time for the PCP to discuss recommendations and to answer questions (American Psychiatric Association, 2007; Doody et al., 2001; Post & Whitehouse, 1995). Ideally, a follow-up session should be scheduled to continue discussion since the information may be overwhelming at first, and patients and their families will have more questions over time (American Psychiatric Association; Lyketsos et al., 2006). If a key family member is unable to attend a face-to-face information session regarding disclosure of the diagnosis, the disease prognosis, treatment alternatives, and expected treatment outcomes, the PCP needs to identify and communicate with that person. Also, for those patients who do not have family, the PCP should identify other members of the patient's informal support system who may be able to provide relevant history and observations or be enlisted to help monitor the patient's treatment plan recommendations, pending his or her consent and release for communication.

It is often difficult for family members to discuss critical health care decisions. Strategies for PCPs to assist families in discussing these decisions include: (a) initiating a discussion of goals for treatment to encourage families to talk about difficult choices in advance; (b) enhancing the patient's and family's knowledge and understanding of health care procedures and care options so that caregivers can ask more informed questions and better assess information they receive from health care professionals at different stages of the Alzheimer's Disease process; (c) helping families develop successful problem-solving strategies; and (d) respecting the wishes of the person with Alzheimer's Disease (Feil et al., 2007; Fillit et al., 2006; Lyketsos et al., 2006; National Institute for Health and Clinical Excellence & Social Care Institute for Excellence [NICE-SCIE], 2006).

**Recommendation:** *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.*

**Table P2: Checklist for Early-Stage Care**

- Conduct regular follow-up assessments to monitor the patient's cognitive status and abilities, as well as effectiveness and side effects of any pharmacological treatments.
- Discuss implications with respect to work, driving, and other safety issues (e.g., risk of falls; see Appendix F for a safety assessment checklist).
- Recommend the following non-pharmacological interventions (preferably in combination) to protect and promote continuing functioning, assist with independence, and maintain cognitive health:
  1. Physical exercise, preferably aerobic exercises if tolerated (or less-strenuous exercises that promote strength, balance, and coordination, such as Tai Chi);
  2. Cognitive therapies, preferably focusing on cognitive training and rehabilitation or memory rehabilitation
  3. Comprehensive recreational therapies (e.g., art, writing, social engagement, individualized hobbies)
  4. Support group participation (continuous, not time-limited)
  5. Programs to improve sleep, such as NITE-Alzheimer's Disease (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005)
  6. Driving evaluations at least every 6 months, including an on-road test with an experienced driving specialist
  7. Individualized instruction in activities to promote independence (e.g., cell phone usage, computer e-mail programs, etc.)
  8. Electronic reminder and monitoring programs (if not cost-prohibitive).

*Table adapted from Family Caregiver Alliance, 2006*

## **Patient and Family: Early-stage Alzheimer's Disease**

There is increasing expert consensus that people with early-stage Alzheimer's Disease require a different approach to care and management than those in the moderate or advanced stages of the disease (Alzheimer's Association, 2007; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). Since Alzheimer's Disease often progresses slowly in the early stages, the affected individual has much to invest in improving and maintaining quality of life, being involved in treatment planning, and contributing opinions and expressing desires related to specific plans for the future (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). Increasingly, people in the early stages of Alzheimer's Disease are making their voices heard, requesting involvement in such future planning and insisting that their humanity not be abrogated by the event of their diagnosis (Alzheimer's Association; Young, 2002).

Recommendations should be based on thorough knowledge of the individual's retained abilities (Lyketsos et al., 2006), particularly as factors such as level of awareness have been shown to affect responsiveness to certain interventions (Clare, Wilson, Carter, Roth, & Hodges, 2004). The recommendations in Table P2 are based on the recent Consensus Report on Early Stage Alzheimer's Dementia issued by the Alzheimer's Association (2007a). While some of these recommendations have not yet been fully researched in controlled clinical trials, there is at least some evidence that they may be beneficial and little reason to believe they will cause harm.

Recent best practice guidelines for early-stage or newly diagnosed patients recommend follow-up two months after diagnosis and every six months thereafter (Fillit et al., 2006). Regular re-evaluation will help determine the cognitive, functional, or behavioral effects of treatment and other management interventions, facilitating prompt adjustments in the event of negative effects and early intervention with needed therapies to maximize quality of life (American Psychiatric Association, 2007; Fillit et al.) (see Assessment section).

### **Cognitive Stimulation**

Cognitive stimulation, such as activities provided in adult day services programs, has been shown to benefit persons with Alzheimer's Disease more than drug therapy alone (Femia, Zarit, Stephens, & Greene, 2007). In one study, adult day services participants with mild Alzheimer's Disease receiving cognitive stimulation and donepezil over a one-year period improved their scores by 1.5 points on the Mini-Mental State Exam (from an average of 22.95 to 24.45), while those receiving medication only saw their scores decline (from an average of 21.17 to 17.8) (Requena et al., 2004). While systematic Alzheimer's Disease-specific memory rehabilitation programs conducted by skilled professionals have demonstrated benefits (De Vreese, Neri, Fioravanti, Belloi, & Zanetti, 2001), such services are not yet readily available in the community.

### **Physical Exercise**

Physical exercise has multiple health benefits for the person with early Alzheimer's Disease, as demonstrated in studies examining both aerobic and non-aerobic forms (e.g., strength training, endurance, balance) of exercise (Logsdon, McCurry, & Teri, 2005). As reported in a meta-analysis of studies of exercise programs for Alzheimer's Disease patients (Heyn, Abreu, & Ottenbacher, 2004), exercise has been shown to benefit cognitive performance, strength, physical fitness, functional performance, flexibility, and cardiovascular measures. Although studies are limited, cognitive benefits have been associated with aerobic exercises such as walking and using an exercise bicycle (Palleschi et al., 1996; Rolland et al., 2000). Additionally, engaging in physical exercise has been associated with reductions in depression and improvement in mood and behavioral problems (Regan, Katona, Walker, & Livingston, 2005; Teri et al., 2003; Williams & Tappen, 2007).

### **Psychosocial Support**

Early diagnosis has provided an opportunity to offer early psychosocial support directly to individuals affected by Alzheimer's Disease. PCPs have developed group interventions offering both support and psychotherapy, with qualitative and observational data suggesting that these interventions have a positive impact. Reported benefits of early-stage support groups include the opportunity to share experiences and increased social support (Zarit et al., 2004). Although individual or group psychotherapy with a trained professional can help early-stage individuals make sense of their experiences and reduce depression (Cheston, Jones, & Gilliard, 2003), few professionals have developed the specialized skills needed, and early-stage support groups are not readily available. Most that do exist, however, use a model that includes some combination of education and supportive peer discussions, involving either early-stage individuals only or both those affected and their care partners in parallel groups (Yale, 1995; Alzheimer's Association, 2007).

*Recommendation: 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.*

## **Patient and Family: Advance Planning for Care Needs**

Moderate evidence suggests that there is a lack of knowledge and understanding of end-of-life care among the general population (Silveira, DiPiero, Gerrity, & Feudtner, 2000). Therefore, it is important for the PCP to discuss end-of-life treatment goals and options with patients and families early on (Kettl, 2007). End-of-life treatment options and decisions need to take into account effective pain management, the goals of the patient (via advance directive), and patient and caregiver satisfaction (Kettl) (see Assessment section and Treatment section).

Issues of informed consent and capacity may be among the first to arise after diagnosis when plans are being made for patients with Alzheimer's Disease. The PCP should provide sufficient information so that reasonably informed decisions can be made with respect to medical treatment and other matters (Lyketsos et al., 2006; Marson, Cody, Ingram, & Harrell, 1995a; Marson, Cody, Ingram, & Harrell, 1995b). For this purpose, "informed consent" is operationally defined as consent to a specified medical treatment given by a patient who is able to understand the exact nature of the diagnosis, the prognosis, and what course of treatment is to be expected (Overman & Stoudemire, 1988). Capacity to make medical decisions involves ability to understand, reason about, and appreciate the consequences of the disease and particular course of treatment, and to communicate a choice of treatment, all of which decline as Alzheimer's Disease progresses (Huthwaite et al., 2006) (see Assessment section and Legal Considerations section).

Advance directives and designation of healthcare surrogates should be put in place early, while the patient can still have input (American Psychiatric Association, Brock, 1996; 2007; Ham, 1997). The PCP should also discuss values, preferences, and goals related to death and dying with patients in early stages of Alzheimer's Disease, including do-not-resuscitate orders, artificial nutrition plans, and healthcare proxies (Karel, Moye, Bank, & Azar, 2007; Kettl, 2007). Expert opinion and Workgroup consensus suggest that PCPs should initiate conversations with patients and their families about late-stage care and appointing a proxy (Braun, Pietsch, & Blanchette, 2000; Potkins et al., 2000; Silveira et al., 2000; Young, 2001). Proxies should have extensive conversations with the patient about his or her wishes with respect to a variety of circumstances and situations (Alpers & Lo, 1999; Post, Blustein, & Dubler, 1999; Potkins et al.).

PCPs need to respect the decisions of patients and their proxies, even though their cultural beliefs or wishes may be counter to medical recommendations (Alpers & Lo, 1999;

Post et al., 1999). Special care should also be taken to protect the rights of cognitively impaired adults through the use of advance directives and durable powers of attorney. Advance planning is also important in long-term care to help patients maintain a sense of control when they lose decisional capacity and to ensure that their preferences are followed where possible (McCullough & Wilson, 1995; Morrison, Siu, Leipig, Cassel, & Meier, 2000).

A major barrier to completing informed consent forms, appointment of surrogates, and other legal documentation is that these documents are often written at the college or graduate school level and many patients do not understand what they say (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association, 1999). The PCP should refer the family to the Alzheimer's Association, Caregiver Resource Center, or other community organization to identify appropriate local legal resources with experience in dealing with non-English-speaking and/or low-literacy populations. It is especially important for there to be legal documentation of a patient's wishes because certain cultures rely on "fictive kin" (non-blood relatives who are considered family) to make medical treatment decisions. Because the law does not recognize non-blood relatives, PCPs may inadvertently discount them, while the family may not only value the input of non-blood relatives but actually depend on them with regard to important decisions on treatment and other matters (Valle, 2001).

**Recommendation:** *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.*

### **Patient and Family: End-of-life Care Decisions (Hospice and Palliative Care)**

As the end of the patient's life approaches, the PCP needs to present care options that maximize comfort and other potential benefits while avoiding futile treatments that may not provide comfort and may actually prolong the dying process. The checklist in Table P3 may facilitate this process.

Tube feeding and hydration are often done as a matter of course for hospitalized or nursing home patients who have difficulty swallowing (Volicer, 2005). Generally, tube feeding is not recommended for patients with severe dementia, as nasogastric tube feeding has been found to reduce survival and increase the risk of complications such as pneumonia and urinary tract infections, without improving patients' nutritional status (Alvarez-Fernández, García-Ordoñez, Martínez-Manzanares, & Gómez-Huelgas, 2005; Garrow et al., 2007; Volicer). Decisions to use tube feeding should be consistent with previously discussed care plans. The initiation of a hospice protocol when swallowing becomes an issue may bring great comfort to both family members and professional staff, and help avoid the complications of tube feeding and use of medications or other restraints (Volicer).

**Table P3: Factors to Consider in Planning for End-of-Life Care**

Maximize options for comfort care through hospice referral
Avoid futile care and prolongation of the dying process
Discuss the benefits and risks of tube feeding
Review and simplify the patient's medication regimen
Assess and respect the patient's and family's cultural values and preferences

*Table adapted from Wolf-Klein, Pekmezaris, Chin, & Weiner, 2007*

As clinicians and families weigh the use of such aggressive treatments, it may be helpful to consider them in the context of benefits versus burdens. When patients cannot understand the purpose of treatment and need to be restrained, or suffer some discomfort or pain from treatment, the burden of treatment may become greater than its benefit to the patient (Robinson et al., 2005). In such a case, it may be permissible to discontinue the use of ongoing treatments (Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2006; Weissman, 2004).

***Recommendation: 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

## Overview

In addition to discussing the medical and behavioral symptoms of Alzheimer's Disease, the Primary Care Practitioner (PCP) should also convey the importance of basic legal and financial planning and make the appropriate referrals when formulating treatment plans. The PCP can make clinical evaluations concerning the capacity of the patient and, when the patient is no longer legally capable of making particular kinds of decisions, should provide guidance to families, attorneys, and courts to assist the patient to live within boundaries that constitute the least restrictive alternatives. PCPs are required by law to report the diagnosis of Alzheimer's Disease, as well as instances of elder or dependent adult abuse, to appropriate agencies. The PCP should monitor for abuse as well as offer interventions to the patient and caregiver through medical treatment and referrals to community agencies. Reporting requirements and standards and procedures for making capacity determinations may vary by state; the recommendations below are for the State of California.

### Recommendations

- **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.

## Legal Considerations: Planning

Since cognitive decline deprives Alzheimer's Disease patients over time of the ability to think clearly, major legal and financial decisions ideally should be made while the patient is still capable of making them. PCPs can use their unique position of trust and influence to find the right time in the treatment discussion to convey the importance of basic legal and financial planning and to make the appropriate referrals for professional assistance (Lyketsos et al., 2006). It may be necessary to introduce this discussion more than once before

the patient and family are able to process the information, recognize the need, and act on the PCP recommendations.

*Recommendation: 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.*

## Legal Considerations: Capacity Evaluations

There may be times when the patient has done legal planning, but a capacity declaration is required before the patient's chosen substitute decision maker can be authorized to act on the patient's behalf. In other situations, the patient may not have done advance legal planning, and may be diagnosed too late to be able to make legally capable decisions. In these circumstances, the PCP may be called upon to render a capacity evaluation to assist the court in determining whether the patient should be placed under a probate conservatorship.

The California Due Process in Competence Determination Act (DPCDA) (California Probate Code §§810-813; California Probate Code §§1881, 3201, 3204, 3208) codifies standards for a court to use in determining whether a person has the capacity to perform particular acts in a variety of contexts. Mere diagnosis of Alzheimer's Disease is not enough (California Probate Code §811[d]), and without evidence to the contrary, there is a legal presumption in favor of capacity (e.g., regarding marriage and domestic partnership [California Probate Code §§810(a), 1900]). The determination of incapacity must be based on evidence of a deficit in one or more specific functions (California Probate Code §§810[c], 811[a]), and a particular deficit may be considered for this purpose only if it "significantly impairs the person's ability to understand and appreciate the consequences of his or her actions with regard to the type of act or decision in question" (California Probate Code §811[b]).

The following structured approach should be taken when determining capacity under DPCDA:

**Step 1:** Determine whether the decision or act in question is one of those listed below:

1. Making a testamentary disposition, including creating or revoking a trust (California Probate Code §6100.5[a]);
2. Making a contract (California Civil Code §§39-40; California Family Code §§297, 301; California Probate Code §1872);
3. Making a conveyance (California Civil Code §§39-40; California Probate Code §1872);
4. Making a medical decision (California Probate Code §813);
5. Managing personal and financial affairs (California Probate Code §1801);
6. Driving (California Health and Safety Code §103900);
7. Nominating a conservator (California Probate Code §1810); or

8. Authorizing release of “protected health information” under the U.S. Health Insurance Portability and Accountability Act of 1996 (HIPAA) (45 C.F.R. §§160.101-160.570, 164.102-164.534) or the California Confidentiality of Medical Information Act (CMIA) (California Civil Code §§56-56.37).

**Step 2:** Apply the rebuttable presumption in favor of capacity, keeping in mind that mere diagnosis does not affect the presumption.

**Step 3:** Apply the applicable communication standard, if any. For instance, the DPCDA provides that apart from the specific functional tests regarding management of personal and financial affairs and driving, the ability to engage in some form of communication—speaking, writing, drawing, or gesturing—is required to satisfy the presumption of capacity (California Probate Code §811[a]). If the person cannot or refuses to communicate as needed in order to perform a specific action, then capacity cannot be established, and that fact should be noted in the PCP’s written assessment.

**Step 4:** If the communication standard is satisfied, identify the patient’s cognitive deficits (as listed in California Probate Code §811[a]) and determine whether they affect the specific act or decision in question, and whether there is significant impairment of ability to understand and appreciate the consequences of that action.

**Step 5:** Determine whether undue influence has or may have been used. Even if the patient is found to have capacity to make a particular decision, he or she may be particularly vulnerable to fraud and undue influence.

If the patient is being assessed for the purpose of determining whether or not a conservatorship is necessary, then the PCP must complete a capacity declaration for the patient. The Capacity Declaration-Conservatorship form (Judicial Council Form GC-335; see Appendix G) is a multipurpose form required in any proceeding for conservatorship in which the petitioner alleges that the proposed conservatee either: (a) will be unable to attend the conservatorship hearing (California Probate Code §1825[b]); (b) lacks the capacity to give informed consent to medical treatment (California Probate Code §1890[c]); or (c) has dementia. Form GC-335 is also used to submit evidence of mental function deficits when required (California Probate Code §811[a]), and may be used with the Petition for Exclusive Authority to Give Informed Consent to Medical Treatment (California Probate Code §1891) (Judicial Council Form GC-380; see Appendix G) or Petition for Authority to Place Conservatee in a Locked Facility and/or Consent to the Administration of Medications (California Probate Code §2356.5) (Judicial Council Form

GC-335A; see Appendix G). Even in proceedings for which Form GC-335 is not required, the evidence it calls for can be very helpful in establishing the need for a conservatorship. The form is intended to make the written assessment of capacity easier for the PCP by allowing boxes to be checked to record impressions of the conservatee’s mental abilities and by making it unnecessary for the PCP to testify in court as to the proposed conservatee’s abilities.

If the proposed conservatee has dementia, then the Dementia Attachment to Capacity Declaration-Conservatorship (Judicial Council Form GC-335A; see Appendix G) must be completed as well. In situations where a patient with Alzheimer’s Disease needs to be placed in a secured-perimeter residential care facility for the elderly or in a secured skilled nursing facility that specializes in the care of persons with Alzheimer’s Disease, or when a patient would benefit from appropriate medication for Alzheimer’s Disease but is unable to give informed consent, the PCP making the capacity evaluation is required to make additional findings: (a) that the patient would benefit from the secured placement and that it would be the least restrictive placement appropriate to his or her needs, and/or (b) that the patient would benefit from the administration of appropriate medications for Alzheimer’s Disease but is incapable of giving consent (California Probate Code §2356.5).

In conservatorship proceedings, there is no physician-patient privilege (California Evidence Code §1004). PCPs may not use or disclose “protected health information” except as HIPAA permits (45 C.F.R. §164.502[a]). HIPAA allows disclosure to “a government authority authorized by law to receive such reports, such as a protective services agency...” (45 C.F.R. §164.512[i][1][i]). In addition, under HIPAA, a conservator of the person, as well as the agent named in an advance health care directive who has power to make healthcare decisions for the conservatee, is entitled to be treated as the patient (45 C.F.R. §164.502[g][i][2]) for purposes of disclosure.

Judicial Council Forms are available for download at [www.courtinfo.ca.gov](http://www.courtinfo.ca.gov).

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

### Legal Considerations: Elder Abuse

PCPs must report all known and suspected instances of physical abuse to law enforcement authorities (California Welfare and Institutions Code §15610.17) (see Appendix G). The applicable standard is “reasonable suspicion,” which means that the facts and circumstances in question could cause a reasonable person in a like position, drawing upon his or her training and experience, to suspect abuse (California Welfare and Institutions Code §15610.65). Under HIPAA, a PCP making such a report may disclose protected health

information about an individual whom he or she reasonably believes to be the victim of abuse (45 C.F.R. §§160.203, 164.512[c][1]), and HIPAA's "minimum necessary rule" does not apply to these disclosures (45 C.F.R. §164.502[b][2][v]).

PCPs may report instances of emotional or financial abuse to Adult Protective Services. The Long Term Care Ombudsman will also accept such reports if the patient is in a long-term care facility such as a nursing home or residential care facility.

The major challenge in identifying elder abuse is that it may not assume easily identifiable patterns, and it is especially hard to obtain information from a patient who is functionally or cognitively impaired. PCPs, as mandated reporters, are immune from civil and criminal liability for reporting abuse or suspected abuse unless it is proven that the report was false and the PCP knew the report was false (California Welfare and Institutions Code §15634[a]; California Penal Code §11166.01). California law punishes PCPs who fail to report a known or suspected incident of abuse, and the punishment is greater if the abuse results in death or severe bodily injury (California Welfare and Institutions Code §15630). The California Medical Board must obtain an acknowledgement from every PCP that he or she understands and agrees to comply with the dependent and elder abuse reporting statutes (California Welfare and Institutions Code §15659[d]-[e]).

The prevention and treatment of elder abuse focuses on intervention with caregivers to mitigate caregiver burden and stress, which are seen as risk factors for abuse (Friedman & Newberger, 1993). There is evidence that certain patient attributes (e.g., cognitive or functional impairment and physical dependence) may be predictors of risk for violence in Alzheimer's Disease families, and that caregiver depression and living arrangements as well as other factors are associated with both verbal and physical abuse (Reay & Browne, 2002) (see Assessment section). Thus, the health care team has the responsibility to monitor and intervene where required (American Psychiatric Association, 2007). Monitoring should include being alert not only to patient and caregiver circumstances, but also to the patient's behavioral symptoms, which may be a reaction to a disturbing or dangerous situation in his or her environment (Warshaw, Gwyther, Phillips, & Koff, 1995). Effective interventions include assessing caregivers for depression and perceived burden and offering psychopharmacological treatment, supportive psychotherapy, support and education groups, and respite services to alleviate caregiver burden (Coyne, Reichman, & Berbig, 1993; Reay & Browne, 2002). Mutual violence (where abuse is seen both in terms of caregivers directing abusive behavior towards patients and patients abusing caregivers) may also be a concern (Coyne et al.; Paveza et al., 1992). The obligation of the PCP is to provide support and referrals to both patient and caregiver and to intervene appropriately if abuse is suspected.

The Report of Suspected Dependent Elder Abuse Form (SOC 341) is available for download at <http://www.dss.cahwnet.gov>

**Recommendation:** *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.*

### **Legal Considerations: Driving**

The PCP is required to report a diagnosis of Alzheimer's Disease in accordance with California law (California Health and Safety Code §103900; California Code of Regulations, Title 17 §§2800-2812) (see Appendix G). After receiving the report, California DMV personnel evaluate the driver individually using medical evaluations, personal interviews, and other information when indicated to determine his or her driving ability. The statute provides that a physician shall not be civilly or criminally liable to any patient for making any report that it requires or authorizes (California Health and Safety Code §103900[f]). The cognitive, visual-spatial, and other impairments associated with Alzheimer's Disease increase the risks of driving. Patients with moderate and severe dementia should not be driving (Dubinsky, Stein, & Lyons, 2000; Fitten, 1997), and even mild Alzheimer's Disease should trigger careful consideration of the patient's ability to continue operating a motor vehicle (Lyketsos et al., 2006).

The Request for Driver Re-evaluation form (DS 699) and the Driver Medical Evaluation form (DS 326) are available for download at <http://www.dmv.ca.gov>

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



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# Appendix A

## Functional Assessment Tools



# THE BARTHEL INDEX

Patient Name: \_\_\_\_\_

Rater Name: \_\_\_\_\_

Date: \_\_\_\_\_

Activity	Score
----------	-------

## FEEDING

0 = unable

5 = needs help cutting, spreading butter, etc., or requires modified diet

10 = independent

\_\_\_\_\_

## BATHING

0 = dependent

5 = independent (or in shower)

\_\_\_\_\_

## GROOMING

0 = needs to help with personal care

5 = independent face/hair/teeth/shaving (implements provided)

\_\_\_\_\_

## DRESSING

0 = dependent

5 = needs help but can do about half unaided

10 = independent (including buttons, zips, laces, etc.)

\_\_\_\_\_

## BOWELS

0 = incontinent (or needs to be given enemas)

5 = occasional accident

10 = continent

\_\_\_\_\_

## BLADDER

0 = incontinent, or catheterized and unable to manage alone

5 = occasional accident

10 = continent

\_\_\_\_\_

## TOILET USE

0 = dependent

5 = needs some help, but can do something alone

10 = independent (on and off, dressing, wiping)

\_\_\_\_\_

## TRANSFERS (BED TO CHAIR AND BACK)

0 = unable, no sitting balance

5 = major help (one or two people, physical), can sit

10 = minor help (verbal or physical)

15 = independent

\_\_\_\_\_

## MOBILITY (ON LEVEL SURFACES)

0 = immobile or < 50 yards

5 = wheelchair independent, including corners, > 50 yards

10 = walks with help of one person (verbal or physical) > 50 yards

15 = independent (but may use any aid; for example, stick) > 50 yards

\_\_\_\_\_

## STAIRS

0 = unable

5 = needs help (verbal, physical, carrying aid)

10 = independent

\_\_\_\_\_

**TOTAL (0-100):** \_\_\_\_\_

## The Barthel ADL Index: Guidelines

---

1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

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---

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*Maryland State Medical Journal* 1965;14:56-61. Used with permission.

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*Maryland State Med Journal* 1965;14:56-61. Used with permission.

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## Katz Index of Independence in Activities of Daily Living (ADL)

By: Meredith Wallace, PhD, APRN, BC, Fairfield University School of Nursing, and  
Mary Shelkey, PhD, ARNP, Virginia Mason Medical Center

**WHY:** Normal aging changes and health problems frequently show themselves as declines in the functional status of older adults. Decline may place the older adult on a spiral of iatrogenesis leading to further health problems. One of the best ways to evaluate the health status of older adults is through functional assessment which provides objective data that may indicate future decline or improvement in health status, allowing the nurse to intervene appropriately.

**BEST TOOL:** The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client's ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of *bathing, dressing, toileting, transferring, continence, and feeding*. Clients are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.

**TARGET POPULATION:** The instrument is most effectively used among older adults in a variety of care settings, when baseline measurements, taken when the client is well, are compared to periodic or subsequent measures.

**VALIDITY AND RELIABILITY:** In the thirty-five years since the instrument has been developed, it has been modified and simplified and different approaches to scoring have been used. However, it has consistently demonstrated its utility in evaluating functional status in the elderly population. Although no formal reliability and validity reports could be found in the literature, the tool is used extensively as a flag signaling functional capabilities of older adults in clinical and home environments.

**STRENGTHS AND LIMITATIONS:** The Katz ADL Index assesses basic activities of daily living. It does not assess more advanced activities of daily living. Katz developed another scale for instrumental activities of daily living such as heavy housework, shopping, managing finances and telephoning. Although the Katz ADL Index is sensitive to changes in declining health status, it is limited in its ability to measure small increments of change seen in the rehabilitation of older adults. A full comprehensive geriatric assessment should follow when appropriate. The Katz ADL Index is very useful in creating a common language about patient function for all practitioners involved in overall care planning and discharge planning.

### MORE ON THE TOPIC:

Best practice information on care of older adults: [www.ConsultGerRN.org](http://www.ConsultGerRN.org).

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# Katz Index of Independence in Activities of Daily Living

<b>ACTIVITIES</b> POINTS (1 OR 0)	<b>INDEPENDENCE:</b> (1 POINT) <b>NO</b> supervision, direction or personal assistance	<b>DEPENDENCE:</b> (0 POINTS) <b>WITH</b> supervision, direction, personal assistance or total care
<b>BATHING</b>  POINTS: _____	<b>(1 POINT)</b> Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.	<b>(0 POINTS)</b> Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
<b>DRESSING</b>  POINTS: _____	<b>(1 POINT)</b> Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	<b>(0 POINTS)</b> Needs help with dressing self or needs to be completely dressed.
<b>TOILETING</b>  POINTS: _____	<b>(1 POINT)</b> Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	<b>(0 POINTS)</b> Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
<b>TRANSFERRING</b>  POINTS: _____	<b>(1 POINT)</b> Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable.	<b>(0 POINTS)</b> Needs help in moving from bed to chair or requires a complete transfer.
<b>CONTINENCE</b>  POINTS: _____	<b>(1 POINT)</b> Exercises complete self control over urination and defecation.	<b>(0 POINTS)</b> Is partially or totally incontinent of bowel or bladder.
<b>FEEDING</b>  POINTS: _____	<b>(1 POINT)</b> Gets food from plate into mouth without help. Preparation of food may be done by another person.	<b>(0 POINTS)</b> Needs partial or total help with feeding or requires parenteral feeding.

**TOTAL POINTS = \_\_\_\_\_ 6 = High (patient independent) 0 = Low (patient very dependent)**

Slightly adapted from Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970) Progress in the development of the index of ADL. *The Gerontologist*, 10(1), 20-30.  
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# Appendix B

## Cognitive Assessment Tools



## Mental Status Assessment of Older Adults: The Mini-Cog

By: Deirdre M. Carolan Doerflinger, CRNP, PhD, Inova Fairfax Hospital, Falls Church, Virginia

**WHY:** There is increased incidence of cognitive impairment with age. Increasing age is the greatest risk factor for Alzheimer's disease. One in 10 individuals over 65 and nearly half of those over 85 are affected (Evans, et al, 1989). The advent of treatment for dementing illness necessitates the early identification of cognitive impairment using a reliable and valid tool which can be quickly implemented in the primary care setting. Early diagnosis allows the person to plan for the future; medications may slow disease progression, delay functional dependency and nursing home placement. Cholinesterase inhibitors show less effectiveness initiated later in disease course.

**BEST TOOL:** The Mini-Cog exam is composed of three item recall and the Clock Drawing Test (CDT). This tool can be used to detect dementia quickly and easily in various settings, either during routine visits or hospitalization. Clinicians may use the tool to assess a person's registration, recall and executive function. The scoring algorithm is as follows: Unsuccessful recall of all three items after the CDT distractor is classified as demented. Successful recall of all three items is classified as non-demented. Those individuals able to recall one or two of the items are classified based on the CDT. An abnormal CDT equates with demented and a normal CDT is considered normal and equates with non-demented (Borson, S., et al, 2000).

**TARGET POPULATION:** The Mini-Cog is appropriate for use in all health care settings. It is appropriate to be used with older adults at various heterogeneous language, culture and literacy levels.

**VALIDITY AND RELIABILITY:** The Mini-Cog was developed as a brief screening tool to differentiate patients with dementia from those without dementia. The Mini-Cog has sensitivity ranging from 76-99%, and specificity ranging from 89-93% with 95% confidence interval. A chi square test reported 234.4 for Alzheimer's dementia and 118.3 for other dementias ( $p < 0.001$ ). This tool has strong predictive value in multiple clinical settings (Borson, et al, 2000; Borson, et al, 2003).

### STRENGTHS AND LIMITATIONS:

The Mini-Cog takes about 3 minutes to administer. The Clock Drawing component of the test is scored as normal or abnormal, for the purpose of the Mini-Cog. Some researchers suggest the clock drawing tool should be scored to quantify impairment. This would increase complexity and training requirements. The Mini-Cog is not influenced by education, culture or language. Simple, short training is required to perform the Mini-Cog accurately. Assessment using the Mini-Cog was perceived as less stressful to the patient than other longer mental status tests. Its accuracy in heterogeneous groups may increase the identification of dementias in populations less diagnosed, increasing minority participation in research and improving parity of early treatment.

### MORE ON THE TOPIC:

Best practice information on care of older adults: [www.ConsultGeriRN.org](http://www.ConsultGeriRN.org).

Borson, S., Scanlan, J.M., Brush, M., Vitallano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry*, 15(11), 1021-1027.

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# The Mini Cog

## ADMINISTRATION

The test is administered as follows:

1. Instruct the patient to listen carefully to and remember 3 unrelated words and then to repeat the words.
2. Instruct the patient to draw the face of a clock, either on a blank sheet of paper or on a sheet with the clock circle already drawn on the page. After the patient puts the numbers on the clock face, ask him or her to draw the hands of the clock to read a specific time.
3. Ask the patient to repeat the 3 previously stated words.

## SCORING

Give 1 point for each recalled word after the CDT distractor.

Patients recalling none of the three words are classified as demented (Score = 0).

Patients recalling all three words are classified as non-demented (Score = 3)

Patients with intermediate word recall of 1-2 words are classified based on the CDT (Abnormal = demented; Normal = non-demented)

Note: The CDT is considered normal if all numbers are present in the correct sequence and position, and the hands readably display the requested time.

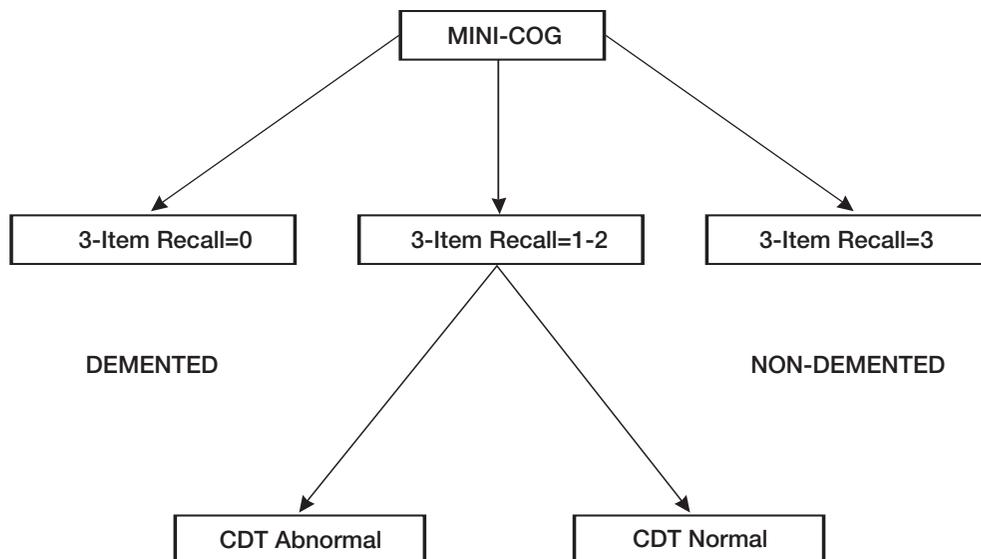


Fig. 1. Mini-Cog scoring algorithm (Borson, et al, p 1024).

From Borson, S., Scanlan, J., Brush, M., Vitallano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry*, 15(11), 1021-1027. Copyright John Wiley & Sons Limited. Reproduced with permission.

Patient: \_\_\_\_\_  
Age: \_\_\_\_\_

DATE: \_\_\_\_\_

### Short Blessed Test (SBT)<sup>1</sup>

“Now I would like to ask you some questions to check your memory and concentration. Some of them may be easy and some of them may be hard.”

- |                                |                |                  |
|--------------------------------|----------------|------------------|
| 1. What year is it now? _____  | Correct<br>(0) | Incorrect<br>(1) |
| 2. What month is it now? _____ | Correct<br>(0) | Incorrect<br>(1) |

Please repeat this name and address after me:

John Brown, 42 Market Street, Chicago

John Brown, 42 Market Street, Chicago

John Brown, 42 Market Street, Chicago

(underline words repeated correctly in each trial)

Trials to learning \_\_\_\_\_ (can't do in 3 trials = C)

Good, now remember that name and address for a few minutes.

- |  |                |                  |
|--|----------------|------------------|
| 3. Without looking at your watch or clock, tell me about what time it is.<br>(If response is vague, prompt for specific response)<br>(within 1 hour) _____<br>Actual time: _____ | Correct<br>(0) | Incorrect<br>(1) |
|--|----------------|------------------|

- |   |   |   |   |        |
|---|---|---|---|--------|
| 4. Count aloud backwards from 20 to 1<br>(Mark correctly sequenced numerals)<br>If subject starts counting forward or forgets the task, repeat instructions and score one error | 0 | 1 | 2 | Errors |
|---|---|---|---|--------|

20 19 18 17 16 15 14 13 12 11

10 9 8 7 6 5 4 3 2 1

- |   |   |   |   |        |
|---|---|---|---|--------|
| 5. Say the months of the year in reverse order.<br>If the tester needs to prompt with the last name of the month of the year, one error should be scored<br>(Mark correctly sequenced months) | 0 | 1 | 2 | Errors |
|---|---|---|---|--------|

D N O S A JL JN MY AP MR F J

- |  |   |   |   |   |   |   |        |
|--|---|---|---|---|---|---|--------|
| 6. Repeat the name and address I asked you to remember.<br>(The thoroughfare term (Street) is not required)<br>(John Brown, 42 Market Street, Chicago) | 0 | 1 | 2 | 3 | 4 | 5 | Errors |
|--|---|---|---|---|---|---|--------|

\_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_

**Check correct items**

**USE ATTACHED SCORING GRID & NORMS**

<sup>1</sup> Katzman R, Brown T, Fuld P, Peck A, Schechter R, Schimmel, H. Validation of a short orientation-memory concentration test of cognitive impairment. Am J Psychiatry 140:734-739, 1983.

## Short Blessed Test (SBT) Administration and Scoring Guidelines<sup>2</sup>

*A spontaneous self-correction is allowed for all responses without counting as an error.*

1. What is the year?

Acceptable Response: The exact year must be given. An incomplete but correct numerical response is acceptable (e.g., 01 for 2001).

2. What is the month?

Acceptable Response: The exact month must be given. A correct numerical answer is acceptable (e.g., 12 for December).

3. The clinician should state: "I will give you a name and address to remember for a few minutes. Listen to me say the entire name and address and then repeat it after me."

It is important for the clinician to carefully read the phrase and give emphasis to each item of the phrase. There should be a one second delay between individual items.

The trial phrase should be re-administered until the subject is able to repeat the entire phrase without assistance or until a maximum of three attempts. If the subject is unable to learn the phrase after three attempts, a "C" should be recorded. This indicates the subject could not learn the phrase in three tries.

Whether or not the trial phrase is learned, the clinician should instruct "Good, now remember that name and address for a few minutes."

4. Without looking at your watch or clock, tell me about what time it is?

This is scored as correct if the time given is within plus or minus one hour. If the subject's response is vague (e.g., "almost 1 o'clock), they should be prompted to give a more specific response.

5. Counting. The instructions should be read as written. If the subject skips a number after 20, an error should be recorded. If the subject starts counting forward during the task or forgets the task, the instructions should be repeated and one error should be recorded. The maximum number of errors is two.

6. Months. The instructions should be read as written. To get the subject started, the examiner may state "Start with the last month of the year. The last month of the year is\_\_\_\_\_." If the subject cannot recall the last month of the year, the examiner may prompt this test with "December"; however, one error should be recorded. If the subject skips a month, an error should be recorded. If the subject starts saying the months forward upon initiation of the task, the instructions should be repeated and no error recorded. If the subject starts saying the months forward during the task or forgets the task, the instructions should be repeated and one error recorded. The maximum number of errors is two.

7. Repeat. The subject should state each item verbatim. The address number must be exact (i.e. "4200" would be considered an error for "42"). For the name of the street (i.e. Market Street), the thoroughfare term is not required to be given (ie. Leaving off "drive" or "street") or to be correct (ie. Substituting "boulevard" or lane") for the item to be scored correct.

8. The final score is a weighted sum of individual error scores. Use the table on the next page to calculate each weighted score and sum for the total.

---

<sup>2</sup> These guidelines and scoring rules are based on the administration experience of faculty and staff of the Memory and Aging Project, Alzheimer's Disease Research Center, Washington University School of Medicine, St. Louis (John C. Morris, MD, Director & PI; [morrisj@abraxas.wustl.edu](mailto:morrisj@abraxas.wustl.edu)). For more information about the ADRC, please visit our website: <http://alzheimer.wustl.edu> or call 314-286-2881.

## Final SBT Score & Interpretation

Item #	Errors (0 - 5)	Weighting Factor	Final Item Score
1		X 4	
2		X 3	
3		X 3	
4		X 2	
5		X 2	
6		X 2	
			<b>Sum Total =</b> _____ (Range 0 – 28)

### Interpretation

A screening test in itself is insufficient to diagnose a dementing disorder. The SBT is, however, quite sensitive to early cognitive changes associated with Alzheimer's disease. Scores in the impaired range (see below) indicate a need for further assessment. Scores in the "normal" range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

- In the original validation sample for the SBT (Katzman et al., 1983), 90% of normal scores 6 points or less. Scores of 7 or higher would indicate a need for further evaluation to rule out a dementing disorder, such as Alzheimer's disease.
- Based on clinical research findings from the Memory and Aging Project<sup>3</sup>, the following cut points may also be considered:
  - 0 – 4            Normal Cognition
  - 5 – 9            Questionable Impairment (evaluate for early dementing disorder)
  - 10 or more    Impairment Consistent with Dementia (evaluate for dementing disorder)

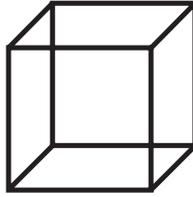
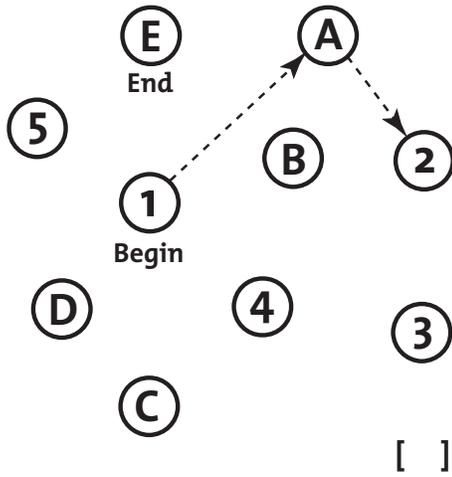
<sup>3</sup> Morris JC, Heyman A, Mohs RC, Hughes JP, van Belle G, Fillenbaum G, Mellits ED, Clark C. (1989). The Consortium to Establish a Registry for Alzheimer's Disease (CERAD). Part I. Clinical and neuropsychological assessment of Alzheimer's disease. Neurology, 39(9):1159-65.



# MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME : \_\_\_\_\_  
 Education : \_\_\_\_\_ Date of birth : \_\_\_\_\_  
 Sex : \_\_\_\_\_ DATE : \_\_\_\_\_

## VISUOSPATIAL / EXECUTIVE



Copy cube

Draw CLOCK (Ten past eleven)  
(3 points)

POINTS

[ ]

[ ]

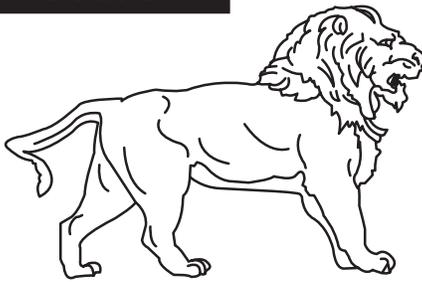
[ ]  
Contour

[ ]  
Numbers

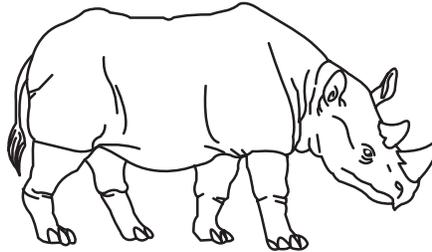
[ ]  
Hands

\_\_\_/5

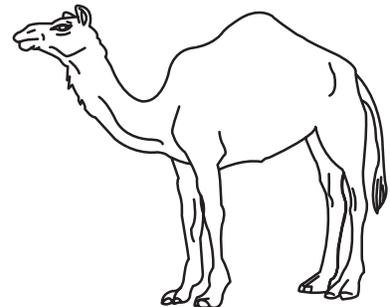
## NAMING



[ ]



[ ]



[ ]

\_\_\_/3

## MEMORY

Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

FACE

VELVET

CHURCH

DAISY

RED

1st trial

2nd trial

No points

## ATTENTION

Read list of digits (1 digit/ sec).

Subject has to repeat them in the forward order

[ ] 2 1 8 5 4

Subject has to repeat them in the backward order

[ ] 7 4 2

\_\_\_/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] FBACMNAAJKLBFAKDEAAAJAMOF AAB

\_\_\_/1

Serial 7 subtraction starting at 100

[ ] 93

[ ] 86

[ ] 79

[ ] 72

[ ] 65

4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt

\_\_\_/3

## LANGUAGE

Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ]

\_\_\_/2

Fluency / Name maximum number of words in one minute that begin with the letter F

[ ] \_\_\_\_\_ (N ≥ 11 words)

\_\_\_/1

## ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler

\_\_\_/2

## DELAYED RECALL

Has to recall words

FACE

VELVET

CHURCH

DAISY

RED

Points for UNCUED recall only

WITH NO CUE

[ ]

[ ]

[ ]

[ ]

[ ]

\_\_\_/5

Optional

Category cue

Multiple choice cue

## ORIENTATION

[ ] Date

[ ] Month

[ ] Year

[ ] Day

[ ] Place

[ ] City

\_\_\_/6



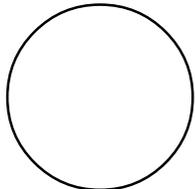
# VAMC SLUMS Examination

Questions about this assessment tool? E-mail [aging@slu.edu](mailto:aging@slu.edu).

Name \_\_\_\_\_ Age \_\_\_\_\_  
Is patient alert? \_\_\_\_\_ Level of education \_\_\_\_\_

\_\_\_\_/1  
\_\_\_\_/1  
\_\_\_\_/1  
  
\_\_\_\_/3  
\_\_\_\_/3  
\_\_\_\_/5  
  
\_\_\_\_/2  
  
\_\_\_\_/4  
\_\_\_\_/2  
  
\_\_\_\_/8



- ① 1. What day of the week is it?
- ① 2. What is the year?
- ① 3. What state are we in?
4. Please remember these five objects. I will ask you what they are later.  
Apple      Pen      Tie      House      Car
5. You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20.
  - ① How much did you spend?
  - ② How much do you have left?
6. Please name as many animals as you can in one minute.
  - ① 0-4 animals    ② 5-9 animals    ③ 10-14 animals    ④ 15+ animals
7. What were the five objects I asked you to remember? 1 point for each one correct.
8. I am going to give you a series of numbers and I would like you to give them to me backwards.  
For example, if I say 42, you would say 24.
  - ① 87      ② 649      ③ 8537
9. This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.
  - ② Hour markers okay
  - ② Time correct
- ① 10. Please place an X in the triangle.
 
- ① Which of the above figures is largest?
11. I am going to tell you a story. Please listen carefully because afterwards, I'm going to ask you some questions about it.  
Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.
  - ② What was the female's name?
  - ② When did she go back to work?
  - ② What work did she do?
  - ② What state did she live in?

\_\_\_\_\_ TOTAL SCORE



SCORING		
HIGH SCHOOL EDUCATION		LESS THAN HIGH SCHOOL EDUCATION
27-30	Normal	25-30
21-26	MNCN*	20-24
1-20	Dementia	1-19

\* Mild Neurocognitive Disorder

SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. J am Geriatri Psych (in press).



# Appendix C

## Nutritional Assessment Tool



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## Mini Nutrition Assessment

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### Score

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\_\_\_\_\_ Has food intake declined over the past three months due to loss of appetite, digestive problems, chewing or swallowing difficulties?

- 0 = severe loss of appetite
- 1 = moderate loss of appetite
- 2 = no loss of appetite

\_\_\_\_\_ Weight loss during last three months

- 0 = weight loss greater than 3kg (6.6 lbs)
- 1 = does not know
- 1 = weight loss between 1 and 3kg (2.2 and 6.6 lbs)
- 3 = no weight loss

\_\_\_\_\_ Mobility

- 0 = bed or chair bound
- 1 = able to get out of bed/chair but does not go out
- 2 = goes out

\_\_\_\_\_ Has suffered psychological stress or acute disease in the past three months

- 0 = yes
- 2 = no

\_\_\_\_\_ Neuropsychological problems

- 0 = severe dementia or depression
- 1 = mild dementia
- 2 = no psychological problems

\_\_\_\_\_ Body Mass Index (BMI) (weight in kg)/(height in m)<sup>2</sup>

- 0 = BMI less than 19
- 1 = BMI 19 to less than 21
- 2 = BMI 21 to less than 23
- 3 = BMI 23 or greater

===== **TOTAL (0-14)**

- 12 points or greater: Normal; no need for further assessment
- 11 points or below: Possible malnutrition; continue assessment

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Rubenstein, L. Z., Harker, J. O., Salvà, A., Guigoz, Y., & Vellas, B. (2001). Screening for undernutrition in geriatric practice: Developing the short-form Mini-Nutritional Assessment (MNA-SF). *Journal of Gerontology*, 56A, M366-M372.

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Appendix D  
Behavioral Symptoms Assessment Tool



## Behavioral Symptoms Checklist

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scale for your reaction (RC3).

Reaction Ratings:  
 0 = not at all  
 1 = a little  
 2 = moderately  
 3 = very much  
 4 = extremely

Behavior	Has it occurred in the past week? (circle one)		Reaction (how much it bothered you; 0-4)
	yes	no	
Asking the same question over and over	yes	no	_____
Trouble remembering recent events (i.e. items in newspaper or TV)	yes	no	_____
Trouble remembering significant past events	yes	no	_____
Losing or misplacing things	yes	no	_____
Forgetting what day it is	yes	no	_____
Starting, but not finishing, things	yes	no	_____
Difficulty concentrating on a task	yes	no	_____
Destroying property	yes	no	_____
Doing things that embarrass you	yes	no	_____
Waking you or other family members up at night	yes	no	_____
Talking loudly and rapidly	yes	no	_____
Appears anxious or worried	yes	no	_____
Engaging in behavior that is potentially dangerous to self or others	yes	no	_____
Threats to hurt oneself	yes	no	_____
Threats to hurt others	yes	no	_____
Aggressive to others verbally	yes	no	_____
Appears sad or depressed	yes	no	_____
Expressing feelings of hopelessness or sadness about the future	yes	no	_____
Crying and tearfulness	yes	no	_____
Commenting about death of self or others	yes	no	_____
Talking about feeling lonely	yes	no	_____
Comments about feeling worthless or being a burden to others	yes	no	_____
Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	yes	no	_____
Arguing, irritability, and/or complaining	yes	no	_____



Appendix E  
Depression Assessment Tool



## Cornell Scale for Depression in Dementia

Name \_\_\_\_\_ Age \_\_\_\_\_ Sex \_\_\_\_\_ Date \_\_\_\_\_

Inpatient

Nursing Home Resident

Outpatient

### Scoring System

A = unable to evaluate      0 = absent      1 = mild or intermittent      2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given in symptoms result from physical disability or illness.

#### A. Mood-Related Signs

- |   |   |   |   |   |
|---|---|---|---|---|
| 1. Anxiety: anxious expression, ruminations, worrying | a | 0 | 1 | 2 |
| 2. Sadness: sad expression, sad voice, tearfulness    | a | 0 | 1 | 2 |
| 3. Lack of reactivity to pleasant events              | a | 0 | 1 | 2 |
| 4. Irritability: easily annoyed, short-tempered       | a | 0 | 1 | 2 |

#### B. Behavioral Disturbance

- |  |   |   |   |   |
|--|---|---|---|---|
| 5. Agitation: restlessness, handwringing, hairpulling  | a | 0 | 1 | 2 |
| 6. Retardation: slow movement, slow speech, slow reactions   | a | 0 | 1 | 2 |
| 7. Multiple physical complaints (score 0 if GI symptoms only)  | a | 0 | 1 | 2 |
| 8. Loss of interest: less involved in usual activities<br>(score only if change occurred acutely, i.e. in less than 1 month) | a | 0 | 1 | 2 |

#### C. Physical Signs

- |  |   |   |   |   |
|--|---|---|---|---|
| 9. Appetite loss: eating less than usual   | a | 0 | 1 | 2 |
| 10. Weight loss (score 2 if greater than 5 lb. in 1 month)   | a | 0 | 1 | 2 |
| 11. Lack of energy: fatigues easily, unable to sustain activities<br>(score only if change occurred acutely, i.e., in less than 1 month) | a | 0 | 1 | 2 |

#### D. Cyclic Functions

- |   |   |   |   |   |
|---|---|---|---|---|
| 12. Diurnal variation of mood: symptoms worse in the morning        | a | 0 | 1 | 2 |
| 13. Difficulty falling asleep: later than usual for this individual | a | 0 | 1 | 2 |
| 14. Multiple awakenings during sleep                                | a | 0 | 1 | 2 |
| 15. Early morning awakening: earlier than usual for this individual | a | 0 | 1 | 2 |

#### E. Ideational Disturbance

- |   |   |   |   |   |
|---|---|---|---|---|
| 16. Suicide: feels life is not worth living, has suicidal wishes,<br>or makes suicide attempt | a | 0 | 1 | 2 |
| 17. Poor self esteem: self-blame, self-depreciation, feelings of failure                      | a | 0 | 1 | 2 |
| 18. Pessimism: anticipation of the worst  | a | 0 | 1 | 2 |
| 19. Mood congruent delusions: delusions of poverty, illness, or loss                          | a | 0 | 1 | 2 |



# Appendix F

## Safety Assessment Tools



## Safety

Providing for safety is an important job for caregivers. A safe environment can help prevent injuries, and it can help the person with dementia feel relaxed and less overwhelmed. To enhance safety, assess the environment for hazards. Try to see the world through the eyes of a person who has Alzheimer's and adapt the environment to his or her needs.

### Focus on prevention

- Don't expect the person to do things safely.
- Eliminate potential hazards.
- Be patient and slow down. Accidents can happen when a person is rushed.
- Simplify routines and provide step-by-step guidance, especially during complex personal care activities such as bathing, toileting and dressing.
- Be prepared to balance safety with needs for privacy and independence.
- Be realistic. You can't anticipate every risk or prevent every problem.

### Guard against choking and poisoning

- Due to changes in the brain, the person may not understand swallowing foreign substances could cause choking or poisoning.
- Lock cabinets and work rooms that contain toxic chemicals.
- Lock up all medications. Keep track of how many pills are being taken.
- Hide potentially dangerous toiletry items such as razor blades.
- Remove toxic plants such as poinsettias or mistletoe.
- Don't let food spoil in the refrigerator or pantry.
- Test the temperature of food before it's served. The person may not be able to tell when food is too hot to eat.
- Be prepared for the unusual. Some people may eat items such as gravel and dirt.

### Be careful about knives, appliances and electric tools

- Be aware that the person may not remember how to use appliances and tools. Potential hazards include toaster ovens, stoves, coffee makers, power tools, lawn mowers and barbecue grills.
- Know that even apparently safe devices can be hazards. For example, a person may try to open a can by jabbing it with a screwdriver.
- Place at eye level appliances that the person can safely use.
- Discourage the person from entering the kitchen without you.
- Consider precautions such as locking up knives, hiding appliances and removing knobs from the stove when not in use.
- Unplug all heat-producing appliances, such as coffeemakers, when not in use.
- Consider turning off the gas and electricity in certain areas.
- Regularly check electrical cords for frays, breaks and other damage.
- Don't let electrical cords dangle.
- Put safety covers on electrical outlets.

### **Be careful about heat, cold and fire**

- Keep in mind that a person with Alzheimer's may lose sensitivity to temperature extremes and may forget about their dangers.
- Be cautious about items such as stoves, space heaters, curling irons, microwave-prepared food, and electric blankets and heating pads.
- Take precaution against scalding hot water. Set your hot water heater to 110 degrees F. Install anti-scald devices on faucets. Help the person test water temperatures and mix cold water with hot.
- Avoid accidents associated with cooking and eating:
  - Turn pan handles toward the middle of the stovetop.
  - Do not let the person wear loose clothes while cooking.
  - Do not place containers of hot liquid near the edges of tables and countertops.
  - Pour hot liquids away from the person's body; keep the pot as far away as possible.
  - Test the temperature of microwave-prepared foods.
  - Use place mats instead of tablecloths.
- Listen for sizzling and crackling sounds that indicate something is heating up.
- Cover all light bulbs with shades or globes.
- Hide matches and cigarette lighters.
- Keep the person from smoking, if possible. Or supervise an individual with dementia while he or she smokes.
- Install fire extinguishers and smoke alarms; check them monthly.

### **Prevent slips and falls**

- Make sure the person wears non-skid shoes.
- Reduce clutter.
- Remove throw rugs, extension cords and other obstacles; don't let pets sleep in traffic areas.
- Provide sturdy items to lean against along frequently traveled paths.
- Avoid rearranging furniture.
- Make sure carpets are properly tacked down on all sides.
- Wipe up spills immediately.
- Make stairways safe. Keep them well-lit, provide handrails on both sides, make sure steps are even and uniformly deep, and consider using a contrasting color along the edge of steps.
- Install child-proof gates at both the head and foot of stairs.
- Make sure lighting is evenly distributed to avoid "hot spots" and shadows.
- Install night lights on the path to the bathroom.

### **Ensure safety in bathrooms**

- Install devices such as grab bars, bath seats and commode chairs.
- Put non-slip mats or appliqués in tubs and showers.
- Remove electrical appliances to reduce the chance of electrocution or shock.
- Install ground-fault outlets near all water sources.

### **Prevent wandering**

- Consider installing safety doorknobs.
- Put locks at the top or bottom of doors, out of the person's line of sight.
- Camouflage the outside door or place a dark rug in front of it to discourage the person from approaching.
- Get an intercom system (such as those used in infants' rooms) or install Dutch doors, so you can stay aware of the person's activities while in another room.
- Hang chimes on doors.
- Install electronic alert alarms.
- Make sure the person wears an identification bracelet, like the one available through MedicAlert® + Alzheimer's Association's Safe Return®.

### **Get rid of guns**

- Remove guns from the house. At minimum, lock guns away in a cabinet or drawer.
- Don't keep guns loaded; store ammunition in a separate place.
- Never let a person with Alzheimer's handle a gun.

### **Create emergency plans**

- Prepare a list of emergency phone numbers, such as the police and fire departments, hospitals and poison control centers.
- Develop escape plans in case of fire.
- Recruit someone who lives nearby to help in case of emergency.

### **Resources**

MedicAlert + Safe Return is a 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia that wander or who have a medical emergency.

To learn more or to enroll, contact your local Alzheimer's Association, call 1.888.572.8566 or register online at [www.alz.org](http://www.alz.org).

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

**Updated** November 2007



# Appendix G

## California Forms



Note: This form is 8.5" x 14," and has been altered to fit 8.5" x 11" for demonstration purposes only. Please download the correct form from <http://www.dmv.ca.gov>.



A Public Service Agency

**INSTRUCTIONS:**

1. Complete this form if you wish the Department of Motor Vehicles (DMV) to reevaluate a driver's ability to drive safely.
2. Sign this request in the signature block provided. Anonymous reports will not be considered unless you are an immediate family member. You may request that your name not be revealed to the individual being reported. Confidentiality will be honored to the fullest extent possible.
3. Take your completed request to any DMV office or mail to: DMV, Driver Safety Office (see addresses below for your local office.)

NAME OF PERSON BEING REPORTED (FIRST, M.I., LAST)		DATE OF BIRTH OR APPROXIMATE AGE	TELEPHONE NUMBER ( )
DRIVER LICENSE NUMBER	VEHICLE LICENSE PLATE NUMBER, IF AVAILABLE		
STREET ADDRESS	CITY	STATE	ZIP CODE

**DRIVER CONDITION—Check all appropriate boxes below. Please use the space below to provide specific details, if known, about the driver's medical (physical or mental) condition such as name of disease or illness, any medications taken, etc.**

- |  |   |
|--|---|
| <input type="checkbox"/> Medical Condition                 | <input type="checkbox"/> Confused/Disoriented   |
| <input type="checkbox"/> Physical Condition                | <input type="checkbox"/> Alcohol/Drug Use (Describe below)  |
| <input type="checkbox"/> Mental/Emotional Condition        | <input type="checkbox"/> Blackouts, Seizures, Fainting Spells   |
| <input type="checkbox"/> Vision Condition                  | <input type="checkbox"/> Needs help with daily activities (i.e., cooking, dressing, bathing, balancing checkbook) |
| <input type="checkbox"/> Weakness or Coordination Problems | <input type="checkbox"/> Other: _____   |
| <input type="checkbox"/> Difficulty Walking                |   |

**DRIVER BEHAVIOR—Check appropriate boxes for driving problems you have observed: (Use space below if needed for additional comments.)**

- |   |   |
|---|---|
| <input type="checkbox"/> Does not see or react to other cars, pedestrians, etc.           | <input type="checkbox"/> Turns in front of on-coming cars                                   |
| <input type="checkbox"/> Drives in wrong lane   | <input type="checkbox"/> Allows car to drift in and out of lane                             |
| <input type="checkbox"/> Drives on wrong side of the road                                 | <input type="checkbox"/> Backs up or changes lanes without looking back or checking mirrors |
| <input type="checkbox"/> Acts violent or aggressive when driving                          | <input type="checkbox"/> Applies brake and gas pedals at the same time                      |
| <input type="checkbox"/> Drives too slow, or stops, for no reason                         | <input type="checkbox"/> Slow reactions that may be caused by medications or drugs          |
| <input type="checkbox"/> Has trouble steering, braking, or otherwise controlling car      | <input type="checkbox"/> Drives on sidewalk   |
| <input type="checkbox"/> Is confused by traffic   | <input type="checkbox"/> Makes driving mistakes while talking to passengers                 |
| <input type="checkbox"/> Gets lost or confused while driving near home                    | <input type="checkbox"/> Falls asleep while driving   |
| <input type="checkbox"/> Fails to react to traffic signals, other cars, pedestrians, etc. | <input type="checkbox"/> Other actions (Describe below)                                     |
| <input type="checkbox"/> Makes turns from wrong lane                                      |   |

You may use the space below to further describe the driver's condition(s) or action(s) which lead you to believe this driver should be reevaluated by DMV.

**YOUR RELATIONSHIP TO DRIVER:**

- Relative (Please state exact relationship): \_\_\_\_\_
- Friend  Caregiver  Vision Specialist  Other: \_\_\_\_\_

Check here if you would like to have your name kept confidential. Confidentiality will be honored to the fullest extent possible.

NAME (Please print)	DAYTIME TELEPHONE NUMBER ( )
---------------------	---------------------------------

YOUR MAILING ADDRESS (City, State, Zip Code)

SIGNATURE <b>X</b>	DATE
-----------------------	------

**YOU MAY MAIL OR TAKE THIS COMPLETED FORM TO YOUR LOCAL DRIVER SAFETY OFFICE AT ONE OF THESE LOCATIONS:**

- |  |   |
|--|---|
| <p><b>City of Commerce</b>, 5801 E. Slauson Ave., Ste. 250<br/>City of Commerce, 90040-3050</p> <p><b>El Segundo</b>, 390 N. Sepulveda Blvd. Ste. 2075, El Segundo, 90245-4470</p> <p><b>Fresno</b>, 2510 S. East Ave., Ste. 310, Fresno, 93706-5112</p> <p><b>Irvine</b>, 16735 Von Karman Ave., #110, Irvine, 92606-4953</p> <p><b>Oakland</b>, 303 Hegenberger Rd., Ste. 400, Oakland, 94621-1452</p> <p><b>Oxnard</b>, 4050 S. Saviers Rd., Oxnard, 93033-6444</p> | <p><b>Sacramento</b>, 4700 Broadway, 2nd Flr., Sacramento, 95820-1501</p> <p><b>San Bernardino</b>, 1845 Business Center Dr., Ste 212,<br/>San Bernardino, 92408-3447</p> <p><b>San Diego</b>, 9174 Sky Park Court, Ste. 200, San Diego, 92123-2666</p> <p><b>San Francisco</b>, 1377 Fell St., 2nd Floor, San Francisco, 94117-2296</p> <p><b>San Jose</b>, 90 Great Oaks Blvd., Ste. 104, San Jose, 95119</p> <p><b>Van Nuys</b>, 6150 Van Nuys Blvd., Ste. 205, Van Nuys, 91401-3333</p> |
|--|---|

## DRIVER MEDICAL EVALUATION

(Medical information is CONFIDENTIAL under Section 1808.5 CVC)

**PHYSICIAN RETURN FORM TO:**

**INSTRUCTIONS TO THE DRIVER:** Please take this form to the doctor most familiar with your health history and current medical condition. **Before** giving this form to your doctor, complete name/address, complete and sign the **HEALTH HISTORY** and the **MEDICAL INFORMATION AUTHORIZATION** sections on this page.

**INSTRUCTIONS TO THE DOCTOR:** Please complete the section, **DOCTOR'S MEDICAL EVALUATION**, on pages 2 through 5. The Department of Motor Vehicles' records indicate your patient may have a condition that could affect the safe operation of a motor vehicle. In this case, the department is concerned about the following condition(s):

TO BE COMPLETED BY DMV HEARING OFFICER

RETURN BY:

NAME (LAST, FIRST, MIDDLE)	DRIVER LICENSE NO.	BIRTH DATE	FIELD FILE
STREET ADDRESS	CITY	ZIP	PATIENT'S DAYTIME OR HOME PHONE NO.

**PATIENT MUST COMPLETE HEALTH HISTORY BELOW. (Please explain any "YES" answers)**

YES	NO		YES	NO	
		Head, neck, spinal injury, disorders or illnesses			Kidney disease, stones, blood in urine, or dialysis
		Seizure, convulsions, or epilepsy			Muscular disease
		Dizziness, fainting, or frequent headaches			Any permanent impairment
		Eye problem (except corrective lenses)			Nervous or psychiatric disorder
		Cardiovascular (heart or blood vessel) disease			Regular or frequent alcohol use
		Heart attack, stroke, or paralysis			Problems with the use of alcohol or drugs
		Lung disease (include tuberculosis, asthma) or emphysema			Suffering from any other disease
		Nervous stomach, ulcer, or digestive problems			Any major illness, injury, or operations in last 5 years
		Diabetes or high blood sugar			Currently taking medications

**EXPLANATION:** (Include onset date, diagnosis, medication, doctor's name and address and any current condition or limitation. Attach additional sheet, if needed).

**I certify under the penalty of perjury, under the laws of the State of California, that I have provided true and complete information concerning my health.**

DATE	DRIVER'S SIGNATURE
------	--------------------

**DRIVER'S ADVISORY STATEMENT**

Medical information is required under the authority of Divisions 6 and 7 of the California Vehicle Code. Failure to provide the information is cause for refusal to issue a license or to withdraw the driving privilege.

All records of the Department of Motor Vehicles, relating to the physical or mental condition of any person, are confidential and not open to public inspection (California Vehicle Code Section 1808.5). Information used in determining driving qualifications is available to you and/or your representative with your signed authorization.

*The department has sole responsibility for any decision regarding your driving qualifications and licensure. The department will also consider non-medical factors in reaching a decision.*

**MEDICAL INFORMATION AUTHORIZATION (Valid for three years)**

DOCTOR, HOSPITAL, OR MEDICAL FACILITY (NAME AND ADDRESS)	
DATE	MEDICAL RECORD/PATIENT FILE NO.

**I hereby authorize** my doctor or hospital to answer any questions from the Department of Motor Vehicles, or its employees, relating to my physical or mental condition, and/or drug and/or alcohol use, and to release any related information or records to the Department of Motor Vehicles or its employees. Any expense involved is to be charged to me and not to the Department of Motor Vehicles.

**I hereby authorize** the Department of Motor Vehicles to receive any information relating to my physical or mental condition, and/or drug and/or alcohol use or abuse, and to use the same in determining whether I have the ability to operate a motor vehicle safely.

**NOTE:** You may wish to make a copy of the completed Driver Medical Evaluation for your records.

SIGNED	DATE
WITNESS	DATE

**DOCTOR'S MEDICAL EVALUATION**

**INSTRUCTIONS TO THE DOCTOR:** The Department of Motor Vehicles' records indicate your patient may have a condition that could affect the safe operation of a motor vehicle. (See Instructions to the Doctor, page 1 for the specific medical condition(s) that is a concern to the department.) With your assistance, the department hopes to resolve the matter with a minimum of inconvenience to all concerned.

The Health History and Medical Information Authorization sections on page 1 must be completed and signed by the patient before you complete this Driver Medical Evaluation form.

Your experience and knowledge of the patient's condition, results of medical examinations and treatment plans, will be of great value in assisting the department to determine a proper licensing decision. PLEASE ANSWER ALL QUESTIONS on this form that are applicable to your patient's condition(s). You may furnish a narrative report if you prefer, but please include all information pertinent to your patient. The department has sole responsibility for any decision regarding the patient's driving qualifications and licensure. The department will also consider non-medical factors in reaching a decision.

**VISION**

<b>VISUAL ACUITY (without bioptic telescope)</b>	<b>BOTH EYES</b>	<b>RIGHT EYE</b>	<b>LEFT EYE</b>
Without Lenses	20/	20/	20/
With Present Lenses	20/	20/	20/

ANY EYE INJURY OR DISEASE? (LIST)

IS FURTHER EYE EXAMINATION SUGGESTED?

Yes  No

**TREATMENT BY OTHER DOCTOR(S)**

IS THIS PATIENT BEING TREATED FOR ANY CONDITION BY ANOTHER DOCTOR?

Yes  No

IF YES, PLEASE INDICATE NAME OF TREATING DOCTOR(S)

CONDITION BEING TREATED

**TREATMENT UNDER YOUR SUPERVISION**

**DIAGNOSIS** (IF THE DIAGNOSIS IS A DISORDER CHARACTERIZED BY LAPSES OF CONSCIOUSNESS, DEMENTIA, OR DIABETES, COMPLETE PAGE 3 OR 4.)

DO YOU NEED TO SEE YOUR PATIENT AT REGULAR INTERVALS? IF YES, HOW OFTEN?

Yes  No

**PROGNOSIS**

IS THE CONDITION

Improving  Stable  Worsening or deteriorating  Subject to change (IF MULTIPLE CONDITIONS, PLEASE DESCRIBE STATUS AND PROGNOSIS IN COMMENTS BELOW.)

MANIFESTATIONS: (SYMPTOMS)

(PRESENT)

(PAST) MAY CONDITION IMPAIR VISION?  Yes  No

HOW LONG HAS THIS PERSON BEEN YOUR PATIENT? DATE OF LAST EXAMINATION

IS YOUR PATIENT UNDER A CONTROLLED MEDICAL PROGRAM?  Yes  No HOW LONG HAS CONTROL BEEN MAINTAINED?

IS THE PATIENT ADHERING TO THE MEDICAL REGIMEN? IF NO, PLEASE EXPLAIN:  Yes  No IS THE PATIENT KNOWLEDGEABLE ABOUT THE MEDICAL CONDITION?  Yes  No

LIST THE MEDICATIONS PRESCRIBED. PLEASE INCLUDE DOSAGE AND FREQUENCY OF USE

WHEN WAS THE LAST MEDICATION CHANGE MADE?

WOULD THE SIDE EFFECTS FROM THE PRESCRIBED MEDICATIONS INTERFERE WITH THE SAFE OPERATION OF A MOTOR VEHICLE?

Yes  No If yes, please describe:

IN YOUR OPINION, DOES YOUR PATIENT'S MEDICAL CONDITION AFFECT SAFE DRIVING?

Yes  No  Uncertain

HAVE YOU ADVISED AGAINST DRIVING?

DOCTOR'S COMMENTS:



**LAPSE OF CONSCIOUSNESS DISORDER**

PLEASE IDENTIFY THE LAPSE OF CONSCIOUSNESS DISORDER BEING REPORTED (Type of seizure, nocturnal, isolated, DATE(S) OF EPISODE(S) IN THE PAST THREE YEARS  
*syncope, blackouts, etc.*)

DATE OF ONSET, IF KNOWN

DATE AND TIME OF LAST EPISODE

Please indicate the impairments identified below that are presently shown by your patient.

	YES	NO	UNCERTAIN
Sporadic loss of conscious awareness.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of consciousness .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Impaired motor function.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**EFFECTS AFTER EPISODE**

	YES	NO	UNCERTAIN
Confusion .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diminished concentration .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diminished judgment.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory loss .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If medication is taken to control seizures, are the serum levels recorded? .....

YES       NO

Are the serum levels medically acceptable? .....

YES       NO

**DIABETES**

PLEASE INDICATE THE TYPE OF DIABETES THIS PATIENT HAS

Type 1     Type 2     Gestational

DATE OF DIAGNOSIS

WHAT METHOD OF TREATMENT IS REQUIRED?

Controlled diet     Oral diabetes medication     Insulin injections     Insulin pump     Other:

HAS THIS PATIENT RECEIVED DIABETES EDUCATION FROM A HEALTH CARE TEAM?

Yes     No

DOES THIS PATIENT COMPLY WITH THE PRESCRIBED TREATMENT PLAN?

Yes     No

IF NO, PLEASE EXPLAIN

IS THE DIABETES CONTROLLED AT THIS TIME?

Yes     No

IF YES, HOW LONG HAS CONTROL BEEN MAINTAINED?

IF NO, PLEASE EXPLAIN

WHAT ARE THIS PATIENT'S FASTING BLOOD GLUCOSE LEVELS?

AFTER HOW MANY HOURS OF FASTING?

WITHIN THE LAST THREE YEARS, HAS THIS PATIENT EXPERIENCED

Hypoglycemic episodes?     Hypoglycemic episodes?

REASON FOR EPISODES (e.g., non-compliance w/regimen, change in condition, insulin unavailable, illness, etc.)

Please indicate the complications manifested by the hypoglycemic or hyperglycemic episodes and rate the severity of each.

	NONE	MILD	MODERATE	SEVERE	UNCERTAIN
Abdominal pain.....	<input type="checkbox"/>				
Cognitive deficits .....	<input type="checkbox"/>				
Confusion .....	<input type="checkbox"/>				
Confusion or disorientation.....	<input type="checkbox"/>				
Incoordination.....	<input type="checkbox"/>				
Hypoglycemic unawareness.....	<input type="checkbox"/>				
Lack of stamina .....	<input type="checkbox"/>				
Loss of consciousness .....	<input type="checkbox"/>				
Stupor.....	<input type="checkbox"/>				
Visual changes .....	<input type="checkbox"/>				
Ketoacidosis .....	<input type="checkbox"/>				
Slowed reactions .....	<input type="checkbox"/>				
Seizures.....	<input type="checkbox"/>				
Weakness or fatigue.....	<input type="checkbox"/>				
Other.....					



CONFIDENTIAL REPORT - NOT SUBJECT TO PUBLIC DISCLOSURE

REPORT OF SUSPECTED DEPENDENT ADULT/ELDER ABUSE

DATE COMPLETED:

TO BE COMPLETED BY REPORTING PARTY. PLEASE PRINT OR TYPE. SEE GENERAL INSTRUCTIONS.

A. VICTIM Check box if victim consents to disclosure of information [Ombudsman use only - WIC 15636(a)]

Form section A containing fields for victim name, age, date of birth, SSN, gender, ethnicity, language, address, city, zip code, telephone, and checkboxes for various conditions like elderly, disabled, etc.

B. SUSPECTED ABUSER Check if Self-Neglect

Form section B containing fields for name of suspected abuser, care custodian, health practitioner, address, zip code, telephone, gender, ethnicity, age, D.O.B., height, weight, eyes, and hair.

C. REPORTING PARTY: Check appropriate box if reporting party waives confidentiality to: All, All but victim, All but perpetrator

Form section C containing fields for reporting party name, signature, occupation, agency name, relation to victim, street, city, zip code, e-mail address, and telephone.

D. INCIDENT INFORMATION - Address where incident occurred:

Form section D containing fields for date/time of incident, place of incident (own home, community care facility, hospital, nursing facility, etc.), and other (specify).

E. REPORTED TYPES OF ABUSE CHECK ALL THAT APPLY.

Form section E containing two columns of checkboxes for types of abuse: 1. PERPETRATED BY OTHERS (WIC 15610.07 & 15610.63) and 2. SELF-NEGLECT (WIC 15610.57(b)(5)).

F. REPORTER'S OBSERVATIONS, BELIEFS, AND STATEMENTS BY VICTIM IF AVAILABLE. DOES ALLEGED PERPETRATOR STILL HAVE ACCESS TO THE VICTIM? PROVIDE ANY KNOWN TIME FRAME (2 days, 1 week, ongoing, etc.). LIST ANY POTENTIAL DANGER FOR INVESTIGATOR (animals, weapons, communicable diseases, etc.).

G. TARGETED ACCOUNT

Form section G containing fields for account number, type of account (deposit, credit, other), trust account, power of attorney, direct deposit, and other accounts.

H. OTHER PERSON BELIEVED TO HAVE KNOWLEDGE OF ABUSE. (family, significant others, neighbors, medical providers and agencies involved, etc.)

Form section H containing fields for name, address, telephone no., and relationship of the other person.

I. FAMILY MEMBER OR OTHER PERSON RESPONSIBLE FOR VICTIM'S CARE. (If unknown, list contact person).

Form section I containing fields for name, address, city, zip code, telephone, and relationship of the family member or other person.

J. TELEPHONE REPORT MADE TO: Local APS, Local Law Enforcement, Local Ombudsman, Calif. Dept. of Mental Health, Calif. Dept. of Developmental Services

Form section J containing fields for name of official contacted by phone, telephone, and date/time.

K. WRITTEN REPORT Enter information about the agency receiving this report. Do not submit report to California Department of Social Services Adult Programs Bureau.

Form section K containing fields for agency name, address or fax #, date mailed, and date faxed.

L. RECEIVING AGENCY USE ONLY Telephone Report, Written Report

Form section L containing fields for report received by, assigned status, approved by, assigned to, cross-reported to, and APS/Ombudsman/Law Enforcement Case File Number.

## REPORT OF SUSPECTED DEPENDENT ADULT/ELDER ABUSE GENERAL INSTRUCTIONS

### PURPOSE OF FORM

This form, as adopted by the California Department of Social Services (CDSS), is required under Welfare and Institutions Code (WIC) Sections 15630 and 15658(a)(1). This form documents the information given by the reporting party on the suspected incident of abuse of an elder or dependent adult. "Elder," means any person residing in this state who is 65 years of age or older (WIC Section 15610.27). "Dependent Adult," means any person residing in this state, between the ages of 18 and 64, who has physical or mental limitations that restrict his or her ability to carry out normal activities or to protect his or her rights including, but not limited to, persons who have physical or developmental disabilities or whose physical or mental abilities have diminished because of age (WIC Section 15610.23). Dependent adult includes any person between the ages of 18 and 64 who is admitted as an inpatient to a 24-hour health facility (defined in the Health and Safety Code Sections 1250, 1250.2, and 1250.3).

### COMPLETION OF THE FORM

1. This form may be used by the receiving agency to record information through a telephone report of suspected dependent adult/elder abuse. Complete items with an asterisk (\*) when a telephone report of suspected abuse is received as required by statute and the California Department of Social Services.
2. If any item of information is unknown, enter "unknown."
3. Item A: Check box to indicate if the victim waives confidentiality.
4. Item C: Check box if the reporting party waives confidentiality. Please note that mandated reporters are required to disclose their names, however, non-mandated reporters may report anonymously.

### REPORTING RESPONSIBILITIES

Mandated reporters (see definition below under "Reporting Party Definitions") shall complete this form for each report of a known or suspected instance of abuse (physical abuse, sexual abuse, financial abuse, abduction, neglect, (self-neglect), isolation, and abandonment (see definitions in WIC Section 15610) involving an elder or a dependent adult. **The original of this report shall be submitted within two (2) working days of making the telephone report to the responsible agency as identified below:**

- The county Adult Protective Services (APS) agency or the local law enforcement agency (if abuse occurred in a private residence, apartment, hotel or motel, or homeless shelter).
- Long-Term Care Ombudsman (LTCO) program or the local law enforcement agency (if abuse occurred in a nursing home, adult residential facility, adult day program, residential care facility for the elderly, or adult day health care center).
- The California Department of Mental Health or the local law enforcement agency (if abuse occurred in Metropolitan State Hospital, Atascadero State Hospital, Napa State Hospital, or Patton State Hospital).
- The California Department of Developmental Services or the local law enforcement agency (if abuse occurred in Sonoma Developmental Center, Lanterman Developmental Center, Porterville Developmental Center, Fairview Developmental Center, or Agnews Developmental Center).

### WHAT TO REPORT

Any mandated reporter who, in his or her professional capacity, or within the scope of his or her employment has observed, suspects, or has knowledge of an incident that reasonably appears to be physical abuse (including sexual abuse), abandonment, isolation, financial abuse, abduction, or neglect (including self-neglect), or is told by an elder or a dependent adult that he or she has experienced behavior constituting physical abuse, abandonment, isolation, financial abuse, abduction, or neglect, shall report the known or suspected instance of abuse by telephone immediately or as soon as practicably possible, and by written report sent within two working days to the appropriate agency.

### REPORTING PARTY DEFINITIONS

Mandated Reporters (WIC) "15630 (a) Any person who has assumed full or intermittent responsibility for care or custody of an elder or dependent adult, whether or not that person receives compensation, including administrators, supervisors, and any licensed staff of a public or private facility that provides care or services for elder or dependent adults, or any elder or dependent adult care custodian, health practitioner, clergy member, or employee of a county adult protective services agency or a local law enforcement agency, is a mandated reporter."

Care Custodian (WIC) "15610.17 'Care custodian' means an administrator or an employee of any of the following public or private facilities or agencies, or persons providing care or services for elders or dependent adults, including members of the support staff and maintenance staff: (a) Twenty-four-hour health facilities, as defined in Sections 1250, 1250.2, and 1250.3 of the Health and Safety Code. (b) Clinics. (c) Home health agencies. (d) Agencies providing publicly funded in-home supportive services, nutrition services, or other home and community-based support services. (e) Adult day health care centers and adult day care. (f) Secondary schools that serve 18- to 22-year-old dependent adults and postsecondary educational institutions that serve dependent adults or elders. (g) Independent living centers. (h) Camps. (i) Alzheimer's Disease Day Care Resource Centers. (j) Community care facilities, as defined in Section 1502 of the Health and Safety Code, and residential care facilities for the elderly, as defined in Section 1569.2 of the Health and Safety Code. (k) Respite care facilities. (l) Foster homes. (m) Vocational rehabilitation facilities and work activity centers. (n) Designated area agencies on aging. (o) Regional centers for persons with developmental disabilities. (p) State Department of Social Services and State Department of Health Services licensing divisions. (q) County welfare departments. (r) Offices of patients' rights advocates and clients' rights advocates, including attorneys. (s) The Office of the State Long-Term Care Ombudsman. (t) Offices of public conservators, public guardians, and court investigators. (u) Any protection or advocacy

## GENERAL INSTRUCTIONS (Continued)

agency or entity that is designated by the Governor to fulfill the requirements and assurances of the following: (1) The federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, contained in Chapter 144 (commencing with Section 15001) of Title 42 of the United States Code, for protection and advocacy of the rights of persons with developmental disabilities. (2) The Protection and Advocacy for the Mentally Ill Individuals Act of 1986, as amended, contained in Chapter 114 (commencing with Section 10801) of Title 42 of the United States Code, for the protection and advocacy of the rights of persons with mental illness. (v) Humane societies and animal control agencies. (w) Fire departments. (x) Offices of environmental health and building code enforcement. (y) Any other protective, public, sectarian, mental health, or private assistance or advocacy agency or person providing health services or social services to elders or dependent adults."

Health Practitioner (WIC) "15610.37 'Health practitioner' means a physician and surgeon, psychiatrist, psychologist, dentist, resident, intern, podiatrist, chiropractor, licensed nurse, dental hygienist, licensed clinical social worker or associate clinical social worker, marriage, family, and child counselor, or any other person who is currently licensed under Division 2 (commencing with Section 500) of the Business and Professions Code, any emergency medical technician I or II, paramedic, or person certified pursuant to Section 2913 of the Business and Professions Code, a marriage, family, and child counselor trainee, as defined in subdivision (c) of Section 4980.03 of the Business and Professions Code, or an unlicensed marriage, family, and child counselor intern registered under Section 4980.44 of the Business and Professions Code, state or county public health or social service employee who treats an elder or a dependent adult for any condition, or a coroner."

Officers and Employees of Financial Institutions (WIC) "15630.1. (a) As used in this section, "mandated reporter of suspected financial abuse of an elder or dependent adult" means all officers and employees of financial institutions. (b) As used in this section, the term "financial institution" means any of the following: (1) A depository institution, as defined in Section 3(c) of the Federal Deposit Insurance Act (12 U.S.C. Sec. 1813(c)). (2) An institution-affiliated party, as defined in Section 3(u) of the Federal Deposit Insurance Act (12 U.S.C. Sec. 1813(u)). (3) A federal credit union or state credit union, as defined in Section 101 of the Federal Credit Union Act (12 U.S.C. Sec. 1752), including, but not limited to, an institution-affiliated party of a credit union, as defined in Section 206(r) of the Federal Credit Union Act (12 U.S.C. Sec. 1786 (r)). (c) As used in this section, "financial abuse" has the same meaning as in Section 15610.30. (d)(1) Any mandated reporter of suspected financial abuse of an elder or dependent adult who has direct contact with the elder or dependent adult or who reviews or approves the elder or dependent adult's financial documents, records, or transactions, in connection with providing financial services with respect to an elder or dependent adult, and who, within the scope of his or her employment or professional practice, has observed or has knowledge of an incident that is directly related to the transaction or matter that is within that scope of employment or professional practice, that reasonably appears to be financial abuse, or who reasonably suspects that abuse, based solely on the information before him or her at the time of reviewing or approving the document, records, or transaction in the case of mandated reporters who do not have direct contact with the elder or dependent adult, shall report the known or suspected instance of financial abuse by telephone immediately, or as soon as practicably possible, and by written report sent within two working days to the local adult protective services agency or the local law enforcement agency."

### **MULTIPLE REPORTERS**

When two or more mandated reporters are jointly knowledgeable of a suspected instance of abuse of a dependent adult or elder, and when there is agreement among them, the telephone report may be made by one member of the group. Also, a single written report may be completed by that member of the group. Any person of that group, who believes the report was not submitted, shall submit the report.

### **IDENTITY OF THE REPORTER**

The identity of all persons who report under WIC Chapter 11 shall be confidential and disclosed only among APS agencies, local law enforcement agencies, LTCO coordinators, California State Attorney General Bureau of Medi-Cal Fraud and Elder Abuse, licensing agencies or their counsel, Department of Consumer Affairs Investigators (who investigate elder and dependent adult abuse), the county District Attorney, the Probate Court, and the Public Guardian. Confidentiality may be waived by the reporter or by court order.

### **FAILURE TO REPORT**

Failure to report by mandated reporters (as defined under "Reporting Party Definitions") any suspected incidents of physical abuse (including sexual abuse), abandonment, isolation, financial abuse, abduction, or neglect (including self-neglect) of an elder or a dependent adult is a misdemeanor, punishable by not more than six months in the county jail, or by a fine of not more than \$1,000, or by both imprisonment and fine. Any mandated reporter who willfully fails to report abuse of an elder or a dependent adult, where the abuse results in death or great bodily injury, may be punished by up to one year in the county jail, or by a fine of up to \$5,000, or by both imprisonment and fine.

Officers or employees of financial institutions (defined under "Reporting Party Definitions") are mandated reporters of financial abuse (effective January 1, 2007). These mandated reporters who fail to report financial abuse of an elder or dependent adult are subject to a civil penalty not exceeding \$1,000. Individuals who willfully fail to report financial abuse of an elder or dependent adult are subject to a civil penalty not exceeding \$5,000. These civil penalties shall be paid by the financial institution, which is the employer of the mandated reporter to the party bringing the action.

## GENERAL INSTRUCTIONS (Continued)

### EXCEPTIONS TO REPORTING

Per WIC Section 15630(b)(3)(A), a mandated reporter who is a physician and surgeon, a registered nurse, or a psychotherapist, as defined in Section 1010 of the Evidence Code, shall not be required to report a suspected incident of abuse where all of the following conditions exist:

- (1) The mandated reporter has been told by an elder or a dependent adult that he or she has experienced behavior constituting physical abuse (including sexual abuse), abandonment, isolation, financial abuse, abduction, or neglect (including self-neglect).
- (2) The mandated reporter is not aware of any independent evidence that corroborates the statement that the abuse has occurred.
- (3) The elder or the dependent adult has been diagnosed with a mental illness or dementia, or is the subject of a court-ordered conservatorship because of a mental illness or dementia.
- (4) In the exercise of clinical judgment, the physician and surgeon, the registered nurse, or the psychotherapist, as defined in Section 1010 of the Evidence Code, reasonably believes that the abuse did not occur.

Per WIC Section 15630(b)(4)(A), in a long-term care facility, a mandated reporter who the California Department of Health Services determines, upon approval by the Bureau of Medi-Cal Fraud and the Office of the State Long-Term Care Ombudsman (OSLTCO), has access to plans of care and has the training and experience to determine whether all the conditions specified below have been met, shall not be required to report the suspected incident of abuse:

- (1) The mandated reporter is aware that there is a proper plan of care.
- (2) The mandated reporter is aware that the plan of care was properly provided and executed.
- (3) A physical, mental, or medical injury occurred as a result of care pursuant to clause (1) or (2).
- (4) The mandated reporter reasonably believes that the injury was not the result of abuse.

### DISTRIBUTION OF SOC 341 COPIES

**Mandated reporter:** After making the telephone report to the appropriate agency, the reporter shall send the original and one copy to the agency; keep one copy for the reporter's file.

**Receiving agency:** Place the original copy in the case file. Send a copy to a cross-reporting agency, if applicable.

**DO NOT SEND A COPY TO THE CALIFORNIA DEPARTMENT OF SOCIAL SERVICES ADULT PROGRAMS BUREAU.**

ATTORNEY OR PARTY WITHOUT ATTORNEY (Name, State Bar number, and address):  TELEPHONE NO.: _____ FAX NO. (Optional): _____ E-MAIL ADDRESS (Optional): _____ ATTORNEY FOR (Name): _____	<b>FOR COURT USE ONLY</b>
<b>SUPERIOR COURT OF CALIFORNIA, COUNTY OF</b>  STREET ADDRESS: MAILING ADDRESS: CITY AND ZIP CODE: BRANCH NAME:	
CONSERVATORSHIP OF THE <input type="checkbox"/> PERSON <input type="checkbox"/> ESTATE OF (Name):  <input type="checkbox"/> CONSERVATEE <input type="checkbox"/> PROPOSED CONSERVATEE	
<b>CAPACITY DECLARATION—CONSERVATORSHIP</b>	CASE NUMBER
<p style="text-align: center;"><b>TO PHYSICIAN, PSYCHOLOGIST, OR RELIGIOUS HEALING PRACTITIONER</b></p> <p>The purpose of this form is to enable the court to determine whether the (proposed) conservatee (check all that apply):</p> <p>A. <input type="checkbox"/> is able to attend a court hearing to determine whether a conservator should be appointed to care for him or her. The court hearing is set for (date): <input style="width: 150px;" type="text"/>. (Complete item 5, sign, and file page 1 of this form.)</p> <p>B. <input type="checkbox"/> has the capacity to give informed consent to medical treatment. (Complete items 6 through 8, sign page 3, and file pages 1 through 3 of this form.)</p> <p>C. <input type="checkbox"/> has dementia and, if so, (1) whether he or she needs to be placed in a secured-perimeter residential care facility for the elderly, and (2) whether he or she needs or would benefit from dementia medications. (Complete items 6 and 8 of this form and form GC-335A; sign and attach form GC-335A. File pages 1 through 3 of this form and form GC-335A.)</p> <p>(If more than one item is checked above, sign the last applicable page of this form or form GC-335A if item C is checked. File page 1 through the last applicable page of this form; also file form GC-335A if item C is checked.)</p> <p><b>COMPLETE ITEMS 1–4 OF THIS FORM IN ALL CASES.</b></p>	

**GENERAL INFORMATION**

1. (Name):
2. (Office address and telephone number):
3. I am
  - a.  a California licensed  physician  psychologist acting within the scope of my licensure  with at least two years' experience in diagnosing dementia.
  - b.  an accredited practitioner of a religion whose tenets and practices call for reliance on prayer alone for healing, which religion is adhered to by the (proposed) conservatee. The (proposed) conservatee is under my treatment. (Religious practitioner may make the determination under item 5 ONLY.)
4. (Proposed) conservatee (name):
  - a. I last saw the (proposed) conservatee on (date):
  - b. The (proposed) conservatee  is  is NOT a patient under my continuing treatment.

**ABILITY TO ATTEND COURT HEARING**

5. A court hearing on the petition for appointment of a conservator is set for the date indicated in item A above. (Complete a or b.)
  - a.  The proposed conservatee is able to attend the court hearing.
  - b.  Because of medical inability, the proposed conservatee is NOT able to attend the court hearing (check all items below that apply).
    - (1)  on the date set (see date in box in item A above).
    - (2)  for the foreseeable future.
    - (3)  until (date):
    - (4) **Supporting facts** (State facts in the space below or check this box  and state the facts in Attachment 5):

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

Date:

\_\_\_\_\_  
(TYPE OR PRINT NAME)

\_\_\_\_\_  
(SIGNATURE OF DECLARANT)

Page 1 of \_\_\_\_

CONSERVATORSHIP OF THE <input type="checkbox"/> PERSON <input type="checkbox"/> ESTATE OF (Name):	CASE NUMBER:
<input type="checkbox"/> CONSERVATEE <input type="checkbox"/> PROPOSED CONSERVATEE	

## 6. EVALUATION OF (PROPOSED) CONSERVATEE'S MENTAL FUNCTIONS

**Note to practitioner:** This form is *not* a rating scale. It is intended to assist you in recording your *impressions* of the (proposed) conservatee's mental abilities. Where appropriate, you may refer to scores on standardized rating instruments.

**(Instructions for items 6A–6C):** Check the appropriate designation as follows: **a** = no apparent impairment; **b** = moderate impairment; **c** = major impairment; **d** = so impaired as to be incapable of being assessed; **e** = I have no opinion.)

### A. Alertness and attention

(1) Levels of arousal (lethargic, responds only to vigorous and persistent stimulation, stupor)

a  b  c  d  e

(2) Orientation (types of orientation impaired)

a  b  c  d  e  Person

a  b  c  d  e  Time (day, date, month, season, year)

a  b  c  d  e  Place (address, town, state)

a  b  c  d  e  Situation ("Why am I here?")

(3) Ability to attend and concentrate (give detailed answers from memory, mental ability required to thread a needle)

a  b  c  d  e

### B. Information processing. Ability to:

(1) Remember (ability to remember a question before answering; to recall names, relatives, past presidents, and events of the past 24 hours)

i. Short-term memory a  b  c  d  e

ii Long-term memory a  b  c  d  e

iii Immediate recall a  b  c  d  e

(2) Understand and communicate either verbally or otherwise (deficits reflected by inability to comprehend questions, follow instructions, use words correctly, or name objects; use of nonsense words)

a  b  c  d  e

(3) Recognize familiar objects and persons (deficits reflected by inability to recognize familiar faces, objects, etc.)

a  b  c  d  e

(4) Understand and appreciate quantities (deficits reflected by inability to perform simple calculations)

a  b  c  d  e

(5) Reason using abstract concepts. (deficits reflected by inability to grasp abstract aspects of his or her situation or to interpret idiomatic expressions or proverbs)

a  b  c  d  e

(6) Plan, organize, and carry out actions (assuming physical ability) in one's own rational self-interest (deficits reflected by inability to break complex tasks down into simple steps and carry them out)

a  b  c  d  e

(7) Reason logically.

a  b  c  d  e

### C. Thought disorders

(1) Severely disorganized thinking (rambling thoughts; nonsensical, incoherent, or nonlinear thinking)

a  b  c  d  e

(2) Hallucinations (auditory, visual, olfactory)

a  b  c  d  e

(3) Delusions (demonstrably false belief maintained without or against reason or evidence)

a  b  c  d  e

(4) Uncontrollable or intrusive thoughts (unwanted compulsive thoughts, compulsive behavior).

a  b  c  d  e

(Continued on next page)

CONSERVATORSHIP OF THE <input type="checkbox"/> PERSON <input type="checkbox"/> ESTATE OF (Name):  <input type="checkbox"/> CONSERVATEE <input type="checkbox"/> PROPOSED CONSERVATEE	CASE NUMBER:
---	--------------

6. (continued)

D. **Ability to modulate mood and affect.** The (proposed) conservatee  has  does NOT have a pervasive and persistent or recurrent emotional state that appears inappropriate in degree to his or her circumstances. (If so, complete remainder of item 6D.)  I have no opinion.

*(Instructions for item 6D: Check the degree of impairment of each inappropriate mood state (if any) as follows: a = mildly inappropriate; b = moderately inappropriate; c = severely inappropriate.)*

Anger	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Euphoria	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Helplessness	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>
Anxiety	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Depression	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Apathy	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>
Fear	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Hopelessness	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Indifference	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>
Panic	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>	Despair	a <input type="checkbox"/>	b <input type="checkbox"/>	c <input type="checkbox"/>				

E. The (proposed) conservatee's periods of impairment from the deficits indicated in items 6A–6D

- (1)  do NOT vary substantially in frequency, severity, or duration.
- (2)  do vary substantially in frequency, severity, or duration (*explain; continue on Attachment 6E if necessary*):

F.  (Optional) Other information regarding my evaluation of the (proposed) conservatee's mental function (e.g., diagnosis, symptomatology, and other impressions) is  stated below  stated in Attachment 6F.

**ABILITY TO CONSENT TO MEDICAL TREATMENT**

7. Based on the information above, it is my opinion that the (proposed) conservatee
- a.  has the capacity to give informed consent to any form of medical treatment. This opinion is limited to medical consent capacity.
  - b.  lacks the capacity to give informed consent to any form of medical treatment because he or she is **either** (1) unable to respond knowingly and intelligently regarding medical treatment **or** (2) unable to participate in a treatment decision by means of a rational thought process, **or both**. The deficits in the mental functions described in item 6 above significantly impair the (proposed) conservatee's ability to understand and appreciate the consequences of medical decisions. This opinion is limited to medical consent capacity.

*(Declarant must initial here if item 7b applies: \_\_\_\_\_.)*

8. Number of pages attached: \_\_\_\_\_

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

Date: \_\_\_\_\_

_____ (TYPE OR PRINT NAME)		_____ (SIGNATURE OF DECLARANT)
-------------------------------	--	-----------------------------------

CONSERVATORSHIP OF THE <input type="checkbox"/> PERSON <input type="checkbox"/> ESTATE OF (Name):	CASE NUMBER:
<input type="checkbox"/> CONSERVATEE <input type="checkbox"/> PROPOSED CONSERVATEE	

**ATTACHMENT TO FORM GC-335, CAPACITY DECLARATION—CONSERVATORSHIP,  
ONLY FOR (PROPOSED) CONSERVATEE WITH DEMENTIA**

9. It is my opinion that the (proposed) conservatee  HAS  does NOT have dementia as defined in the current edition of *Diagnostic and Statistical Manual of Mental Disorders*.
- a.  **Placement of (proposed) conservatee.** (If the (proposed) conservatee requires placement in a secured-perimeter residential care facility for the elderly, please complete items 9a(1)–9a(5).)
- (1) The (proposed) conservatee needs or would benefit from placement in a restricted and secure facility because (state reasons; continue on Attachment 9a(1) if necessary):
  
  - (2) The (proposed) conservatee's mental function deficits, based on my assessment in item 6 of form GC-335, include (describe; continue on Attachment 9a(2) if necessary):
  
  - (3)  The (proposed) conservatee HAS capacity to give informed consent to this placement.
  - (4)  The (proposed) conservatee does NOT have capacity to give informed consent to this placement. The deficits in mental function assessed in item 6 of form GC-335 and described in item 9a(2) above significantly impair the (proposed) conservatee's ability to understand and appreciate the consequences of his or her actions with regard to giving informed consent to placement in a restricted and secure environment.
  - (5) A locked or secured-perimeter facility  is  is NOT the least restrictive environment appropriate to the needs of the (proposed) conservatee.
- b.  **Administration of dementia medications.** (If the (proposed) conservatee requires administration of psychotropic medications appropriate to the care of dementia, please complete items 9b(1)–9b(5).)
- (1) The (proposed) conservatee needs or would benefit from the following psychotropic medications appropriate to the care of dementia, for the reasons stated in item 9b(5) (list medications; continue on Attachment 9b(1) if necessary):
  
  - (2) The (proposed) conservatee's mental function deficits, based on my assessment in item 6 of form GC-335, include (describe; continue on Attachment 9b(2) if necessary):
  
  - (3)  The (proposed) conservatee HAS capacity to give informed consent to the administration of psychotropic medications appropriate to the care of dementia.
  - (4)  The (proposed) conservatee does NOT have the capacity to give informed consent to the administration of psychotropic medications appropriate to the care of dementia. The deficits in mental function assessed in item 6 of form GC-335 and described in item 9b(2) above significantly impair the (proposed) conservatee's ability to understand and appreciate his or her actions with regard to giving informed consent to the administration of psychotropic medications for the treatment of dementia.
  - (5) The (proposed) conservatee needs or would benefit from the administration of the psychotropic medications listed in item 9b(1) because (state reasons; continue on Attachment 9b(5) if necessary):

10. Number of pages attached: \_\_\_\_\_

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

Date:

\_\_\_\_\_  \_\_\_\_\_  
(TYPE OR PRINT NAME) (SIGNATURE OF DECLARANT)

ATTORNEY OR PARTY WITHOUT ATTORNEY (Name, state bar number, and address):	TELEPHONE AND FAX NOS.:	FOR COURT USE ONLY
ATTORNEY FOR (Name):		
<b>SUPERIOR COURT OF CALIFORNIA, COUNTY OF</b> STREET ADDRESS: MAILING ADDRESS: CITY AND ZIP CODE: BRANCH NAME:		
CONSERVATORSHIP OF THE <input type="checkbox"/> PERSON <input type="checkbox"/> ESTATE OF (Name): <div style="text-align: right;">CONSERVATEE</div>		
<b>PETITION FOR EXCLUSIVE AUTHORITY TO GIVE          CONSENT FOR MEDICAL TREATMENT</b>		CASE NUMBER:

1. **Petitioner (name):** \_\_\_\_\_ **requests that**
- a. the conservatee be adjudged to lack the capacity to give informed consent for medical treatment or healing by prayer.
  - b. the conservator of the person be granted the exclusive authority to give consent for medical treatment or healing by prayer that the conservator in good faith based on medical advice determines to be necessary.
  - c. the treatment be performed by  a licensed medical practitioner  a licensed psychologist within the scope of his or her licensure  an accredited practitioner of a religion that relies on prayer alone for healing.
  - d.  orders related to dementia treatment or placement as specified in the *Attachment Requesting Special Orders Regarding Dementia* be granted. (Attach form GC-313.)
  - e.  the order dated (specify): \_\_\_\_\_ made under Probate Code section 1880  
 be revoked  be modified as specified in Attachment 1e  be modified as follows (specify): \_\_\_\_\_
  - f.  other orders be granted  as specified in Attachment 1f  as follows (specify): \_\_\_\_\_
  - g. *Letters of Conservatorship* be reissued to include a statement that conservator has the powers requested in this petition.
2. There is no form of medical treatment for which the proposed conservatee has the capacity to give informed consent.
3. Attached to this petition is a declaration executed by a licensed physician stating that the conservatee lacks the capacity to give informed consent for any form of medical treatment and giving reasons and the factual basis for this conclusion. (Label as Attachment 3.)
4. Conservatee  is  is not an adherent of a religion that relies on prayer alone for healing as defined in Probate Code section 2355(b).

(Continued on reverse)

CONSERVATORSHIP OF (Name): <hr style="border: 0; border-top: 1px solid black; margin-top: 10px;"/>	CASE NUMBER:  
CONSERVATEE	

5. ATTENDANCE AT THE HEARING **Conservatee**

- a.  will attend the hearing.
- b.  is able but unwilling to attend the hearing AND  does  does not wish to contest this petition.
- c.  is unable to attend the hearing because of medical inability. An affidavit or certificate of a licensed medical practitioner or an accredited religious practitioner is affixed as Attachment 5c.
- d.  is not the petitioner, is out of state, and will not attend the hearing.

6. **Special notice**  has  has not been requested. (Specify the names and addresses of persons requesting special notice in Attachment 6.)

7.  Filed with this petition is a proposed *Order Appointing Court Investigator* (form GC-330) that specifies the duties to be performed before granting an order relating to medical consent.

8. The names, residence addresses, and relationships of the spouse and all relatives within the second degree of the conservatee so far as known to petitioner are  listed below  listed in Attachment 8.

	<u>Relationship and name</u>	<u>Residence address</u>
a. Spouse:		
b.		

9. Number of pages attached: \_\_\_\_\_

Date: \_\_\_\_\_  
 \* (Signature of all petitioners also required (Prob. Code, § 1020).) ▶ \_\_\_\_\_  
(SIGNATURE OF ATTORNEY \*)

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.  
 Date: \_\_\_\_\_  
 ..... (TYPE OR PRINT NAME) ▶ \_\_\_\_\_  
(SIGNATURE OF PETITIONER)

..... (TYPE OR PRINT NAME) ▶ \_\_\_\_\_  
(SIGNATURE OF PETITIONER)

Appendix H  
Caregiver Assessment Tool



# Caregiver self-assessment questionnaire

## How are YOU?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

### During the past week or so, I have ...

- |  |   |
|--|---|
| <p>1. Had trouble keeping my mind on what I was doing ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>2. Felt that I couldn't leave my relative alone ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>3. Had difficulty making decisions ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>4. Felt completely overwhelmed ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>5. Felt useful and needed..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>6. Felt lonely..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>7. Been upset that my relative has changed so much from his/her former self ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>8. Felt a loss of privacy and/or personal time ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>9. Been edgy or irritable..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>10. Had sleep disturbed because of caring for my relative ..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>11. Had a crying spell(s)..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>12. Felt strained between work and family responsibilities..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> | <p>13. Had back pain..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>14. Felt ill (<i>headaches, stomach problems or common cold</i>)..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>15. Been satisfied with the support my family has given me..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>16. Found my relative's living situation to be inconvenient or a barrier to care..... <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.<br/>_____</p> <p>18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____</p> |
|--|---|

### Comments:

*(Please feel free to comment or provide feedback.)*

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