

# GUIDELINES FOR ALZHEIMER'S DISEASE MANAGEMENT

California Workgroup on Guidelines for Alzheimer's Disease Management

FINAL REPORT

This material is based on work supported by the State of California, Department of Health Services under Contract No. 97-11347 and 00-91317; the Alzheimer's Disease and Related Disorders Association, Inc., Los Angeles Chapter; and the California Geriatric Education Center, that is supported in part by the Bureau of Health Professions, Health Resources and Services Administration, U.S. Public Health Service.

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## Acknowledgments

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# GUIDELINES FOR ALZHEIMER'S DISEASE MANAGEMENT

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

### Final Report

#### ACKNOWLEDGEMENT

This material provides an update to the original California Workgroup Guidelines for Alzheimer's Disease Management (1998) and is based upon work initiated by the Ad Hoc Standards of Care Committee of the Alzheimer's Disease Diagnostic and Treatment Centers (ADDTC's) of California (Hewitt, et al., 1995) and is supported in part by the State of California, Department of Health Services and the Alzheimer's Association, Los Angeles, under Contract Nos. 97-11347 and 00-91317. The California Geriatric Education Center received subcontracts to assist the Alzheimer's Association of Los Angeles. Members of the California Workgroup for Alzheimer's Disease Management Project have donated their time and expenses to improve the quality of care for people with Alzheimer's disease and their families.

#### PURPOSE AND SCOPE

Alzheimer's Disease (AD), the most common of the dementias, is a progressive brain disorder that occurs gradually and results in irreversible memory loss, unusual behavioral changes, personality changes, and a decline in thinking abilities (National Institute on Aging, 1997). Primarily a disease of older persons, AD affects an estimated four million people in the United States (Alzheimer's Association, 1997). Although no disease-modifying treatment is currently available to halt or reverse the course of the disease, many steps can be taken to minimize the adverse effects of AD on the individuals' physical and mental status, functioning and quality of life. This clinical practice guideline represents core care recommendations for AD management, which are clear, measurable, practical, and based on scientific evidence, as available. The California Workgroup has provided its expert opinion when research evidence has been unavailable or when research results were inconsistent. The guideline suggests care management principles and is based on the assumption that a proper diagnosis of AD using reliable and valid diagnostic techniques has been made.

**The guideline is intended to serve as a general guide for the ongoing management of people with AD. The intended audience of this guideline is primary care practitioners, including physicians, nurse practitioners, physician assistants, social workers, and other professionals providing primary care to AD patients and their families. The guideline comprises basic recommendations for care and treatment, including treatment of the condition and its symptoms, but also addresses other coexisting medical conditions and related issues. Inclusion of a recommended action in this guideline does not necessarily imply that the action should be taken by the primary care practitioner alone; the guideline is intended to cover recommended actions that the primary practitioner may refer to others to address (e.g. a social worker, a community support group, or the Alzheimer's Association).**

#### *Alzheimer's Disease and Its Treatment: Critical Features and Issues*

Several features of AD are important in understanding the approach contained in this guideline. Early symptoms may be mistaken by people with AD, caregivers, and physicians as normal aging changes (Small, 1997; Veterans Health Administration, 1997). However, AD and aging are not synonymous – dementia is a progressive and disabling condition that brings turmoil and anguish to those involved. Beyond the emotional and psychological damage, there are high costs of caring for people with AD. Estimates of direct and total national costs are \$20.6 and \$67.3 billion, respectively. Nursing homes and paid home health care comprise 85 percent of the total direct cost of AD (Ernst and Hay, 1994). There are more societal implications as the elderly population in the U.S. increases from 31.1 million in 1990 to approximately 69.8 million by the year 2030 (Malmgren, et al., 1994).

Furthermore, the prevalence of AD doubles every five years beyond age 65 (National Institute on Aging, 1997). It is this most vulnerable, old-old segment of the population that is increasing most rapidly in the U.S. (Malmgren, et al., 1994). Clearly, addressing the issue of AD is of urgent concern in our nation.

The primary care practitioner (PCP) plays a central role in managing persons with AD. Although the PCP's primary responsibilities entail management of medical aspects of AD and other conditions, the care needs of the person with AD and family also require the PCP's assistance with many psychosocial aspects of AD and referral within his or her organization (e.g. social work department) or to community agencies. The PCP also plays a critical role in providing guidance to the family to seek expertise on financial and legal issues related to the progression of AD. PCPs must be aware that AD is a chronic, progressive illness and approach it as one would approach other chronic conditions. There should be a focus on physical, psychological, and social function. Comprehensive care requires, when possible, the use of a multidisciplinary team, community resources, as well as a high level of family involvement. Two recent studies documented that, despite increased dissemination about assessment and management of AD, PCPs generally have limited knowledge about AD care (Barrett, et al., 1997) and use of community-based long-term care services (Damron-Rodriguez, et al., 1998).

Finally, many specialized services are available to manage psychosocial aspects of AD, including adult day services, respite care, skilled nursing care provided by home health agencies or within nursing homes; Helplines of the Alzheimer's Association, and outreach services as offered by Area Agencies on Aging and Councils on Aging. Caregiver Resource Centers also offer information, advice, referral, and assessment. The PCP should routinely provide information about these community resources and sources for referral and should discuss these issues with caregivers, helping them explore options for outside help. Often there are departments or individuals within the organization or office who can assist the PCP with these referral sources. Given the nature of the disease and its impact on persons' families, seamless resource referral and access to critical services for both people with AD and caregivers are essential. Social workers within the PCPs provider organization or from outside agencies can link people with AD and family with community resources, in addition to providing counseling and support directly.

## **GUIDELINE DEVELOPMENT and ORGANIZATION**

These revised guidelines are based upon the results of an extensive literature review, coupled with recommendations by the California Guidelines Workgroup and the project's executive committee. The original guidelines relied on a review of 275 articles. For this revision, over 222 articles published since 1998 were reviewed and coded as primary or supplementary by publishing date and content area. The most recent primary articles were chosen as supporting evidence for the guidelines, along with several key seminal articles on AD care. Primary articles were graded as to the strength of supporting research. Executive committee and workgroup meetings were held to establish and choose the most vital guidelines for post-diagnostic assessment, treatment, patient and caregiver education and reporting requirements. Each recommendation is supported by the latest available research findings, expert opinion, and Workgroup consensus. The revised guideline and report also focus attention on AD care concerns of diverse populations. Considerations for special populations of people with AD are provided in text boxes throughout the report.

The guideline was designed to fit on one page for handy reference and organized by major care issues (assessment, treatment, patient and caregiver education and support, and reporting requirements). This supporting chapter follows the organization of the guideline. It first lists the care issue (e.g. assessment) and provides an overview of the issue, then lists the care recommendations, and lastly provides a review of the literature to support the care recommendations in a discussion section. The language used throughout the report reflects the strength of the evidence. Articles were graded based on study design and the strength of the conclusions from the study. In the report, these studies are referred to as "strong" evidence (e.g. randomized clinical trial), or "moderate". In certain instances

the current literature does not provide sufficient evidence-based recommendations, however, expert opinion and Workgroup consensus were used to develop recommendations. This general organization is used for each of the four sections of recommendations. Each of the care recommendations within each major subsection is discussed in a sequential order.

## ASSESSMENT

### Overview

Comprehensive and appropriate treatment goals and plans that meet all patients' needs can only be developed as a result of thorough assessment of the patient, the family, and the home environment. The assessment should address the patient's medical condition, including functional status, cognitive status, other medical conditions, behavioral symptoms, psychotic symptoms, and depression. The assessment should also address the patient's support system, identify the primary caregiver and the patient's decision-making capacity. The family and caregivers are an important source of information. Physicians should solicit and consider their input in post-diagnostic treatment planning.

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### Recommendations

- Conduct and document an assessment of:
  - Daily function, including feeding, bathing, dressing, mobility, toileting, continence and ability to manage finances and medications
  - Cognitive status using a reliable and valid instrument (e.g. the MMSE)
  - Other medical conditions
  - Behavioral problems, psychotic symptoms, or depression
- Reassessment should occur every 6 months or more frequently with any sudden decline or behavioral change.
- Identify the primary caregiver and assess the adequacy of family and other support systems.
- Assess the patient's decision-making capacity and whether a surrogate has been identified.
- Caregiver's needs and risks should be assessed and reassessed on a regular basis.
- Assess the patient's and family's culture, values, primary language, literacy level and decision-making process.

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### Discussion

#### *Assessment: Daily Function*

Assessment of the person's living environment can 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. Careful and competent functional assessment identifies how to maximize patient independence (Kane, et al., 1994).

Functional assessment includes physical, psychological and socioeconomic domains. Standardized assessment instruments can provide information on the patient's capacity for self-care and independent living. Physical functioning is measured along a continuum and may focus on basic Activities of Daily Living (ADL's) that include feeding, bathing, dressing, mobility and toileting (Kane, et al., 1994; Katz, 1983). In addition, Instrumental (or intermediate) Activities of Daily Living (IADL's) assess more advanced self care activities, such as shopping, cooking, and managing finances and medications. A number of functional assessment instruments can be completed by proxies (Pferrer, et al., 1982, Byrni, et al., 2000; Bucks, et al., 1996).

#### ***Impact of Language, Education Level and Culture:***

In all patient assessment, the PCP needs to be sensitive to the effect the person's language of origin and literacy level can have on patient performance on assessment instruments, and whenever possible, the PCP should use culturally appropriate assessment tools. Cognitive testing is sensitive to language and education level. See Table 1: Special Considerations for Working with Ethnically Diverse Populations, for more information on providing quality care for diverse populations.

Cognitive changes commonly associated with AD often impact both the instrumental and eventually the basic activities of daily living (Fitz and Teri, 1994; Small, et al., 1997). A baseline assessment of functional abilities is important to determine a standard to which future functional deficits can be compared. It will also provide realistic goal setting treatment planning information and allow early supportive interventions to be initiated (Ham, 1997). Assessment of a patient's living environment can identify environmental supports that may be needed to maximize function, ensure safety, and minimize caregiver stress.

*Assessment: Cognitive Status*

The PCP should assess and document the cognitive status of the patient using a valid and reliable instrument. The MMSE is the most common tool used in cognitive assessment, however, it has been criticized for the impact that education and language has on an individual's score (Escobar, et al, 1986; Mulgrew, et al., 1999; Grigoletto, et al., 1999; Yordi, et al., 1997; Mungas, et al., 1996). The MMSE can also be a useful predictor of ADL and IADL impairment in patients diagnosed with dementia (Ford, et al., 1996), however, the PCP needs to consider the effect that education and language can have on cognitive screening scores. The MMSE has been developed and validated in Spanish and other languages for use in cognitive status assessment (Taussig, et al., 1996) and can be adjusted for education level (Malloy, et al., 1997). When assessing patients from diverse cultural backgrounds, the Cognitive Abilities Screening Instrument (CASI) may be a more appropriate cognitive assessment tool (Teng, 1994).

***Impact of Language, Education Level and Culture:***

If the MMSE is used, the PCP should employ age and education normative adjustments (Malloy et al., 1997) (See Table 2: Age and Education Adjustments to MMSE Scores). The Cognitive Abilities Screening Instrument (CASI) works cross-culturally and is more education neutral so that it can be applied to persons of both high and low education , and is especially useful when working with ethnically diverse populations (Teng, 1994).

Neuropsychological testing is also helpful for discerning cognitive functioning deficits of AD and other neurological/psychological disorders (Cammermeyer and Prendergast, 1997; Ritchie, 1997).

*Assessment: Other Medical Conditions*

The PCP should diagnose coexistent diseases and treat these promptly and efficiently (Ham, 1997). Assessment of the patient's medical condition should include obtaining information about the person through structured interviews with the patient and a reliable informant as well as the office-based clinical assessment (Small, et al., 1997). The information gained from the patient's medical assessment can often be augmented by other physician's reports, medical records, and agency case records. The involvement of family members and other caregivers in gathering a history and completing an evaluation to determine other medical conditions is essential, and the use of other health and social service professionals or an interdisciplinary care team is critical to determine the extent of appropriate care and the therapeutic plan. The family is an excellent source of information on the baseline level of the patients' functioning that helps the PCP determine if there is an acute medical condition coexisting with the dementia.

Although some research indicates that ambulatory patients with AD are physically healthier than their age-matched peers, they often have or develop other medical conditions (Besdine, 1991). Specific concerns include infectious disease, nutritional/eating difficulties, bowel/urinary disorders, mobility problems, cardiovascular disease, pulmonary conditions, endocrine disease, coexisting neurological disorders, and pressure sores (Ham, 1997; Fabiszewski, 1988). Further, attention must be given to the medications used to treat these other medical conditions that 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.

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

#### Behavioral Symptoms

The majority of AD patients experience some form of behavioral symptoms such as anxiety and agitation during the course of the disease (Small, et al., 1997; American Psychiatric Association, 1997; Jost and Grossberg, 1996; Post and Whitehouse, 1995; Teri, et al., 1992). AD patients and families along the continuum of the disease process will present for the first assessment with a range of behavioral symptoms, as there is a great deal of variation between families in their views of dementia and tolerance for behavioral symptoms. PCPs should develop a behavioral description of the problem via observation by the PCP, clinic office staff, and/or interview with the caregiver. Depression and medication effects are common “reversible” factors associated with cognitive decline (Kaye and Camicioli, 2000). The patient should be carefully evaluated for general medical, psychiatric, or psychosocial problems that may underlie the disturbance (American Psychiatric Association, 1997). Thus, a medical examination is essential to rule out physical and pharmacological triggers, especially for acute onset behavioral symptoms. Patterns in the behavior’s frequency, duration, potential triggers, and consequences should be documented.

Challenging behaviors have differing causes, emerge at different points in the disease process, and present in a variety of manifestations (Cherry, 1997; Bolger, et al., 1994). Problems may include anxiety, insomnia, wandering, and agitation (see also psychotic symptoms and depression, discussed below). Behavioral symptoms become problematic when they cause the patient significant distress, potentially causing a loss of functional capacity, or creating a risk of harm to the patient or others (Harwood, et al., 2000; Friedman and Newburger, 1993; Small, et al., 1997). Families and care staff are also often distressed by patient behavior that is unusual, threatening or a nuisance (Coen, et al., 1997). Behavioral symptoms are often the most difficult aspect of caregiving. Current literature does not provide strong evidence regarding the effects of treating behavioral symptoms, however, expert opinion and Workgroup consensus suggests that treatment of behavioral symptoms can delay institutionalization (Zgola, 1999; Teri, Logsdon & Schindler, 1999). 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; Teri, Logsdon & Schindler, 1999; Lee, Strauss & Dawson, 2000; Boucher, 1999; Colling, 1999; Cohen-Mansfield & Werner, 1998; Zgola, 1999; Cohen-Mansfield, 2000).

#### Psychotic Symptoms

Psychotic symptoms are less common than the behavioral disturbances identified above; however, there is increased prevalence of psychotic symptoms as the disease progresses into the later stages (Hirono, et al., 1998). Delusions, paranoia and hallucinations are the most common form of psychotic symptoms and are of great concern since these symptoms are often linked to aggressive, combative behaviors (Gilley, et al., 1997; Small, et al., 1997; Koltra, et al., 1995). Psychotic behaviors may be reported by family caregivers and should be documented in the patient’s medical record; however, there is variation in a family’s willingness to report these behaviors due to cultural norms that stigmatize dementia as shameful to the family (Yeo & Gallagher-Thompson, 1996; Valle, 1998). The PCP must pay attention to the possible effect cultural stigmatization may have on family reporting of psychotic symptoms. Moderate evidence suggests the Neuropsychiatric Inventory Questionnaire short format (NPI-Q) is a brief, reliable, informant-based assessment of neuropsychiatric symptoms and associated caregiver distress and is appropriate for use in a general clinical practice (Kaufers, et al., 2000). Another assessment instrument, the Columbia University Scale for Psychopathology in AD, is brief and effective in assessing psychotic symptoms, but is not appropriate for assessing changes in severity of symptoms (Devanand, 1997).

#### Depression

It is important for health care professionals to be sensitive to affective disorders and mood symptoms associated with AD and to facilitate early intervention (Bolger, et al., 1994). Specifically, dementias must be distinguished from delirium and depression (Warshaw, et al., 1995). Recognition of depression as a treatable disorder is a key assessment goal of primary care. However, there appears to be an under-recognition of depression in older persons, and depression is a common disorder in AD patients (American Psychiatric Association, 1997; German, et al., 1985). Consultation with and/or referral to a specialist (e.g. psychiatrist) is also warranted if the presentation or history of depression is atypical or complex (Small, et al., 1997). Since administering assessment tests for depression to AD patients is often challenging (Warshaw, et al., 1995), gathering data from family members becomes especially important (Jones and Reifler, 1994).

Early stage depression should always be treated to alleviate additional confusion and feelings of helplessness (Wolf-Klein, 1993). Treatment of depression is also important due to the moderate evidence that found an association between depression and physical aggression (Lyketsos, et al., 1999). The presence and severity of depression, while modified by level of cognitive impairment, have also been related to the patient's functional impairment level (Fitz and Teri, 1994). The PCP should make it clear to caregivers that there are steps that can be taken to help in managing the AD patient's mental symptoms (Wolf-Klein, 1993). The PCP should evaluate indices of major depression and suicidal potential in AD patients who are depressed (Small, et al., 1997) using a valid instrument such as the Geriatric Depression Scale (Yesavage, et al. 1987), or the Cornell Depression Scale (Alexopoulos, Abrams, Young & Shamoain, 1988). Though there is not strong evidence of higher levels of suicide among AD patients, case studies do suggest the need for assessment of suicidal ideation among AD patients who fear the progression of the disease and those who feel they are not responding to medical treatment (Rohde, Peskind, and Raskind, 1995; Rubio, et al., 2001).

***Assessment: Health Literacy***

Assessment of health literacy is important in all medical care because low literacy affects an individual's ability to care for his/her medical problem and results in ineffective care due to not understanding provider instructions (Baker, et al., 1997; Gazamararian, et al., 1999; William, Baker & Parker, 1998; Parker, et al., 1995).

Concerns of health literacy in AD management focus on both the person with AD (in the early stages) and the patient's primary caregiver (in all disease stages). Health literacy deficits are quite common, with approximately one-quarter of the U.S. population estimated as functionally illiterate (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

Functional health literacy is defined as the ability to read and understand prescription bottles, appointment slips, and other related health materials (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Caregiver health literacy is critical, as the patient care responsibilities shift from the patient to the caregiver with disease progression.

***Assessment Tools for Health Literacy:***

The Test of Functional Health Literacy in Adults (TOFHLA) is a reliable tool that tests the ability to read and comprehend text in a health care setting (Davis, et al., 1998; Baker, et al., 1999; Parker, et al., 1995). There is also a version to test Spanish literacy (TOFHLA-S) (Davis, et al., 1998). Current efforts are focused on developing a shorter version of the TOFHLA (12 minutes to administer versus 22 minutes). Preliminary results show comparable reliability and validity to the original version (Baker, et al., 1999).

### *Regular Reassessments*

Longitudinal monitoring of therapies and regular health maintenance checkups are considered essential (Small, et al., 1997). Ongoing primary care should include medication review, treatment and monitoring of other medical conditions, treatment of dementia by available medications if appropriate, referral to experimental drug studies, monitoring of disease progression, and referral to appropriate specialists (American Psychiatric Association, 1997). Workgroup consensus suggests reassessments should be conducted using the same instruments in order to effectively monitor changes and progression of the disease over time.

### ***Impact of Functional Health Literacy:***

The PCP must be careful not to confuse the number of years of school completed with literacy, as moderate evidence and expert opinion suggest that the number of years of education is an inaccurate measure of true educational attainment (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999; Davis, et al., 1998; Baker, et al., 1998; Baker, et al., 1997). Functional health literacy is context specific (meaning that reading comprehension can be adequate in one area and inadequate in another “Show me” techniques are useful in the clinic/office setting to be sure patients and caregivers understand the PCP’s instructions (Davis, et al., 1998).

Frequency of visits is determined by a number of factors including the patient’s clinical status, likely rate of change, current treatment plan, need for any specific monitoring of treatment effects, and reliability and skill of the patients’ caregivers (American Psychiatric Association, 1997). It is generally necessary to see patients in a routine follow-up visit every six months, or sooner as indicated (American Psychiatric Association, 1997; Small, et al., 1997). Reassessment should be conducted more frequently with any sudden change in decline or behavioral change, as this may indicate the presence of an acute medical problem 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, 1997). Regular appointments will also allow the PCP to monitor dementia-associated behaviors such as sleep disorders and agitation (Warshaw, et al., 1995); the development and evolution of cognitive and non-cognitive psychiatric symptoms and their response to intervention (American Psychiatric Association, 1997); provide regular patient surveillance of cognitive and functional status; and provide a forum for health promotion and maintenance activities (Small, et al., 1997).

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

Establishing and maintaining an alliance with caregivers is critical (Small, et al., 1997). The American Medical Association has recognized the importance of family caregivers by calling on PCPs to form partnerships with families who care for frail older patients (Council on Scientific Affairs, 1993; Barrett, et al., 1996). Family caregivers are central to the physician’s assessment and care of the patient with AD (Barrett, et al., 1996). The PCP should make sure that caregiver’s contact information is noted and kept up to date in the patient demographic section of the patient’s medical record. The PCP depends on family members to report relevant information (Barrett, et al., 1996). 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 or gait and mobility. The real managers of care are family members who implement and monitor treatment (Barrett, et al., 1996; Friss, 1993; Small, et al., 1997). The PCP should note that the individual bringing the patient into the office may not be the primary caregiver, especially if this individual is serving as a translator between physician and patient.

Identification of the primary caregiver of the AD patient may be challenging in certain cultures where there is more than one primary caregiver (See Table 3: Caregiver Assessment). Caregiver assessment should occur on two levels: as the care provider of the AD patient, and as a patient him/herself. Strong evidence suggests the assessment of the caregiver should include: ethnic cultural issues (e.g. primary language), knowledge base (e.g. expectations of treatment outcomes and local

services), social support (availability and satisfaction with), psychiatric symptomatology and burden (e.g. depression, anxiety), and family conflict (quality of the relationship, elder abuse) (Dunkin & Anderson-Hanley, 1998). There is moderate evidence that caregiver strain is an independent contributor to caregiver mortality, particularly among elderly spousal caregivers (Schulz & Beach, 1999); therefore, the PCP should assess the caregiver regularly for signs of depression (Young, 2001). Caregivers should continue to be assessed even if the decision for long-term placement (e.g. nursing home) is made because strong evidence shows that many caregivers continue to provide care after placement and the effects of caregiver strain and burden may still be an issue (Gwyther, 2001; Almborg, et al., 2000).

#### *Patient Decision-Making Capacity and Surrogate Identification*

Through the patient interview and assessment of cognitive status, the PCP will form an opinion as to the patient's capacity to make decisions on his or her own. The literature does not provide strong evidence-based studies regarding patient decision-making and surrogate identification; however, expert opinion and Workgroup consensus support the recommendations made below. In early stage dementia, patients typically retain their decision-making capacity and their ability to appoint a surrogate (Zgola, 1999; Braun, Pietsch & Blanchette, 2000). However, as the disease progresses, this capacity will diminish and eventually be lost. 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, Pietsch & Blanchette, 2000; Post, Blustein & Dubler, 1999; Silveira, et al., 2000; Potkins, et al., 2000; Young, 2001). The PCP should be sensitive to the fact that culture and religion play a role in completing advance directives and providing necessary documentation to appoint a surrogate (Braun, Pietsch & Blanchette, 2000). In initiating these conversations, PCPs need to be sensitive not to use jargon or slang (Braun, Pietsch & Blanchette, 2000). (For additional information please see the Patient & Caregiver Education section, beginning on Page 11.)

#### *Cultural Sensitivity*

In general, cultural values and norms for expected behaviors continue to govern familial relationships and care of elderly people (Cox and Monk, 1993). The most important aspect of cultural competency for providers to recognize is that there is more diversity within ethnic groups than between ethnic groups. Further, cultural identity (practices) is a dynamic process defined by many aspects of life (e.g. religious culture, ethnic culture, regional culture, and other influences) (Braun, Pietsch & Blanchette, 2000; Valle, 2001; Valle, 2001b). "Culture is not a 'thing', but a 'context' in which one constructs ethical meaning." (La Puma, 1995). It is essential to consider cultural and ethnic elements in working with families (Cherry, 1997). In general, it is recommended that the PCP ascertain how a family makes decisions, and identify the major decision-maker in the family. It is important to recognize that the person who does the "hands on" caregiving may not necessarily be the primary decision-maker (Valle, 2001a).

The PCP should consult with the primary caregiver to identify beliefs about health

and aging, learn about cultural taboos (e.g. constant 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 and Gallagher-Thompson, 1996). In some office settings, the PCP can 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, 2001a) (See Table 4: A Model for Cultural Assessment). The PCP can then use this information in patient care planning and treatment.

***Impact of Language, Education Level and Culture:***

It is important for the PCP to distinguish between cultural effects and "status" variables (e.g. SES, health literacy) because status variables are often misused to explain cultural dynamics in medical decision-making (Valle, 2001a). An extensive assessment will help to understand the factors influencing patient and caregiver medical decision-making. Cultural proficiency should not be approached as something that is achieved in one workshop, but as something that is a long-term developmental process (Tripp-Reimer, 1999). Whether it is providing care to patients, or referrals for supportive services to caregivers, providers must always be sensitive to what culturally appropriate options exist for each patient and his/her family.

## TREATMENT

### Overview

Ongoing regular medical management of general health (other medical conditions and prevention), in addition to monitoring of cognitive deficits, is essential. Management **goals and activities** should be based on a solid alliance with the patient and family and thorough psychiatric, neurological, and general medical evaluations of the nature and cause of cognitive deficits and associated non-cognitive symptoms (American Psychiatric Association, 1997). All evaluations must take into account the effect of cultural practices and beliefs on symptomatology and appropriate treatment options. Ongoing efforts should also include periodic monitoring (a minimum of every 6 months) of the development and evolution of cognitive and non-cognitive symptoms and their response to intervention (American Psychiatric Association, 1997). It is important for health care professionals to be sensitive to symptoms associated with AD to facilitate early intervention when unusual or sudden symptoms arise (Bolger, et al., 1994).

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### Recommendations

- Develop and implement an ongoing treatment plan with defined goals. Include:
    - Use of cholinesterase inhibitors, if clinically indicated, to treat cognitive decline
    - Appropriate treatment of medical conditions
    - Referral to adult day services for appropriate structured activities such as exercise and recreation
  - 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 Safe Return Program for people who may wander
  - Medications, if clinically indicated and non-pharmacological approaches prove unsuccessful
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### Discussion

Effective treatment of patients requires development and implementation of a plan with defined goals for the patient. Patient care goals should be developed in consultation with the patient (as capable) and with the patient's family. The treatment plan should include objectives that relate to the accomplishment of these goals. Patient goals should be developed using an individualized approach to the patient's needs, values, and preferences and may likely be modified as the disease progresses. Early discussions of future care options with the patient and family will provide guidance

to the PCP in modifying patient care goals that are acceptable to patients with AD and their family members in time and place.

#### *Treatment Plan: Cholinesterase Inhibitors*

While the available treatments for the cognitive symptoms of dementia are limited (American Psychiatric Association, 1997; Doriswamy 1996; Rabins, 1996), cholinesterase inhibitors are recommended as cognitive and functional enhancers that may improve cognitive functioning or delay decline in patients with mild to moderate AD (Small, et al., 1997; Small, 1998; Hasegawa, 1998, Doody, et al., 2001). Strong evidence suggests cholinesterase inhibitors may be able to decrease the frequency of behavioral symptoms and neuropsychiatric symptoms associated with AD (Cummings & Askin-Edgar, 2000). PCPs should counsel persons with AD and families about realistic expectations of treatment outcomes with cholinesterase inhibitors. Evidence of a beneficial response, temporary stabilization, or modification of deterioration following administration of a cholinesterase inhibitor can be gathered using a clinician's global assessment, caregiver report, neuropsychological assessment or mental status questionnaire, or evidence of behavioral or functional changes. Widely used brief mental status tests are inadequate to measure the cognitive effects of cholinesterase inhibitors (Bowie, 1999) and a substantial observation period of 6 to 12 months is required to assess changes in cognition, rate of cognitive decline, functional benefits or behavioral responses to these agents. (See Table 5: Medical Treatment of Mild to Moderate Alzheimer's Disease). Cholinesterase inhibitors are contraindicated in patients with brachycardia. Gastrointestinal side effects are common.

#### Principles for Prescribing Acetylcholinesterase Inhibitors

Prescribe *only* for patients with:

Probable diagnosis of Alzheimer's disease (NINCDS/ADRDA criteria)

Duration of symptoms more than 6 months

Mini-Mental Status Examination: Evidence suggests using a score range of

10-26; however, expert opinion suggests acetylcholinesterase inhibitors may

be

beneficial for cognitive performance and behavioral symptoms for persons with AD in more advanced stages of the disease

Three-phase evaluation of response:

Early (2 weeks) for adverse effects

Later (3 months) for cognitive state

Continued (6 months) for disease progression

Discontinue treatment:

If poor tolerance or compliance

If, after 6 months, there is continued deterioration at pre-treatment rate

If deterioration accelerates while on drug

There is insufficient evidence to recommend for or against other treatment therapies for all AD patients. Patients and 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 appears to postpone functional decline (Sano, et al., 1997) and delay institutionalization, but it does not improve cognition (Doody, et al., 2001). There is strong evidence that Vitamin E (2,000 I.U. per day) or 10mg of selegiline per day may slow the progression of cognitive symptoms of AD (Doody, et al., 2001). Other medications such as estrogen and ginkgo biloba are in ongoing clinical trials (Small, et al., 1997). There is moderate to strong evidence that estrogen replacement may delay the onset of AD, however, there is no cognitive benefit to initiating estrogen therapy after the onset of AD (Mulnard, et al., 2000; Yaffe, et al., 2000; Birkhauser, et al., 2000). Nonsteroidal anti-inflammatory drugs may reduce neuronal damage and cognitive decline (Ham, 1997), but their use is limited due to their poor tolerability and safety, especially in the elderly (Scharf, et al., 1999). No recommendations

regarding other classes of drugs (benzodiazepines, anticonvulsants, serotonin reuptake inhibitors, B-blockers or lithium carbonate) can be made due to insufficient clinical evidence at this time (Rabins, 1996).

#### *Treatment Plan: Referral to Community Based Services*

The PCP is in a unique and important position to direct the AD patient and family to available resources that may assist in care provision and improve the quality of life of both the patient and caregiver (Small, et al., 1997; Post and Whitehouse, 1995; Besdine, 1991). The “geriatric landscape”, or sites where elders receive care, now includes congregate housing, assisted living, board and care, continuing care communities, senior hotels, foster care, group homes, adult day services, respite care, Programs for the All-Inclusive Care of the Elderly (PACE), retirement homes and communities (Cohen, 1999). Due to the fragmentation of community-based long-term care services, PCP’s may feel unprepared and find it challenging and time-consuming to fulfill this important role (Damron-Rodriguez, et al., 1998). For instance, moderate evidence suggests many PCPs underutilize social-model services that would offer benefits not only to the patient, but the caregiver as well (Damron-Rodriguez, et al., 1998). Culture and language issues play an important role in the use of community-based services, and PCPs must be sure to make referrals to services that are appropriate to cultural values and to organizations that can accommodate the needs of patients of different ethnic backgrounds (e.g. language). Referral to adult day services with staff that cannot communicate with the patient or family members may present a more confusing environment to the person with AD than other community-based services that provide staff members with the appropriate language skills. Several organizations, such as the Alzheimer’s Association and the Caregiver Resource Centers offer helplines, direct services, support groups, information, advice, referral, and assessment (Friss, 1993). These organizations will provide information on local community-based services available to AD patients and caregivers. See Table 6: Support Services for AD Patients and Caregivers for contact information and a list of service referrals available. Social workers can offer counseling and link patients and family with needed community resources in a culturally appropriate environment (Small, et al., 1997).

Specialized services are available including adult day services, respite care, skilled nursing care provided by home health agencies; and outreach services as offered by Area Agencies on Aging and Councils on Aging (Small, et al., 1997). Empirical evidence also suggests that adult day services can substantially reduce levels of caregiver stress, improve psychological well being and provide needed structured environments for the patient that reduce behavioral symptoms (Cox, 1997; Small, et al., 1997; Ham, 1997; Zarit, 1998; Mittleman, 1996). To date there have not been strong evidence-based studies on adult day services, however, expert opinion and Workgroup consensus suggests that while participation in adult day services does not appear to improve cognitive functioning (Cohen-Mansfield, et al, 1996; Palley, 1994), it can result in marked improvements in mood and/or behavior (Curran, 1996). Workgroup consensus also suggests that persons with dementia involved in activities like music therapy experience improved social/emotional skills, decreased behavioral symptoms, and aided in recall and recognition (Brotons, et al., 1999), reminiscence, which can promote interpersonal connections (Kasl-Godley & Gatz, 2000), exercise programs and/or walking. Exercise has been shown to be particularly important for maintaining mobility (Tappen, et al., 2000) and may improve cognition (Palleschi, et al., 1996). The rest and relief that caregivers experience as a result of adult day services, as well as the opportunity to do more things they enjoy, has been shown to have a significant association to an improved relationship with the affected individual (Dziegielewski & Ricks, 2000).

Use of respite programs, such as adult day services, is an underutilized but appropriate strategy for caregivers whose social contacts have become impaired due to caregiver responsibilities. Sustained use of adult day services may also delay or decrease the likelihood of nursing home placement (Kosloski and Montgomery, 1995; Zarit, et. al., 1999). Often families do not initiate and use these types of services on an ongoing basis until institutional placement is imminent. Earlier links with community services may be beneficial since it appears that families may only consider community

service use well after the point of intervention could impact nursing home placement (Collins and Ogle, 1994; Zarit, et al., 1999). This may explain why some research suggests that utilization of community-based services does not impact institutionalization.

#### *Treatment Plan: Other Medical Conditions*

Management of other medical conditions of the AD patient includes focus on prevention, in addition to routine monitoring. Since judgement and memory impairment are key features of AD, the PCP should expect under-reporting of symptoms and problems. The nature of cognitive impairment progression will often impact the patient's ability to manage other concurrent medical conditions (e.g. forgetting to take required medications). Regular surveillance and health maintenance visits should be scheduled at least every six months or more frequently based on the patients' health conditions.

The PCP should:

- directly address security, safety and dependency needs,
- review treatment of existing co-morbid conditions, including review of administration and dosage of medications,
- establish exercise program to maintain safe ambulation,
- evaluate acute changes,
- expect unreported problems (e.g. urinary tract infection) (Larson, 1997, 1998).

#### Sensory Deficits

Visual and auditory deficits are common in older persons and may exacerbate symptoms of cognitive decline. The PCP should ensure that corrections (e.g. glasses, hearing aids) are optimal and used properly (Kane, et al., 1994). Sensory deficits can affect patient performance on assessment/evaluation scales; therefore, it is important to distinguish if low scores are due to sensory deficits or due to actual cognitive decline.

#### Dental Care

Routine dental care is essential for the AD patient, and may be challenging to accomplish due to behavioral or mobility issues (American Dental Association, 1994). Available assessment instruments can determine the safety and behavioral symptoms that may be experienced with an AD patient during a dental visit (Nordenram, et al., 1997). Specialists in geriatric dentistry are available for oral care of the AD patient. Dental providers can also recommend oral devices for use by caregivers of patients unable to continue their daily oral hygiene activities (Henry, 1997-8).

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

##### General Approach to Treatment

Behavioral symptoms are often the most difficult aspect of caregiving, and treatment of behavioral symptoms can help to delay institutionalization (Teri, Logsdon and Schindler, 1999; Zgola, 1999). The literature does not provide strong evidence-based research regarding the development of behavioral symptoms in each individual, however, expert opinion and Workgroup consensus suggest successful management of behavioral symptoms requires the PCP to develop early, appropriate and individualized care plans which must be evaluated regularly (Zgola, 1999; Allen-Burge, Stevens and Burgio, 1999; Teri, Logsdon and Schindler, 1999; Lee, Strauss and Dawson, 2000; Boucher, 1999; Colling, 1999; Cohen-Mansfield and Werner, 1998; Cohen-Mansfield, 2000). Before initiating any kind of care plan to manage behavioral symptoms, it is imperative for the PCP to rule out any medical or medication-related causes of the behavioral symptoms. After ruling out these other factors, a behavioral assessment should be conducted and non-pharmacological interventions – the first approach to behavioral management – should include simplifying the environment and routines; distracting, rather than confronting, arguing or disagreeing; ensuring safety regarding wandering; and assisting the caregiver to understand the underlying cause of the behavior. In addition, strong evidence suggests the PCP should assess for identifiable causes of agitation, such as pain (Doody, et

al., 2001). In general, steps to managing challenging behaviors include identifying the behavior, understanding its cause, and adapting to remedy the situation (Cherry, 1997; Roth and Fonagy, 1996). Table 7 provides examples of behavioral approaches for common behavioral symptoms and mood disorders.

#### Non-pharmacologic Treatment Approaches

Non-pharmacologic interventions consist of a modification of the patient's environment and routine (See Table 7: Non-pharmacological Management Techniques for Behavioral Symptoms). Special attention should be paid to the triggers of the problem behavior to select effective interventions. The PCP should encourage the establishment of an exercise routine for the patient, to maintain ambulation and improve patient behavior and mood (Small, et al., 1997).

There is moderate to strong evidence that supports specific non-pharmacologic treatment suggestions for AD-related behavioral symptoms, including (Small, et al., 1997; Warshaw, et al., 1995; Wolf-Klein, 1993, Doody, et al., 2001):

- Provide the patient with a structured, predictable routine (exercise, meals, and bedtime should be routine and punctual)
- Explain all procedures and activities in simple and straightforward terms to the patient before performing them
- Simplify tasks
- Allow patients to dress in their own clothing and maintain possessions
- Use calendars, clocks, labels, or newspapers for orientation to time
- Reduce excess stimulation and outings to crowded places (overexposure to environmental stimulation can lead to agitation and disorientation)
- Avoid glare from windows and mirrors, noise from TV, household clutter
- Provide a safe environment: no sharp-edged furniture, slippery floors and 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
- Provide music, especially during meals and bathing

Caregivers can be taught techniques for managing behavioral symptoms as well (Larson, 1997; Haupt, Karger and Janner, 2000). One approach is the three R's: Repeat, Reassure, Redirect (Sultzer and Cummings, 1993). Using this technique, caregivers can divert the attention of a person with AD from a problematic situation and provide a useful activity. Another approach for caregivers is the ABC's (Antecedent, Behavior, Consequences) of behavioral analysis. This technique provides insight into the precipitants (antecedents), behavioral interpretations (behavior) and inadvertent reinforcements (consequences) relevant to understanding and managing behavioral alterations. Using the ABC's, caregivers can avoid triggering behavioral symptoms and understand the context in which the AD patient's behavioral symptoms occur. 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 Intervention for Behavioral Symptoms

When non-pharmacological approaches fail to treat agitation or other behavioral symptoms, psychotropic medications can be effective in the management of some symptoms, but must be used with caution due to potential drug interactions and side effects. Utilize medications for specific target symptoms so that improvement or lack of improvement can be monitored. When prescribing pharmaceutical agents, side effects should be closely monitored (American Psychiatric Association,

1997; Small, et al., 1997; Ham, 1997, Doody, et al., 2001). Table 8 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 specified purposes (Gambert, 1997; Small, et al., 1997; Post and Whitehouse, 1995). Physicians 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, 1997).

The use of psychotropic medications has been shown to be very effective, but dementia patients are often more susceptible to severe side effects that necessitate close observation and frequent adjustments in dosage (American Psychiatric Association, 1997). There are several key factors that are influential in medication prescription. These include awareness of potential drug 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 poly-pharmacy (Small, et al., 1997). Standard therapies should be used and any condition that could lead to deterioration of mental function should be treated aggressively to avoid aggravating the symptoms of AD (Besdine, et al., 1991). Strong evidence from two studies have noted that a person's response 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 drug metabolism and distribution in the body (pharmacokinetics), and the body's response to the drug (pharmacodynamics) (Lin, Poland and Anderson, 1995; Lin, Anderson and Poland, 1995). The PCP should review the patient's history with the medication if taken before, or other responses to medications that might come from the same family as the psychotropic medication.

To summarize pharmacologic management of behavioral symptoms:

- Prior to initiating treatment with new medication, consider if 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
- Use of classes of medications that have demonstrated effectiveness in managing problematic behaviors include antidepressants (low mood, irritability), anxiolytics (anxiety, restlessness, verbally disruptive behavior, resistance), antipsychotics (hallucinations, delusions, agitation), and anticonvulsant mood-stabilizers (hostility, agitation, uncooperativeness)
- 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

Periodically reduce psychopharmacologic agents after behavioral symptoms have been controlled for 4 to 6 months to determine if continuing pharmacotherapy is required (Rabins, et al., 1997; Small, et al., 1997; Cummings and Benson, 1992).

#### Common Forms of AD-related Behavioral Symptoms and Treatment Recommendations

Wandering: A main role of the PCP is to advise families of the danger of wandering and provide referrals to community agencies, such as the Alzheimer's Association, that can assist (Small, et al., 1997; American Psychiatric Association, 1997). In terms of decreasing the hazard, patients who wander should wear identification at all times, be provided an unrestricted place to wander, such as a fenced backyard, and daily exercise, such as walking. An in-house alarm or chimes to prevent unsupervised wandering should be considered, and complex door locks, or safety gates can be installed. Those activities or behaviors that decrease wandering such as TV, movies, or music should be identified and utilized. The Alzheimer's Association *Safe Return* program can help identify, locate, and return wandering or lost patients who have been registered with them (Warshaw, et al., 1995).

Pharmacologic treatment is ordinarily not appropriate for nonaggressive behaviors such as wandering, and drugs should only be used when all non-pharmacologic interventions have proven unsuccessful. If it becomes necessary, drug choices include antipsychotics, minor tranquilizers, and antidepressants (Warshaw, et al., 1995).

Depression: The treatment of depression in an AD patient is extremely important, given that strong evidence suggests that concurrent depression in AD patients has been associated with excess disability, increased caregiver burden and greater mortality (Swartz, et al., 2000). There is strong evidence supporting the use of antidepressants (Swartz, et al., 2000; Doody, et al., 2001). With depressed patients with AD, selective serotonin reuptake inhibitors (SSRIs) (fluoxetine, paroxetine, fluvoxamine, sertraline, and citalopram) appear to be the best medications to use due to their better tolerability (Swartz, et al., 2000; Doody, et al., 2001). If a patient has no response to SSRIs, or adverse side effects with them, the PCP should switch to tricyclic antidepressants. The secondary amines with less anticholinergic effects (nortriptyline and desipramine) should be used (Swartz, et al., 2000). Physicians may wish to familiarize themselves with a small number of antidepressants, use them consistently to become clinically experienced with them, and follow the dictum “start low, go slow” in order to avoid potential side effects. The medications most useful in depression superimposed on AD are those with minimal anticholinergic side effects. It is often unclear when treating depression in the demented elderly whether the PCP is treating depression as a symptom or as a major or minor depressive episode (Swartz, et al., 2000), and the selection of the appropriate medication must be based on the patient’s clinical presentation and the side effect profiles of the medication (Warshaw, et al., 1995). (See Table 8: Pharmacological Treatment of Behavior and Mood).

Agitation: There is agreement that agitated behavior is a multidimensional, complex concept in terms of assessment and intervention. Categories of interventions include modifying the environment, interpersonal strategies, and use of physical or chemical restraints (Roper, 1991). However, the use of restraints is not recommended (Post and Whitehouse, 1995; Warshaw, et al., 1995). In terms of medication, anxiety and agitation that cannot be handled by gentle reassurance may respond to short-acting anxiolytics, such as alprazolam or lorazepam (Wolf-Klein, 1993).

Sleep disorders: Sleep disturbances are common and pharmacologic intervention should be considered only when other non-pharmacologic interventions have failed (American Psychiatric Association, 1997). The sleeping area should be free of distractions and might contain nightlights if helpful to the patient. Caregivers should be instructed to try to limit the amount of sleep during the day. Naps should be kept short and there should be increased exercise or activity in the morning/early afternoon. Patient should be dressed during daytime hours. Caffeine and nicotine should be avoided and nighttime fluids and diuretics should be restricted. Warm milk and tryptophan before sleep may be successful, as may a tepid bath or light snack high in carbohydrates (Warshaw, et al., 1995). Pharmacologic treatment of other 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 reactions (incontinence, instability/falls, agitation) with major tranquilizers. 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., 1995). 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).

## PATIENT AND CAREGIVER EDUCATION

### Overview

The PCP should provide information and education about the current level of disease and should talk with the patient and family to establish treatment goals. Based upon the agreed upon goals, the PCP should discuss the expected effects (positive and negative) of intervention and treatment on cognition, mood, and behavior to ensure that the strategy is appropriate to family values and culture (American Psychiatric Association, 1997; Warshaw, et al., 1995, Toth-Cohen, et al., 2001). Studies have shown that the education of caregivers increases chances of adherence with treatment. Thus, family and caregivers must become knowledgeable about the care of the patient and fully aware of the changes that might occur as a result of the disease process (Mittleman, 1996). It is the role of the PCP to assist the family caregiver in understanding the patient and patient behaviors (Winslow, 1997), and to provide information on how to access community services. There is moderate evidence to suggest that the most helpful information for the caregiver from the PCP is help in managing the day to day activities of AD caregiving, either via tips/training or encouraging the use of community-based services (Young, 2001). The PCP should also provide information regarding patient rights and advance planning for informed consent, health care surrogates, and/or durable power of attorney.

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### Recommendations

- Discuss the diagnosis, progression, treatment choices and goals of AD care with the patient and family in a manner consistent with their values, preferences and the patient's abilities.
- Refer to support organizations for educational materials on community resources, support groups, legal and financial issues, respite care, future care needs and options. Organizations include:

Alzheimer's Association	1-800-660-1993	<a href="http://www.alzla.org">www.alzla.org</a>
Family Caregiver Alliance & Caregiver Resource Centers	1-800-445-8106	<a href="http://www.caregiver.org">www.caregiver.org</a>

or your own social service department.
- 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 end of life care decisions with person with AD and family.

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## Discussion

### *Communication with Patient and Family*

Disclosure is significant in terms of planning for short- and long-term circumstances relating to quality of life, and decision-making (Alzheimer's Association, 1997; Overman and Stoudemire, 1988). In terms of how a PCP should handle disclosure, it is recommended that a joint meeting between the individual and family members be arranged with enough time for questions and to discuss recommendations from the physician (Alzheimer's Association, 1997; Barrett, et al., 1996; Post and Whitehouse, 1995). However, what is most important is that disclosure is handled in accordance with the wishes of the patient and family. When possible, all of the professional team members involved in determining the diagnosis should be available and allow sufficient time to answer questions and provide specific recommendations. A follow-up session should be scheduled to continue discussion since the experience may be overwhelming at first, and clients will have more questions over time (Alzheimer's Association, 1997). Communication with caregivers is a necessary and on-going process as the disease progresses and patients needs and caregiver resources change. Goals for care should be determined and reviewed throughout the disease process.

It is important for PCPs not to assume that every person with AD will have a caregiver available. Treatment plans need to be adjusted to meet the needs and abilities of persons with AD who lack caregiver support. Given the increased likelihood that American families may not live in the same city today, it is increasingly important for PCPs to understand the growth in long-distance caregiving. It is necessary for the PCP to communicate with family members who may not be able

to attend a face-to-face information sessions regarding the disease prognosis, treatment alternatives and expected treatment outcomes. Although some patients may not have family, the PCP should identify other members of the person's informal support system who may be able to provide relevant history, observations or be enlisted to help monitor the person's treatment plan recommendations, pending his/her consent and release for communication. Once this source of informal support is identified, the PCP can notify the person about available strategies to assist in patient communication and observation of significant changes.

It is often difficult for family members to discuss critical health care decisions. Strategies for PCPs to assist families in discussing critical health care decisions include: (1) having a discussion of goals for treatment to encourage families to talk about difficult choices in advance; (2) enhancing the patient 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 AD process; (3) helping families develop successful problem-solving strategies; and (4) accepting the wishes of the person with AD (Roberto, 1999; Maslow and Selstad, 2001).

#### *Referrals to Support Services*

Seamless resource referral and access to critical services for both patients and caregivers are considered essential (American Psychiatric Association, 1997; Small, et al., 1997). 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 support groups and community resources such as the Caregiver Resources Centers should be recommended (Small, et al., 1997). (For additional information, please see Table 6: Support Services for AD Patients and Caregivers, and Referral for Community-Based Services in the Treatment section, beginning on p. 12)

Participation in support groups has been shown to be effective in educating patients and families about Alzheimer's disease, promoting compliance with treatment planning, and providing a support system for people who often feel isolated from their community of family and friends (Mittleman, 1996). Support groups may also provide a constructive environment – preliminary studies and clinical practice suggest these interventions may decrease behavioral symptoms and improve mood in patients and family alike (Small, et al., 1997). Additionally, support groups for family members may delay long-term placement (Doody, et al., 2001; Mittleman, 2000). The PCP must address caregiver support on an on-going basis, and as mentioned in the assessment section, assess caregivers' mental and physical health regularly.

The PCP also plays a critical role in providing guidance to the family regarding the need for financial and legal advice (American Psychiatric Association, 1997; Ham, 1997; Warshaw, et al., 1995). Efforts should be made to get the patient and family to seek sound professional advice (Overman and Stoudemire, 1988). Recommendations should include consultation with financial advisors and legal counsel and discussion of conservatorship (Small, et al., 1997).

Psychotherapeutic intervention with family members is often critical to assist families dealing with AD and other related dementia (Small, et al., 1997). The emotional toll placed on patients and families is profound and a significant source of caregiver morbidity (Gwyther, 1998; Small, et al., 1997; Schulz, et al., 1995). A randomized control study suggests that a comprehensive counseling program can reduce the socioeconomic impact of AD and that counseling interventions (individual and family counseling, support group, ad hoc consultation) are an effective way to reduce burden on the family and society (Mittleman, 1996). Further, strong evidence suggests comprehensive psychoeducational training for caregivers may delay institutionalization (Doody, et al., 2001). A suggestion from the PCP that the patient and family find an objective source for counseling may be better received than when this suggestion comes from other sources (Warshaw, et al., 1995). Strong evidence suggests patient and caregiver may also benefit from the use of technological methods such

as computer networks to provide education and virtual support to caregivers, and telephone support programs (Doody, et al., 2001).

#### *Advance Planning and End of Life Care*

Issues of informed consent and competency may be among the first to arise when plans are being made for patients with dementia. The physician's obligation is to inform the patient to such an extent that a reasonably informed decision can be made (Marson, et al., 1995a; Marson, et al., 1995b; Marson, et al., 1996; Marson, et al., 1997; Overman and Stoudemire, 1988). For this, informed consent is operationally defined as the patient being able to understand from the PCP the exact nature of the diagnosis, the prognosis, and what course of treatment is to be expected (Overman and Stoudemire, 1988).

Advance directives and health care surrogates should be determined early while the patient can still have input (Brock, 1996; Ham, 1997). The PCP should also discuss values, preferences and goals with patients in early stages of AD related to death and dying, including do not resuscitate orders, artificial nutrition plans, and health care proxy (Alzheimer's Association, 1997; Wolf-Klein, 1993). Though the research does not provide strong studies, expert opinion and Workgroup consensus suggest PCPs should initiate conversations with patients and their families in regards to appointing a proxy (Braun, Pietsch and Blanchette, 2000; Post, Blustein and Dubler, 1999; Silveira, et al., 2000; Potkins, et al., 2000; Young, 2001). Proxies should have extensive conversations about the wishes of the patient under a variety of circumstances or situations (Alpers and Lo, 1999; Post, Blustein and Dubler, 1999; Potkins, et al., 2000). PCPs need to respect the decisions of patients and their proxies, even though cultural beliefs or wishes may be counter to medical recommendations (Alpers and Lo, 1999; Post, Blustein and Dubler, 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 (Small, et al., 1997). Advance planning is also important in long-term care to help patients maintain a sense of control when they lose decisional capacity and to assure preferences are available (Besdine, et al., 1991; McCullough and Wilson, 1995, Morrison, et al., 2000).

#### ***Impact of Language, Education Level and Culture:***

A major barrier to completing informed consent forms, appointing 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, 1999). The PCP should refer the family to the Alzheimer's Association or other community-based agency to identify 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, and the law does not recognize non-blood relatives so PCPs may discount them (Valle, 2001).

Moderate evidence suggests that there is a lack of knowledge/understanding of end of life care among the general population (Silveira, et al., 2000); therefore, it is important for the PCP to discuss end of life treatment goals and options with patients and families early on. 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 satisfaction. The PCP needs to present the care options that maximize comfort and other potential benefits while avoiding futile care that may not provide comfort care and may actually prolong the dying process. For example, strong evidence has recently discouraged 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 and Travis, 1999). There is strong evidence to suggest that tube feeding does not necessarily prolong life or decrease suffering in severely demented patients (Gillick, 2000; Hoefler, 2000). A particular challenge with tube feeding in patients with severe AD is the tendency of confused patients to pull the feeding tube out, often resulting in the use of physical restraints, which

can lead to an increase in confusion and a decrease in quality of life for the person with AD (Gillick, 2000; Hoefler, 2000). Tube feeding and hydration are often done to alleviate the anxiety of the caregivers and the family of the patient or to comply with medical organization policy. Decisions to use tube feeding should be consistent with care plans the PCP identified with the patient and his/her family.

## **REPORTING REQUIREMENTS**

### **Overview**

PCPs are required by law to report instances of elder abuse as well as the diagnosis of AD to appropriate agencies (California Welfare Institution Code, 1997; Warshaw, et al., 1995). The PCP can monitor for abuse as well as offer interventions to the patient and the caregivers through medical treatments and referrals to community agencies. Reporting requirements may vary by state; the recommendations below are for the State of California.

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### **Recommendations**

- Abuse: Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment) to Adult Protective Services or police department, as required by law (California Welfare Institution Code, Section 15630).
  - Driving: Report the diagnosis of AD to your local health officer in accordance with California law (Sections 2800 - 2812 of Title 17, California Code of Regulations).
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### **Discussion**

#### *Elder Abuse*

PCPs must report all instances and suspected instances of physical abuse to law enforcement (California Welfare Institution Code, 1997). PCPs may report instances of emotional or financial abuse to Adult Protective Services. The Ombudsman will also take reports if the patient is in a long-term care facility (nursing home or board and care). The major challenge in identifying elder abuse is that it does not assume the same identifiable patterns as it does in children, and it is especially hard to obtain information from a patient who is functionally or cognitively impaired (Young, 2000). California law punishes PCPs who fail to report a known incident of abuse, and the punishment is greater if the abuse results in death or severe bodily injury (California Welfare Institution Code, Section 15630).

The issue of elder abuse focuses on interventions with caregivers to mitigate caregiver burden and stress which is seen as a risk factor in abuse (Friedman and Newbrger, 1993). The results from one study indicated that patient attributes (patient's cognitive or functional impairment or physical dependence) were not good predictors of risk for violence in AD families, but that caregiver depression and living arrangements (living with the family but without one's spouse) were associated with violence (Paveza, et al., 1992). Thus, the health care team has the responsibility to monitor and intervene where required (American Psychiatric Association, 1997). Monitoring would include being alert to caregiver circumstances, as well as patient's behavioral symptoms which may be a reaction to a disturbing or pathologic situation in the living arrangements (Warshaw, et al., 1995).

Means of intervention include reducing levels of depression and burden in caregivers.

Psychopharmacological treatment, supportive psychotherapy, support and education groups, and respite services were also suggested as means of alleviating caregiver burden (Coyne, et al., 1993). Mutual violence (where abuse is seen both in terms of caregiver directing abusive behavior towards patients and patients abusing their caregivers) is also of concern (Coyne, et al., 1993; Paveza, et al., 1992). The obligation of the PCP is to provide support and referrals to both patient and caregivers and to intervene appropriately if abuse is suspected.

### *Driving*

The physician is required to report a diagnosis of AD to the local health officer (county health department) in accordance with California law (Sections 2800-2812 of Title 17, California Code of Regulations). The current regulations were promulgated in October 2000, superseding the previous regulations (Sections 2500 and 2572). It should be noted that the statute (Health and Safety Code 103900) provides that a physician shall not be civilly or criminally liable to any patient for making any report required or authorized by the statute.

The cognitive, visual-spatial, and other impairments associated with AD increase the risks of driving. Patients with moderate and severe dementia should not be driving (Fitten, 1997; Dubinsky, Stein and Lyons, 2000).

For reportable health conditions including AD, California DMV personnel evaluate drivers on an individual basis using physician medical evaluation reports, personal interviews, and other information when indicated, to determine a person's driving privilege status.

### **CONCLUSION**

This document reflects approximately six years of collaborative effort by Alzheimer's disease experts to identify key patient management activities to provide quality of care to patients with Alzheimer's disease and their families and caregivers. It does not identify all possible care management activities, rather the basic and essential tasks. The California Work Group on Guidelines for Alzheimer's Disease Management recognizes that in the present health care arena, efficiency in patient care is critical. The Guidelines and supporting materials provide a base for health care providers and medical care organizations upon which to build. Care suggestions for special and/or diverse populations have also been provided in this report. We hope that these documents will be modified, adopted and implemented into the fabric of patient care.

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**TABLE 1:  
SPECIAL CONSIDERATIONS WHEN WORKING WITH ETHNICALLY DIVERSE  
POPULATIONS**

Area of AD Care	Special Considerations
Assessment:	<ul style="list-style-type: none"> <li>• Be sure assessment tools are language and education appropriate</li> <li>• Reporting of behavioral symptoms will differ by patient/family beliefs about dementia and tolerability of behavioral symptoms</li> <li>• Assessment of health literacy is important in providing effective care to patients with low literacy</li> <li>• Identification of the primary caregiver may be more difficult as there may be more than one, and the individual bringing the patient to office visits may only be serving as a translator and not as the primary caregiver</li> <li>• Assessment of a patient’s decision-making capacity may be difficult when there is a language barrier between the patient and medical care provider</li> <li>• Assessment of family decision-making processes is important to understand (e.g. are decisions made by the autonomous individual, or are decisions more collective and family-oriented) so that provider includes all decision-makers in care planning</li> </ul>
Treatment	<ul style="list-style-type: none"> <li>• Treatment options and plans must be culturally appropriate and acceptable to the patient and family</li> <li>• Referrals must be made to facilities that can accommodate language differences (use the Alzheimer’s Association, social workers, Area Agency on Aging, etc. as source of appropriate referrals) and provide culturally appropriate services</li> <li>• Use “show me” techniques to be sure medical care instructions are understood (especially regarding taking medications)</li> <li>• Be aware of possible differential responses to psychotropic medications in ethnically diverse populations</li> </ul>
Caregiver Education and Support	<ul style="list-style-type: none"> <li>• Communication may be difficult due to language barriers or the presence of multiple caregivers</li> <li>• Physicians must acknowledge “fictive kin” (non-blood “family” members) who patients rely on as caregivers and decision-makers</li> </ul>
Ethics/Legal	<ul style="list-style-type: none"> <li>• Encourage the appointment of proxies, surrogates, and other forms of medical decisions makers early on. Physicians should make referrals to services that can aid in preparing these legal documents and have experience working with ethnically diverse populations.</li> <li>• Religious beliefs may affect end of life care decisions. Discussions should begin early on with the patient and family, and the physician should respect religious and cultural beliefs.</li> </ul>

**TABLE 2:**  
**AGE AND EDUCATION ADJUSTMENTS TO MMSE SCORES** <sup>1</sup>

Age (years)	Education (years of schooling completed)					
	0	4	8	12	16	20
60	4	2	0	-1	-3	-5
65	4	3	1	0	-2	-4
70	5	3	1	0	-1	-3
75	6	4	2	0	-1	-3
80	6	5	3	1	0	-2
85	7	5	3	1	0	-1
90	8	6	4	2	0	-1

(Mungas et al., 1996)

<sup>1</sup> *MMSE adjusted scores can be determined by adding the raw MMSE score and the indicated correction that corresponds to the individual's level of education and age.*

**TABLE 3:  
CAREGIVER ASSESSMENT**

The PCP should assess the primary caregiver of the AD patient regarding:	Examples
Ethnic, cultural issues	Primary language spoken, medical beliefs (causal agents), who makes decisions for the patient
Knowledge base	Expected treatment outcomes, knowledge of local services
Social support	The availability of and satisfaction with support network
Psychiatric symptomatology and burden, including physical burden of caregiving	Depression, anxiety, physical injuries, strain or somatic complaints (e.g. back problems due to physical demands of caregiving)
Family conflict	The quality of the caregiver-patient relationship prior to caregiving; possible elder abuse

**TABLE 4:  
A MODEL FOR CULTURAL ASSESSMENT\***

Components of Cultural Assessment	Specific Examples
<p><b>Locus of Culture:</b> <i>Encompasses the individual's preferred means of communication, practiced customs and rituals, and values, beliefs and normative expectations.</i></p>	<ul style="list-style-type: none"> <li>- Language</li> <li>- Relationships</li> <li>- Values/beliefs</li> </ul>
<p><b>Domains of Expression:</b> <i>Pertains to the everyday ways people express their culture.</i></p>	<ul style="list-style-type: none"> <li>- Cognition (thoughts)</li> <li>- Affect (feelings)</li> <li>- Behavior (what they do)</li> </ul>
<p><b>Sources of Evidence:</b> <i>Assessment occurs at the very basic level, either interviewing the patient, the caregiver or family member, or via simple observation.</i></p>	<ul style="list-style-type: none"> <li>- Self-reports</li> <li>- Collateral reports</li> <li>- Observation and study</li> </ul>
<p><b>Confounding Information:</b> <i>Non-cultural elements that can skew the physician's understanding of the cultural factors influencing the manifestation and treatment outcomes of the patient.</i></p>	<ul style="list-style-type: none"> <li>- Socio-economic status</li> <li>- Literacy/education</li> <li>- Social status</li> </ul>

\* adapted from Valle, R. (2001). Cultural assessments in bioethical advocacy: Toward cultural competency in bioethical practice. *Bioethics Reform*, 17(1):15-26.

**TABLE 5:  
MEDICAL TREATMENT OF MILD TO MODERATE ALZHEIMER'S DISEASE**

<b>Cholinesterase Inhibitors</b>			
	<b>Suggested Dosage</b>	<b>Side Effects</b>	<b>Specific Cautions</b>
Donepezil hydrochloride (Aricept®)	Effective dose of 5 mg, once per day can be administered without titration. Can titrate up to a 10 mg dose after 4-6 weeks.	Mild gastrointestinal symptoms including nausea, vomiting, and diarrhea (can be reduced when taken with food).	Conflicting evidence regarding a possible drug interaction with cimetidine, theophylline, warfarin and digoxin. Rarely patients experience increased agitation, which subsides after a few weeks.
Galantamine (Reminyl®)	Recommended starting dose is 8 mg/day for 4 weeks, administered twice daily (with morning and evening meals). After one month, increase to 16 mg/day for at least 4 weeks. Increase to recommended dose of 24 mg/day on an individual basis, depending upon clinical benefit and tolerability.	Mild gastrointestinal symptoms including nausea, vomiting, and diarrhea (can be reduced when taken with food). Sleep disturbances commonly associated with other cholinergic treatments do not appear to be a problem with galantamine.	Contraindicated for patients with hepatic and/or renal impairment.
Rivastigmine tartrate (Exelon®)	1.5 mg/day administered twice daily is a well-tolerated initial dose, but can titrate (takes 4-12 weeks) up to 9-12 mg/day. Increase dosage as tolerated and no more quickly than 3mg/day every 4 weeks.	Mild gastrointestinal symptoms including nausea, vomiting, and diarrhea (can be reduced when taken with food); headaches, dizziness, fatigue, and malaise.	
Tacrine (Cognex®)	Titrate to maximum tolerated dose starting with 10 mg/day taken 4 times daily for 6 weeks, then increase to 20 mg/day for 6 weeks, then 30 mg/day, etc. until maximum tolerated dose is achieved. Maximum dose is 160 mg/day.	Gastrointestinal problems are common. Side effects reduced when taken with food.	Drug interaction with theophylline, cimetidine, amfetidine.  Hepatotoxicity is a problem and should be monitored every other week for 4-6 weeks and then every 3 months.

**TABLE 6:  
SUPPORT SERVICES FOR AD PATIENTS AND CAREGIVERS**

Alzheimer's Association

1-800-660-1993

Website: [www.alz.org](http://www.alz.org)

Alzheimer's Disease Education and Referral (ADEAR) Center:

1-800-438-4380

Website: [www.alzheimer's.org/adear](http://www.alzheimer's.org/adear)

Alzheimer's Disease Research Centers of California:

1-916-327-4662

Website: [www.dhs.ca.gov/alzheimers](http://www.dhs.ca.gov/alzheimers)

Area Agencies on Aging: 1-800-510-2020

Website: [www.c4aging.org](http://www.c4aging.org)

Family Caregiver Alliance (Caregiver Resource Centers):

1-800-445-8106

Website: [www.caregiver.org](http://www.caregiver.org)

Eldercare Locator for Continuum of Services:

1-800-677-1116

Use the contact information above to obtain referrals and information regarding:

- Adult day services
- Assisted living
- Caregiver and patient education programs
- Caregiver – Physician communication education programs
- Continuing care retirement community
- Exercise programs
- Home health care
- Homemaker/companion services
- Hospice
- Home-delivered meals
- Legal services
- Nursing homes
- Residential care (Board and Care)
- Respite care
- Support groups

**TABLE 7**  
**NON-PHARMACOLOGICAL MANAGEMENT TECHNIQUES FOR**  
**BEHAVIORAL SYMPTOMS**

Agitation	Sleep Disorders	Depression
Eliminate or minimize environmental stresses	Decrease dietary caffeine and evening fluid intake	Consider referral of patient to counseling or an early stage program
Consider referral to Geriatric Psychiatry	Consider referral to Geriatric Psychiatry	Consider referral to Geriatric Psychiatry
Advise family to access medical advice if there is sudden onset	Consider referral to respite services	Consider referral to an adult day care center for activities
Refer caregiver to support group	Refer caregiver to support group	
Simplify environment	Increase patient activity level or exercise in daytime	
Distract, don't confront	Adequate light during the daytime	
Use of restraints is not recommended and may be harmful	Consider referral to adult day services.	
For delusions, provide validation, not reality orientation		
If patient wanders, refer to Alzheimer's Association Safe Return Program		
Structured, well-planned activities		
Consider referral to adult day services		

**TABLE 8:  
PHARMACOLOGICAL TREATMENT OF BEHAVIOR AND MOOD**

<i>ANTIPSYCHOTICS</i>			
ATYPICAL			
Recommended Uses		General Cautions	
Used to control problematic delusions, hallucinations, severe psychomotor agitation, and combativeness.		Diminished risk of developing extrapyramidal symptoms (EPS) and tardive dyskinesia. They are rapidly becoming the new "standard".	
<i>Atypical Agents</i>	Clozapine (Clozaril)	Dosage	Specific Cautions
		Initial dose: 12.5 mg bid; Max: 75-150 mg (in divided doses)	Generally not used as a first line agent. 1% risk for agranulocytosis, mandatory weekly blood monitoring. Very anticholinergic.
	Risperidone (Risperdal)	Initial dose: 0.25 mg qhs; Max 2-3 mg/day (usually bid)	Current research supports its use in low doses. EPS may occur at 2 mg.
	Olanzapine (Zyprexa)	Initial dose: 2.5 mg qhs; Max: 10-20 mg/day (usually bid)	Generally well-tolerated.
	Quetiapine (Seroquel)	Initial dose: 12.5 mg bid; Max: 75 mg bid	More sedating; beware of transient orthostasis.
Ziprasidone (Geodon)	Initial dose: 10 mg/day; Max: 80 mg/day	Requires baseline and periodic EKGs	
TYPICAL			
Recommended Uses		General Cautions	
Used to control problematic delusions, hallucinations, severe psychomotor agitation, and combativeness. Second line of therapy for patients intolerant of or unresponsive to atypical antipsychotics.		Current research suggests that these drugs be avoided, if at all possible. They are associated with significant, often severe, side effects involving the cholinergic, 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.	
<i>Typical Agents</i>	Haloperidol (Haldol), fluphenazine (Prolixin), and thiothixene (Navane)	Dosage	Specific Cautions
		Dosage varies by agent	Anticipated EPS. If present, lower the dose or switch to another agent; avoid the use of Cogentin or Artane.
	Thioridazine (Mellaril), chlorpromazine (Thorazine)	Dosage varies by agent	Significant hypotension, anticholinergic symptoms, and drowsiness limit their usefulness. Thioridazine requires baseline and periodic EKGs and regular chemistry panels.
	Trifluoperazine (Stelazine), molindone (Moban), perphenazine (Trilafon), and loxapine (Loxitane)	Dosage varies by agent	Agents with an "in-between" side effect profile.
MOOD STABILIZERS (ANTI-AGITATION AGENTS)			
Recommended Uses		General Cautions	
Used to control problematic delusions, hallucinations, severe psychomotor agitation, and combativeness. Useful alternatives to antipsychotics for severe agitated, impulsive, repetitive, and combative behaviors.		See "Specific Cautions"	
<i>Non-Antipsychotic Agents</i>	Trazodone (Desyrel)	Dosage	Specific Cautions
		Initial dose: 25 mg/day (qd); Max: 200-400 mg/day (in divided doses)	Use with caution in patients with PVCs.
	Carbamazepine (Tegretol)	Initial dose: 100 mg bid; Titrate to	Monitor CBC and liver enzymes regularly. Problematic side effects.
	Valproate (Depakote)	Initial dose: 125 mg bid; Titrate to	Generally better tolerated. Monitor liver enzymes; platelets & PT/PTT as indicated.



TABLE 8 (CONTINUED)

<i>ANXIOLYTICS</i>		
<b>BENZODIAZEPINES</b>		
<i>Recommended Uses</i>		<i>General Cautions</i>
For management of insomnia, anxiety, and agitation.		Regular use can lead to tolerance, addiction, depression, and cognitive impairments. Paradoxical agitation occurs in about 10%. Infrequent, low doses of short half-life agents are least problematic.
<i>Agents</i>	Lorazepam (Ativan), oxazepam (Serax), temazepam (Restoril), alprazolam (Xanax), zolpidem tartrate (Ambien), and triazolam (Halcion)	<i>Dosage</i>
		Dosage varies by agent
		<i>Specific Cautions</i>
		Regular use can lead to tolerance, addiction, depression, and cognitive impairments. Paradoxical agitation occurs in about 10%. Infrequent, low doses of short half-life agents are least problematic.
<b>NON-BENZODIAZEPINES</b>		
<i>Agent</i>	Buspirone (Buspar)	<i>Dosage</i>
		Initial dose: 5 mg bid; Max: 20 mg tid
		<i>Specific Cautions</i>
		Useful in mild-moderate agitation only. May take 2-4 weeks to become effective.
<b>ANTIDEPRESSANTS</b>		
<i>Recommended Uses</i>		<i>General Cautions</i>
See "Specific Cautions" for individual agents.		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. <u>Note:</u> Depressed patients with psychosis require concomitant antipsychotic treatment.
<b>TRICYCLIC ANTIDEPRESSANTS (Norepinephrine reuptake inhibitor)</b>		
<i>Tricyclic Agents</i>	Doxipen (Sinequan/Adapin)	<b>Dosage</b>
		Initial dose: 10-25 mg qhs; Max: 150 mg qhs
		<i>Specific Cautions</i>
	Desipramine (Norpramin/Petrofrane)	Initial dose: 10-25 mg qam; Max: 150 mg qam
	Nortriptyline (Aventil/Pardil)	Initial dose: 10 mg qhs; Anticipated dosage range of 10-40 mg (bid)
		Useful for depressed patients with agitation and insomnia; significant hypotensive and anticholinergic effects are limiting.
		Tends to be activating. Lower risk for cardiotoxic, hypotensive, and anticholinergic side effects. May cause tachycardia. Blood levels may be helpful.
		Tolerance profile similar to desipramine but tends to be more sedating, may be useful for agitated depression and insomnia. Therapeutic blood level "window": 50-150 ng/nl.

TABLE 8 (CONTINUED)

<i>ANTIDEPRESSANTS (Continued)</i>			
HETERO- AND NONCYCLIC ANTIDEPRESSANTS			
<i>Hetero- and Noncyclic Agents</i>	Trazodone (Desyrel)	<i>Dosage</i> Initial dose: 25 mg qhs; Max: 200-400 mg/day (qhs or multiple doses)	<i>Specific Cautions</i> Moderately effective; useful for associated anxiety, agitation, or insomnia. Significant AM orthostatic hypotension. Administer with caution in patients with PVCs.
	Nefazodone (Serzone)	Initial dose: 50 mg bid; Max: 150-300 mg bid	Effective, especially with associated anxiety. <u>Caution:</u> Reduce in half the dose of coadministered Xanax/Halcion.
	Bupropion (Wellbutrin)	Initial dose: 37.50 mg qam, then 37.50 to 75 mg q3 days; Max: 150 mg bid	Activating; possible rapid improvement in energy level. Avoid in agitated patients and those with seizure disorders. To minimize risk of insomnia, give second dose before 3 PM.
	Mirtazapine (Remeron)	Initial dose: 7.5 mg qhs; Max: 30 mg qhs	Potent and well-tolerated. Promotes sleep, appetite, and weight gain.
SELECTIVE SEROTONERGIC REUPTAKE INHIBITORS ( SSRI <sub>s</sub> )			
<i>Recommended Uses</i>		<i>General Cautions</i>	
These agents may prolong the half-life of other drugs by inhibiting various P450 isoenzymes.		As a class, typical side effects can include sweating, tremors, nervousness, insomnia/somnolence, dizziness, and various gastrointestinal and sexual disturbances.	
<i>SSRI Agents</i>	Fluoxetine (Prozac)	<i>Dosage</i> Initial dose: 10 mg every other AM; Max 20 mg qam	<i>Specific Cautions</i> Activating. Very long half life; side effects may not manifest for a few weeks.
	Paroxetine (Paxil)	Initial dose: 10 mg qd; Max: 40 mg qd (AM or PM)	Less activating but more anticholinergic.
	Sertraline (Zoloft)	Initial dose: 25-50 mg qd; Max: 200 mg qd (AM or PM)	Well-tolerated; less effect on metabolism of other medications.
	Citalopram (Celexa)	Initial dose: 10 mg qd; Max: 40 mg qd	Well tolerated; nausea and sleep disturbances in some.
	Fluvoxamine (Luvox)	Initial dose: 50 mg bid; Max: 150 mg bid	Caution when using with Xanax or Halcion (reduce by half).
	Venlafaxine (Effexor)	Initial dose: 37.5 mg bid; Max: 225 mg/day in divided doses	Most potent SSRI- <i>plus</i> (also inhibits norepinephrine reuptake)
LITHIUM			
<i>Recommended Uses</i>		<i>General Cautions</i>	
Anti-cycling agent that may also be used to augment antidepressant medication.		The elderly are prone to develop lithium neurotoxicity at higher doses.	
<i>Agent</i>	Lithium	<i>Dosage</i>	<i>Specific Cautions</i>
		Initial dose: 150 mg qd	Blood levels between 0.2-0.6 meq are generally adequate; usually achieved with 150-300 mg bid.
ELECTROCONVULSIVE THERAPY (ECT)			
<i>Recommended Uses</i>			
For those at risk of injuring or starving themselves; the severely psychotic; and the antidepressant non-responsive or intolerant may require a course in ECT; however, there are no adequate studies of ECT in demented patients to date (Swartz et al., 2000).			

\* Adapted from Roland Jacobs, M.D., "Pharmacological Treatment of Mood & Behavior", unpublished manuscript.