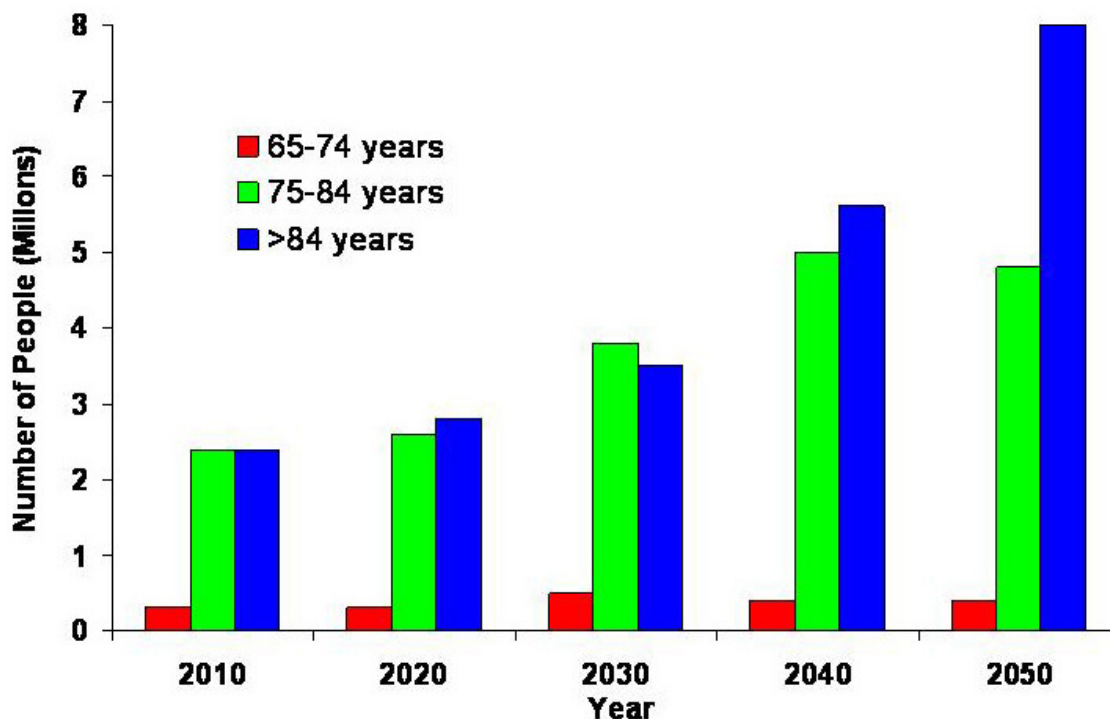


# Early Identification and Management of Patients at Risk for Alzheimer's Disease: A Patient-Centered Approach

Alzheimer's disease (AD), an irreversible, degenerative, and eventually fatal brain disorder, is the most common cause of dementia.<sup>1</sup> Based on middle series United States Census Bureau estimates, prevalence was estimated at 4.5 million people in 2000. Projecting to 2050, approximately 13.2 million Americans will be affected by this disease (Figure 1a) as the population of the oldest old grows through increased



survival.<sup>2</sup> Alarming, the incidence rate of AD at least doubles across 5-year age groups (Figure 1b).<sup>3</sup> Figure 1. The epidemiology of Alzheimer's disease<sup>2</sup>

- a. Projected growth in the number of people with Alzheimer's disease by age, based on the 2000 US Census Bureau middle series estimates

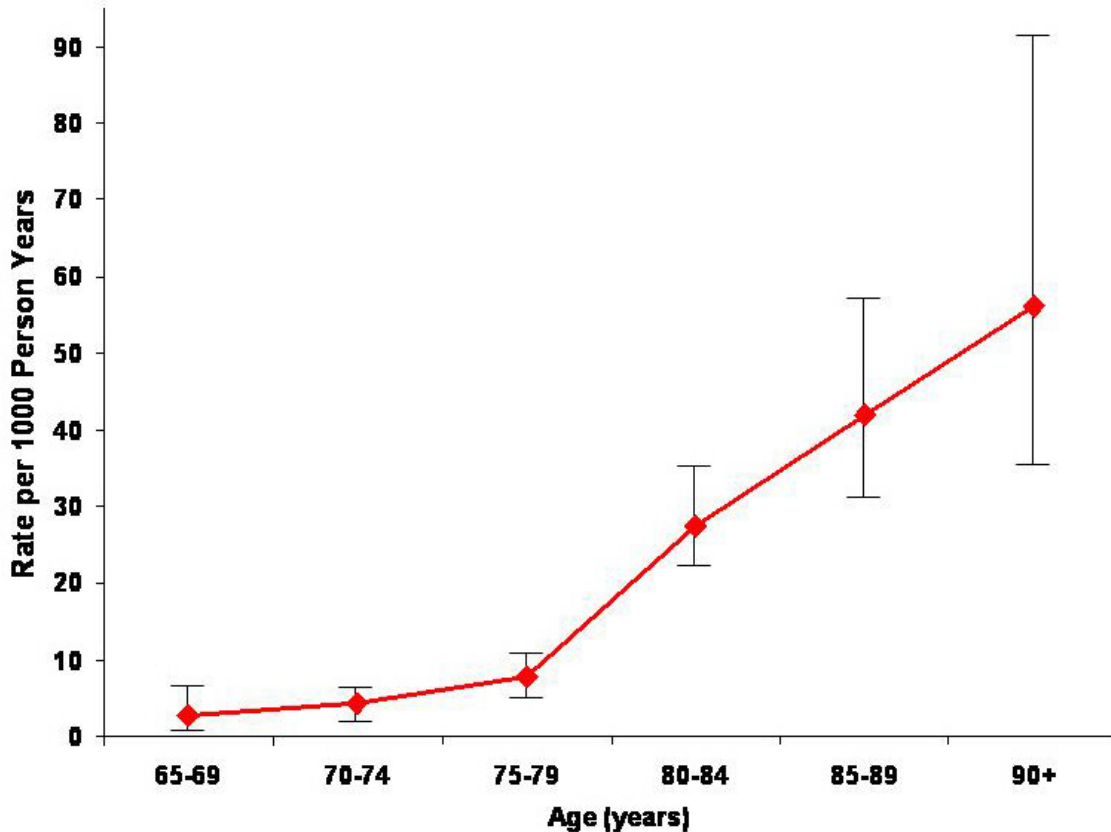


Figure 1. The epidemiology of Alzheimer’s disease<sup>3</sup>  
 b. The incidence rate of Alzheimer’s disease per 1000 person-years across 5-year age groups (% [95% CI])

While age is highly associated with the development of AD, there are several other predisposing risk factors. It is more common in women than in men, although this may reflect a longer life expectancy. Early onset AD has been linked to head trauma.<sup>4</sup> An association between subclinical hyperthyroidism in the elderly and AD also has been recognized.<sup>5</sup> People with lower educational levels have a higher risk of AD.<sup>6</sup> Four genetic mutations—3 that promote increased  $\beta$ -amyloid production and are linked to early-onset AD, and apolipoprotein E (APOE)  $\epsilon$ 4, a risk factor for late-onset AD—have also been implicated.<sup>7</sup> Yet other possibilities are under investigation including the contributions of cardiovascular factors, diabetes, and obesity, along with a variety of lifestyle choices such as smoking and exercise.

**Underdiagnosis**

Unfortunately, because the symptoms of early AD are subtle, it often goes unrecognized and is dismissed as normal aging, particularly in people with mild functional impairment.<sup>8,9</sup> The person with AD is unlikely to seek help for problems with cognition, behavior, or function, and may actually be unaware of or in denial about any difficulties. Family members may overlook changes in memory, behavior, and judgment, indeed adjusting their own responses to their loved one and compensating for any deterioration. This often results in a lag between the time the first symptoms of AD are recognized

and the time that they are brought to the attention of a clinician. In turn, this initial consultation may be followed by another lag before the correct diagnosis is made.<sup>10,11</sup>

Inadequate training and experience in diagnostic procedures and the use of cognitive testing instruments hinder the primary care practitioner (PCP) in the early identification of AD. Despite the fact that a clinical diagnosis can be made accurately, many PCPs still believe that AD can only be diagnosed at autopsy. A further complication may be the presence of comorbidities that can mask AD, especially in the inpatient setting.<sup>11</sup> A delay in diagnosis has considerable medical and social implications, and may result in a greater risk of earlier nursing-home placement.

### **Is Early Detection the Answer?**

To answer an overarching question about screening, several other questions should be considered. Is there additional benefit to be gained by identifying people with cognitive impairment? Can any harm come from the process? Is it cost effective? The answer to these questions should be resoundingly positive.<sup>12</sup> A commitment to early detection of AD will encourage PCPs to perform a more thorough assessment during which they can rule out potentially reversible causes of dementia and choose appropriate treatment-interventions in a timely manner. However, if AD is diagnosed, the initiation of a care plan and the early use of available medications may maximize cognition and the performance of activities of daily living at the highest level of functioning to preserve.<sup>13,14</sup> By slowing the progression of symptoms, independent functioning can be prolonged, thereby lessening disease burden and allowing improved quality of life for both the patient and caregiver.

Early detection can also provide significant social benefits, not least of which is a reduction in direct and indirect costs of care. Eventually, most people with AD will require round-the-clock care, either in the home or in a nursing home. Both options involve substantial direct costs; however, treatment in the community or even in an assisted-living facility is far less expensive than a nursing home. Maintaining a patient at a higher level of functioning by treating early reduces costs.<sup>15</sup>

By identifying Alzheimer's disease in its earliest stage, both the patient and caregiver can plan for the future knowing that the person with AD is still capable of making informed decisions. Such plans might include estate planning, updating a will, and completing other legal documents; granting legal and medical power of attorney; establishing or setting up bank accounts; assigning a healthcare proxy who can make decisions about participation in clinical trials as well as see to it that end-of-life wishes regarding care and medical treatments are observed; and specifying advance directives, possibly in the form of a living will. All healthcare-related documents should be reviewed, and distributed to family members and healthcare providers. A checklist, like the one in Table 1, can be a helpful tool for the caregiver and patient to complete at this time.

Table 1. A Checklist for Important Papers

<i>Check here</i>	<b>Document</b>	<b>Location</b>
	Will	
	Legal power of attorney	
	Medical power of attorney	
	Healthcare proxy	
	Advance directives/living will	
	Savings accounts and numbers	
	Checking accounts and numbers	
	Retirement accounts and numbers	
	Stocks and bonds	
	Credit cards	
	Life insurance policy	
	Health insurance	
	Medicare	
	Social Security	
	Retirement papers	
	Mortgage	
	Deed	
	Homeowner's insurance	
	Car title	
	Car insurance	
	Funeral arrangements	

Other critical issues should be handled during this time, as well. What are the options for housing now and in the future? What changes in the current home should be made to ensure safety? Can the patient and caregiver reach an understanding about important concerns such as driving, cooking, and medication adherence so that caregiver guilt will be diminished or alleviated when the inevitable need for intervention arises?

Arrangements can also be made for caregiver education, addressing not only how the disease can be expected to progress and how the patient can be managed at each stage, but what psychological effects AD can be expected to have on the caregivers. Such knowledge can not only help caregivers plan for future physical care for the patient, but can also promote awareness of support programs as well as services that can relieve caregiver burden and permit the caregivers to find time for themselves, apart from the patient. Some family members may also find relief in learning more about the likelihood of genetic inheritance of AD and in arranging genetic testing.

## **Can Alzheimer's Disease Screening Become Routine in the Primary Care Practice?**

In the context of the 15-minute primary care office visit with many patient complaints vying for attention,<sup>16</sup> it is difficult to imagine how AD screening of patients 75-years and older can become routine. Perhaps screening should begin with greater awareness and sensitivity on the part of all care providers and office staff. If a known patient is answering questions in a way that arouses suspicion or if there have been changes in behavior, cognition, and ability to function over time, the PCP should be alerted to the need for further screening.

Many screening tools have been developed for AD. The ideal test used should be brief, easy to administer and score, free, and available on multiple platforms so that it can be used both in a PCP office and in the community setting. Bear in mind that the test is a tool that can draw attention to the need for more complete assessment. For years, the Mini-Mental State Examination (MMSE) was used extensively to assess patients in studies; however, some feel that it has poor sensitivity and specificity for screening, includes items that complicate the process rather than add necessary discriminatory information, and requires props.<sup>12</sup>

The AD8 approaches screening as an informant interview, asking questions that elicit information about changes in judgment, interests, memory, tool utilization, orientation, and financial abilities. It has been used in conjunction with the Word List Recall to improve AD detection.<sup>17</sup> Patients also have completed it themselves in the absence of reliable informants, though this is more successful in people who have mild dementia than among those who are more severely affected.<sup>18</sup> The Brief Alzheimer Screen (BAS), which includes 3-word recall, number of animals named in 30 seconds, the date, and spelling of WORLD backwards, can distinguish those people who have mild AD from those who have normal cognition, with high sensitivity and specificity.<sup>19</sup> Other screening tests such as the Cognitive Screening Test have been designed to decrease the demands on a PCP, are administered on the Internet, and require little in terms of administration and interpretation.<sup>20</sup>

*Know the 10 Signs* (Table 2),<sup>21</sup> part of an Alzheimer's Association<sup>®</sup> public-outreach campaign to promote the early detection of AD, is similar in content to informant questionnaires. It can be a useful posting in a PCP office as it not only lists the signs of AD, but also contrasts these signs with normal behavior. This can help to alleviate confusion about what indeed is normal.

As might be expected, clinician and organizational opinions differ regarding the need for routine screening. However, recognizing the tremendous impact of AD on society, a recently convened panel of experts developed recommendations for best practices, including screening, in Medicare managed-care organizations. Their recommendation was that brief telephonic screening be conducted, particularly in people aged 75 years and older. They also supported brief in-office screening in this same age group and at any age if someone familiar with the patient notes confusion, memory loss, or any other symptoms of cognitive impairment.<sup>13</sup>

Table 2. Alzheimer's Association Knows the 10 Signs<sup>21</sup>



**Have you noticed any of these warning signs?**

**Please list any concerns you have and take this sheet with you to the doctor.**

*Note: This list is for information only and not a substitute for a consultation with a qualified professional.*

\_\_\_\_ **1. Memory changes that disrupt daily life.** One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. **What's typical?** Sometimes forgetting names or appointments, but remembering them later.

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\_\_\_\_ **2. Challenges in planning or solving problems.** Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. **What's typical?** Making occasional errors when balancing a checkbook.

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\_\_\_\_ **3. Difficulty completing familiar tasks at home, at work or at leisure.** People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. **What's typical?** Occasionally needing help to use the settings on a microwave or to record a television show.

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\_\_\_\_ **4. Confusion with time or place.** People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. **What's typical?** Getting confused about the day of the week but figuring it out later.

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\_\_\_\_ **5. Trouble understanding visual images and spatial relationships.** For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. **What's typical?** Vision changes related to cataracts.

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\_\_\_\_6. **New problems with words in speaking or writing.** People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock"). **What's typical?** Sometimes having trouble finding the right word.

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\_\_\_\_7. **Misplacing things and losing the ability to retrace steps.** A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. **What's typical?** Misplacing things from time to time, such as a pair of glasses or the remote control.

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\_\_\_\_8. **Decreased or poor judgment.** People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. **What's typical?** Making a bad decision once in a while.

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\_\_\_\_9. **Withdrawal from work or social activities.** A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. **What's typical?** Sometimes feeling weary of work, family and social obligations.

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\_\_\_\_10. **Changes in mood and personality.** The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. **What's typical?** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

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**If you have questions about any of these warning signs, the Alzheimer's Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.**

**For more information, go to [www.alz.org/10signs](http://www.alz.org/10signs) or call 877-IS IT ALZ (877.474.8259).**

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### **Making Screening Work**

As discussed, in the busy PCP office, time and staff considerations affect the decision to screen. When possible, the use of trained nurses and allied health personnel to perform cognitive screenings or collect information from informants, who can complete questionnaires at their own convenience prior to the office evaluation, can reduce the demands on the PCP. This process frees the PCP for other elements of a full dementia examination if they are required.<sup>22</sup>

Who should be screened for memory problems and dementia? Patients under 75-years-old should be *tested* only if they complain of memory problems. At 75 years, baseline *screening* should be performed, particularly if there is a history of dementia in the family, if there is a known genetic abnormality, if the patient or family is concerned about changes, or if clinical or cognitive signs lead the PCP to suspect a problem. During this screening, history is obtained, systems are reviewed, and vital signs are taken. Follow-up is then at the discretion of the clinician based on degree of risk, or if the patient or family is concerned. After age 75 years, screening should take place every 2 years unless risk increases or concern is expressed. Thereafter, in the oldest old, those aged 85 years and older, screenings should be a part of the annual examination.

### **Diagnosing Alzheimer's Disease**

If dementia is suspected based on the screen, clinical risk factors, responses to questions, or changes over time, a full dementia assessment should be performed (Table 3).<sup>22-24</sup> This assessment should include a more complete dementia-related history in which the patient and a family member or companion are queried about the presenting problem; the nature of memory problems and their onset; any unusual events around the time of their onset, including injuries, stress, and surgery; whether the symptoms have progressed; and how the symptoms have affected activities of daily living.

A complete medication review as well as physical and neurological examinations should be conducted, and a battery of laboratory tests ordered to rule out other forms of dementia. If indicated, the PCP may do an electrocardiogram or a chest X-ray. The assessment should also include tests for depression, cognitive function, and an informant questionnaire completed by a family member or companion who is familiar with the patient.

### **When to Refer**

It is clear that genetic heritability is a risk factor for AD<sup>25</sup>; however, genetic testing is expensive and does not provide additional information to target therapy. Thus, genetic testing becomes a personal decision; if early-onset AD appears to run in a family, testing may be sought by the family. In a population survey of attitudes toward genetic testing for AD,<sup>26</sup> 79% of people said that they would pay for a completely predictive genetic test for AD. As shown in Figure 2,<sup>26</sup> they stated that they would sign advance directives (84.3%), spend more time with family (80.1%), get finances in control (73.9%), and purchase long-term care insurance (69.3%) if testing was positive.

Table 3. Diagnosing Alzheimer’s Disease in the Primary Care Practice<sup>22-24</sup>

Full Assessment Components	Staff Administrator
Clinical history with informant input	PCP alone or with nurse or clinical assistant
Medication review to rule out medication-related dementias	PCP alone or with nurse or clinical assistant
Complete physical examination to rule out other dementias	PCP alone or with nurse or clinical assistant
Neurologic examination to rule out other dementias <ul style="list-style-type: none"> <li>• Cerebral, cerebellar, cranial nerve, and motor-sensory function</li> </ul>	PCP alone or with nurse or clinical assistant
Laboratory tests to rule-out other dementias <ul style="list-style-type: none"> <li>• Complete blood count</li> <li>• Serum electrolytes</li> <li>• Glucose</li> <li>• Blood urea nitrogen/creatinine</li> <li>• Liver panel</li> <li>• B<sub>12</sub>, folate (consider homocysteine)</li> <li>• Thyroid function</li> <li>• VDRL; HIV (if indicated)</li> <li>• Urinalysis</li> </ul>	PCP alone or with nurse or clinical assistant
Depression screening test	Trained medical assistant or PCP
Cognitive assessment	Trained medical assistant or PCP
Functional assessment completed by caregiver	Medical assistant or PCP
Interpretation of all results	PCP

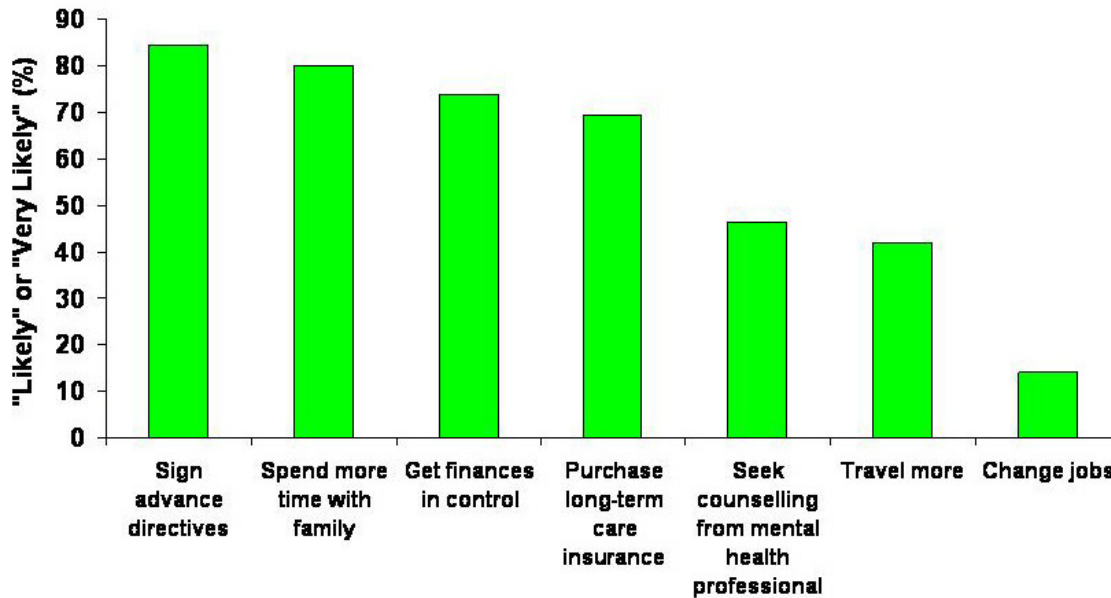


Figure 2. What people would do if they received a positive genetic test for Alzheimer's disease<sup>26</sup>

A referral for anatomical neuroimaging with a noncontrast CT scan or noncontrast MRI should be made to rule-out strokes, tumors, subdural hematomas, and normal-pressure hydrocephalus. When possible, an MRI is preferable because of its greater accuracy. Although functional SPECT and PET scans can provide information, and are approved by Medicare to differentiate frontotemporal dementia from AD, they are recommended as an optional choice.<sup>13</sup>

### Predicting the Risk of Dementia

Quite recently, an index to stratify older adults into low-, moderate-, or high-risk groups has been developed.<sup>27</sup> This risk-assessment tool, evaluated in more than 3000 people without dementia who were participants in the Cardiovascular Health Cognition Study, used a point system based on age, poor cognitive test performance, body mass index, APOE ε4, cerebral MRI findings, ultrasound of the carotid artery, history of bypass surgery, slow physical performance, and lack of alcohol consumption to predict the risk of developing dementia within 6 years. Its developers point to its potential in targeting prevention or intervention strategies.

### Pharmacologic Interventions for Alzheimer's Disease

The Food and Drug Administration has approved 4 cholinesterase inhibitors (CHEIs) for the treatment of mild-to-moderate AD: tacrine (1993), donepezil (1996), rivastigmine (2000), and galantamine (2001); however, tacrine is no longer marketed. Donepezil is the only CHEI that also has been approved in the treatment of severe AD. These agents have been approved in different formulations (Table 4): donepezil as an orally disintegrating tablet that is bioequivalent to donepezil tablets<sup>28</sup>; galantamine as an extended-release capsule<sup>29</sup>; and rivastigmine<sup>30</sup> in oral solution and skin-patch formulations.

The rationale for the use of this class of drugs is logical. Some of the signs and symptoms of AD have

been attributed to a deficiency of cholinergic neurotransmission. By acting to reversibly block the degradation of acetylcholine by acetylcholinesterase, CHEIs increase the concentration of acetylcholine and enhance cholinergic function.<sup>28</sup>

Memantine, a noncompetitive *N*-methyl-D-aspartate (NMDA)-receptor antagonist, was approved in 2003 for the treatment of moderate-to-severe dementia of the Alzheimer’s type. Theoretically, persistent activation of NMDA receptors by the excitatory amino acid, glutamate, may contribute to AD symptoms. Memantine acts as a low-to-moderate affinity noncompetitive NMDA receptor antagonist, binding preferentially to the NMDA receptor-operated cation channels.<sup>31</sup>

Table 4. Comparing Treatment Options for Alzheimer’s Disease<sup>28-31</sup>

<b>Agent</b>	<b>Indication</b>	<b>Formulations</b>
<b><i>Cholinesterase Inhibitors</i></b>		
Donepezil	Treatment of mild-to-moderate and severe dementia of the Alzheimer’s type	Tablets Orally disintegrating tablets
Galantamine	Treatment of mild-to-moderate dementia of the Alzheimer’s type	Tablets Oral solution Extended-release capsules
Rivastigmine	Treatment of mild-to-moderate dementia of the Alzheimer’s type; treatment of dementia of Parkinson’s disease	Capsules Oral solution Transdermal patch
<b><i>NMDA Receptor Antagonist</i></b>		
Memantine	Treatment of moderate-to-severe dementia of the Alzheimer’s type	Tablets Oral solution

The previously discussed consensus panel evaluated the use of approved antidementia therapies for AD and made recommendations for their use in clinical practice. Identifying levels of AD severity using MMSE scores, the panel divided patients into those with mild, moderate, severe, and profound disease. The panel evaluated the use of both the cholinesterase inhibitors and memantine, basing their recommendations on a combination of factors: FDA labeling, formulary policies of major organizations, and the application of these agents in practice.<sup>13</sup>

### ***The Cholinesterase Inhibitors***

The consensus panel pointed to similar effectiveness among the CHEIs. Figures 3 through 5<sup>30,32-34</sup> illustrate some of the changes in cognition and function seen with donepezil, galantamine, and rivastigmine. The effects of donepezil on cognition have also been studied in patients with early-stage AD. Significant improvement on the Alzheimer’s Disease Assessment Scale-Cognitive Subscale (ADAS-Cog) and the MMSE were seen as early as 6 weeks after initiating therapy, indicative of its potential in maintaining independence in higher functioning patients.<sup>14</sup>

Other important distinguishing differences between the CHEIs were pointed out by the panel. Only donepezil is dosed at a clinically effective level initially; galantamine and rivastigmine require dose titration. Donepezil and galantamine are dosed once daily, as is the rivastigmine patch, with other formulations of rivastigmine dosed twice daily. Although the side effects profiles of the CHEIs were similar, rivastigmine may have a higher incidence of gastrointestinal adverse effects. The panel recommended that CHEI therapy should be the first choice in patients with mild AD and suggested that clinicians consider factors such as titration and tolerability in making their treatment decisions.<sup>13</sup>

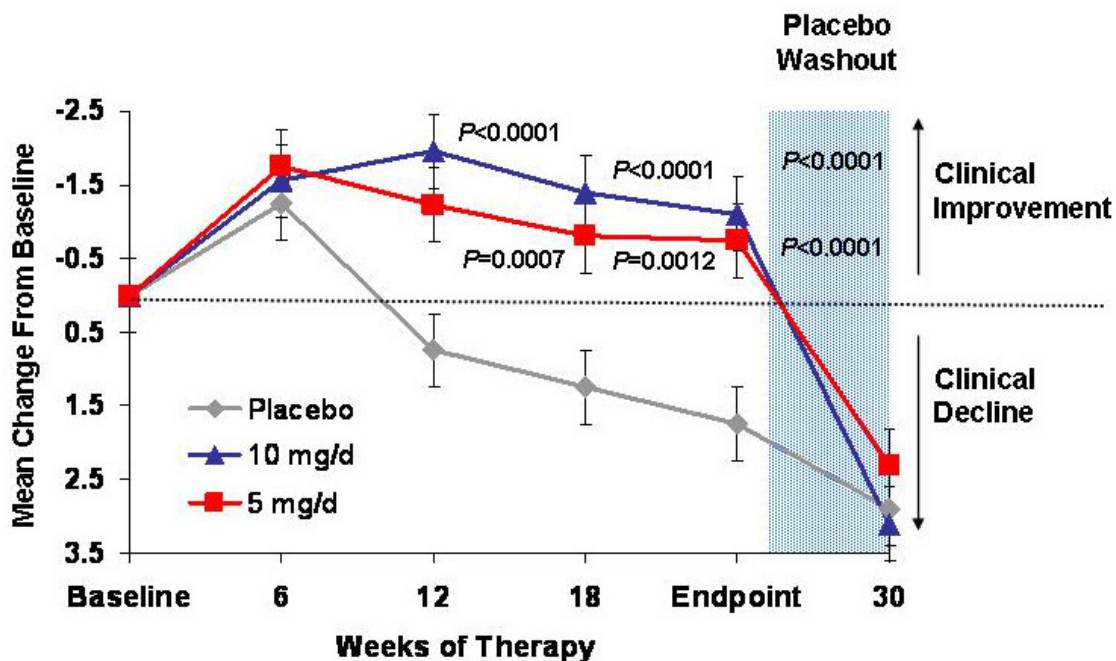


Figure 3. Effects of donepezil on cognition and activities of daily living (ADL)<sup>32</sup>  
a. Mean change in ADAS-Cog scores (ADAS-Cog=Alzheimer’s Disease Assessment Scale-Cognitive Subscale)

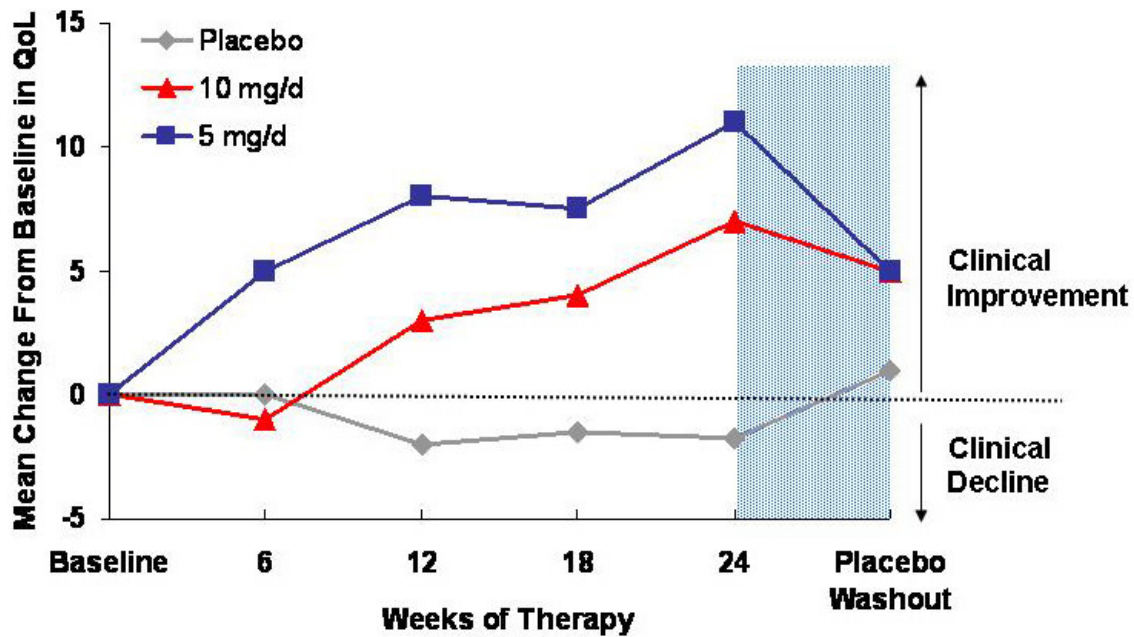


Figure 3. Effects of donepezil on cognition and activities of daily living (ADL)<sup>32</sup>  
 b. Mean change in quality of life (QoL) score

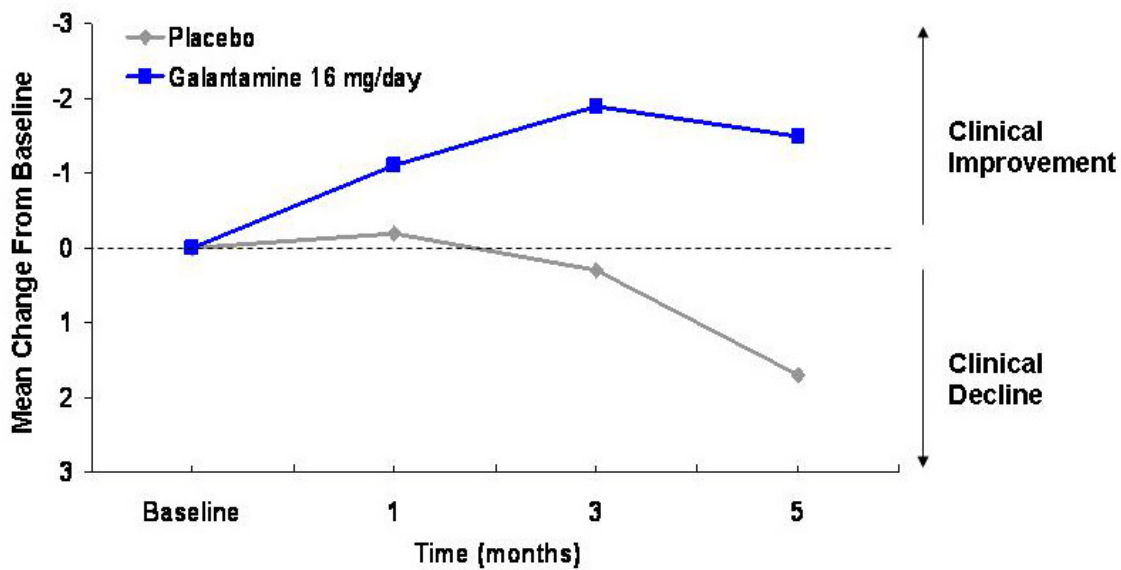


Figure 4. Effects of galantamine on cognition and behavior<sup>33</sup>  
 a. Mean change in ADAS-Cog (ADAS-Cog=Alzheimer's Disease Assessment Scale-Cognitive Subscale) scores

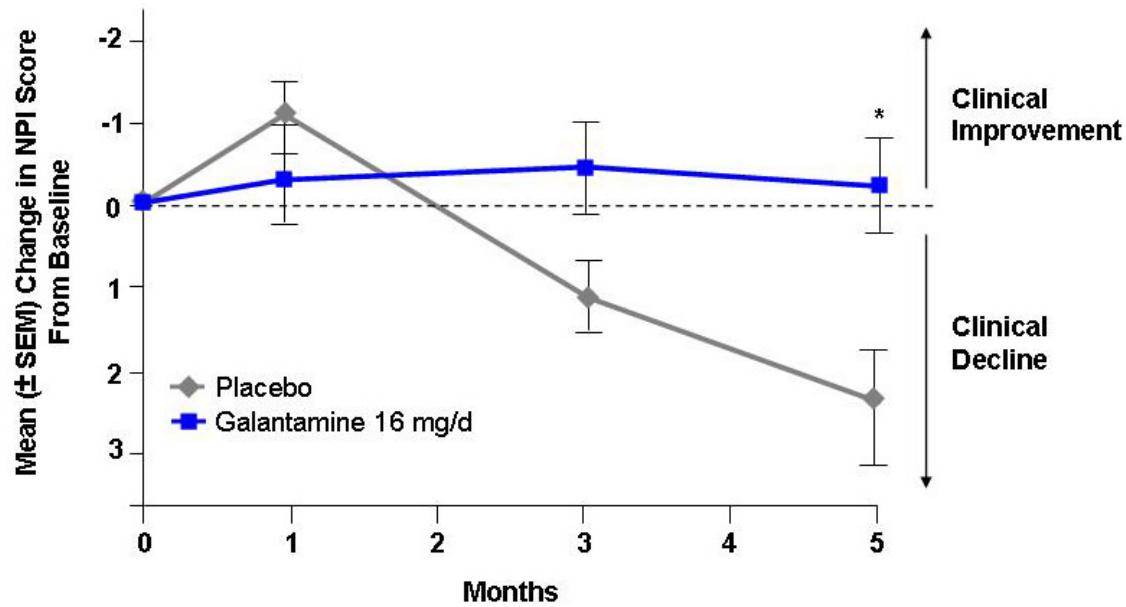


Figure 4. Effects of galantamine on cognition and behavior<sup>33</sup>

b. Effects of galantamine on behavioral outcomes

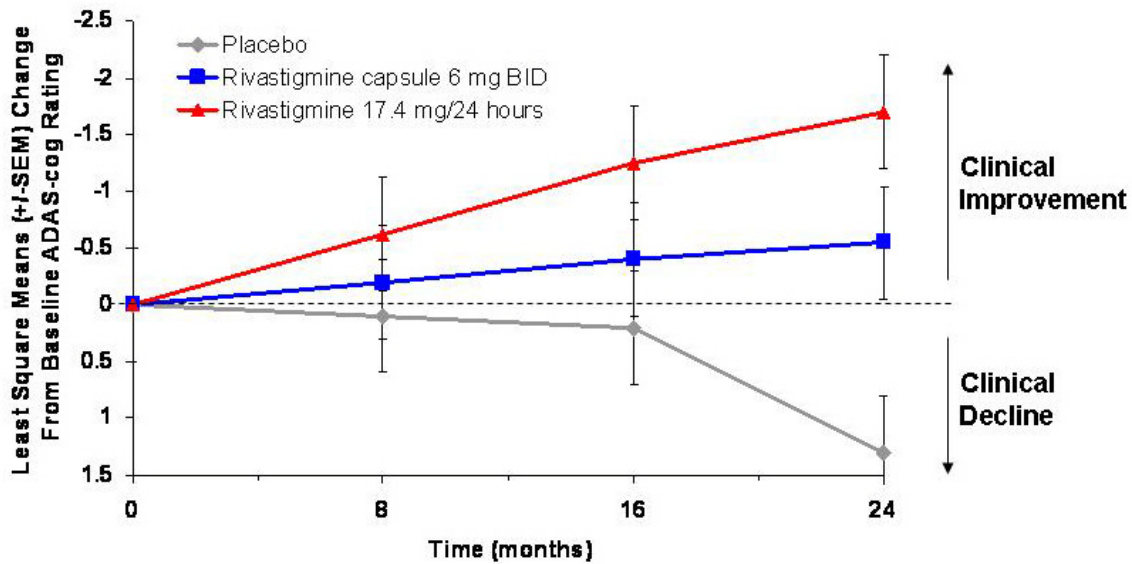


Figure 5. Effects of rivastigmine on cognition and activities of daily living (ADL)<sup>30</sup>

a. Mean change in ADAS-Cog scores (ADAS-Cog=Alzheimer's Disease Assessment Scale-Cognitive Subscale)

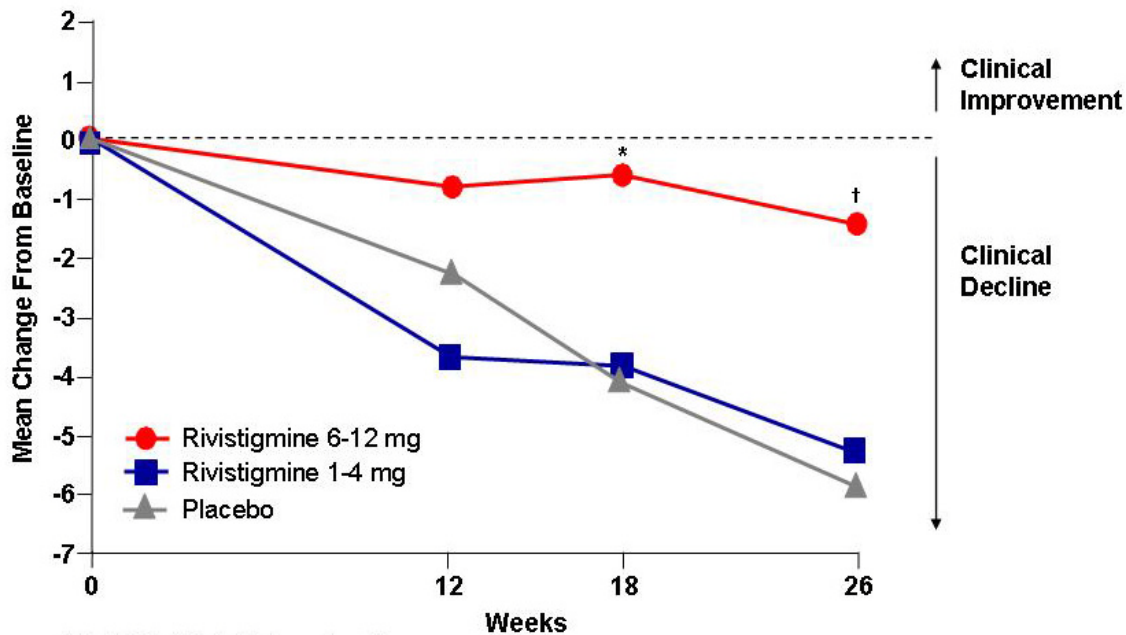


Figure 5. Effects of rivastigmine on cognition and activities of daily living (ADL)<sup>34</sup>

b. Mean change in Activities of Daily Living Progressive Deterioration Scale

### Memantine

The panel recommended that patients who are first diagnosed with severe AD be treated with memantine. In a 28-week, double-blind, randomized, controlled study of memantine versus placebo in 252 patients with moderate-to-severe AD,<sup>35</sup> outcomes significantly improved in the memantine arm on the Severe Impairment Battery and the Alzheimer’s Disease Cooperative Study Activities of Daily Living Inventory modified for severe dementia. However, there was no statistically significant improvement on the MMSE with memantine treatment compared to placebo (Figure 6).

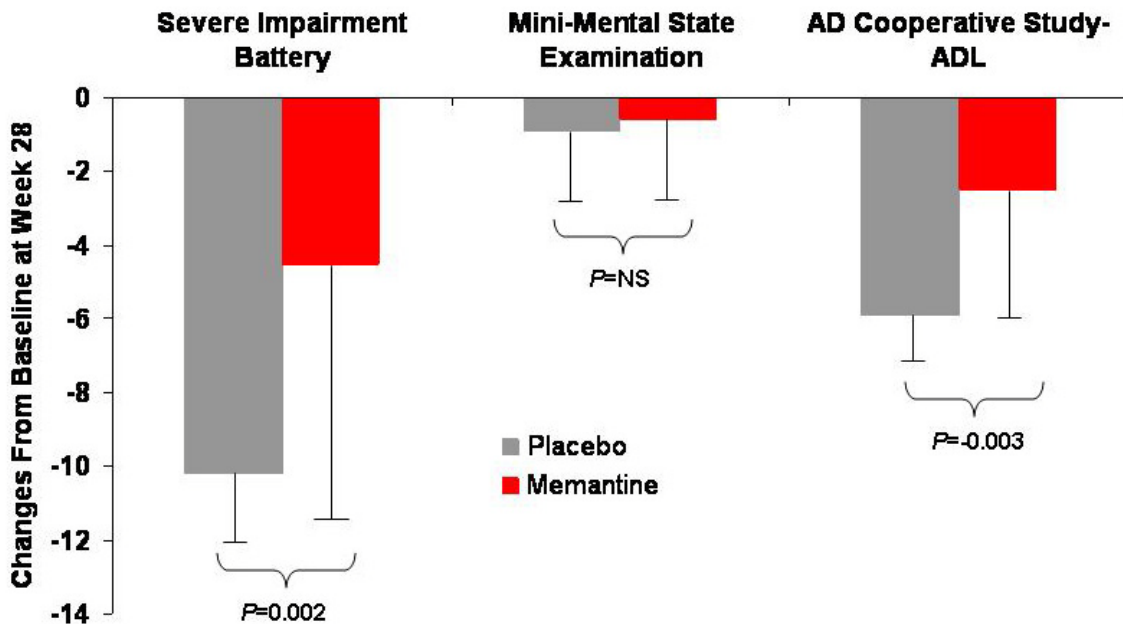


Figure 6. Effects of memantine in the treatment of moderate-to-severe Alzheimer’s disease<sup>35</sup>

The panel also recommended combination therapy with a CHEI in patients with moderate AD,<sup>13</sup> based on a 6-month trial comparing donepezil plus memantine versus donepezil plus placebo.<sup>36</sup> This randomized, double-blind, placebo-controlled, multicenter clinical trial enrolled 404 patients with moderate-to-severe AD who had been receiving stable doses of donepezil. Three hundred and twenty-two patients completed the trial, which evaluated changes on the Severe Impairment Battery (SIB), a test of cognition; a modified 19-item AD Cooperative Study-Activities of Daily Living Inventory (ADCS-ADL<sub>19</sub>); the Clinician's Interview-Based Impression of Change Plus Caregiver Input (CIBIC-Plus); the Neuropsychiatric Inventory; and the Behavioral Rating Scale for Geriatric Patients (BGP Care Dependency Subscale). There was significant improvement in all primary and secondary outcomes at Week 24 and at endpoint. Figure 7<sup>36</sup> shows improvements in cognition and ADL. In patients with mild AD, memantine was only recommended when a CHEI cannot be tolerated or in combination therapy when the disease is progressing rapidly.<sup>13</sup>

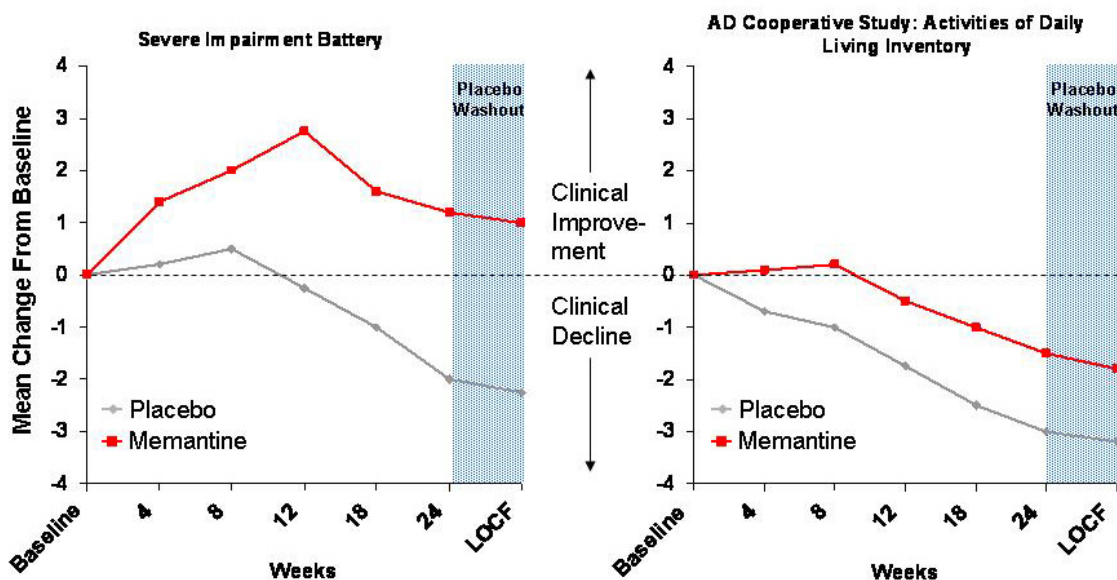


Figure 7. Effects of combination therapy with donepezil plus memantine on cognition and activities of daily living (ADL)<sup>36</sup>

## The Future

Approaches that are directed at a multitude of potential pathways for the treatment of AD are in development. These include anti-amyloid-based agents; changes to the structure of APOE  $\epsilon 4$ ; neuroprotective strategies; targeting the synapse, tangles, and other mechanisms of neuronal injury; and ideas for cognitive enhancement.<sup>37</sup>

## Caring for the Caregiver

Anyone who has ever assumed full responsibility for a loved one can attest to the strain that it puts on both the relationship and the caregiver. Caring for a person with AD is fraught with difficulty, primarily as a result of the behavioral and psychological symptoms of dementia that run the gamut from apathy to aggression. Of course, the physical tasks of helping someone with activities of daily living such as

bathing and dressing also can be daunting, particularly if the caregiver is of an advanced age. Seeing someone you have made a life with in a dependent state is difficult and caregivers may be at risk for depression or illness themselves.

Furthermore, caregivers often lack support and watch their world constrict until it revolves around the patient. To help a loved one, a person must make “me” time. The PCP can help to put the “I” into the caregiving process:

- **Inform the caregiver about AD and what to expect at each stage. Explain its treatment and the effects of treatment on cognition, behavior, and performance of ADLs. Demystification and realistic expectations can reduce the stress that accompanies the unexpected.**
- **Include the caregiver in all discussions and in developing the plan of care.**
- **Inquire about the caregiver’s physical and mental well being, and look for signs of depression or illness.**
- **Identify helpful handouts, coping strategies, and support services.**
- **Improve quality of life. Encourage caregivers to make lists, ask questions, and communicate their needs. Often, they may require your help in discovering their own needs.**

The resources available to caregivers have grown over the years. Books, pamphlets, and Web sites cover everything from positive thinking and managing stress to dealing with the day-to-day issues of AD care: wandering, communicating effectively, finding opportunities and places for respite care, safeguarding a home, long-distance caregiving, and making the transition to assisted living or nursing-home care. National and local organizations listed in the appendix can answer questions, provide opportunities for socialization, help with legal issues, and plan for a manageable future.

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# Appendix

## The ABCs of Caregiver Resources

### AARP

[www.aarp.org](http://www.aarp.org)

This non-profit group has tools, tips, and resources for a broad range of topics for people aged 50 years and older.

### Alzheimer's Association

800 272 3900

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

This group supports families and caregivers of patients with Alzheimer's disease. Its Web site gives news and tips, and has many brochures that can be downloaded. Almost 300 local chapters can help people find assistance, aid in completing forms, or give locations for support groups.

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

800 438 4380

[www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)

This government Web-site is funded by the National Institute on Aging. It provides news and updates on Alzheimer's diagnosis, treatment, care, caregiving and long-term care.

### Alzheimer's Foundation of America

866 232 8482

[www.alzfdn.org](http://www.alzfdn.org)

This agency provides care and services to individuals, caregivers, and families confronting dementia through member organizations.

### Alzheimer's Health Assistance Foundation (Click on Alzheimer's Disease Research)

800 437 2423

[www.ahaf.org](http://www.ahaf.org)

This agency provides information, news updates, resources, and research grants in Alzheimer's disease.

### Benefits Check Up

[www.benefitscheckup.org](http://www.benefitscheckup.org)

This is a service of the National Council on Aging and enables the caregiver to determine benefits that the patient and caregiver might qualify for that can help in paying for prescription drugs, utility bills, meals, and health care.

**Children of Aging Parents**

800 227 7294

[www.caps4caregivers.org](http://www.caps4caregivers.org)

This organization provides information and materials for adult children caring for older parents.

**Eldercare Locator**

[www.eldercare.gov](http://www.eldercare.gov)

This government resource helps older people and caregivers find local support services.

**Family Caregiver Alliance**

800 445 8106

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

This alliance offers caregiver support, including information about public policy and research, caregiver advice, fact sheets and publications.

**Family Caregiving 101**

[www.familycaregiving101.org](http://www.familycaregiving101.org)

Family Caregiving 101 helps with answers, new ideas, and advice for the caregiver.

**Medicaid**

[www.cms.hhs.gov/home/medicaid.asp](http://www.cms.hhs.gov/home/medicaid.asp)

This Web site provides information about a government program that pays for medical assistance for certain people with low incomes and resources.

**Medicare**

[www.medicare.gov](http://www.medicare.gov)

This Web site provides information about the federal health insurance program for people aged 65 years and older, and those with disabilities.

**National Family Caregivers Association**

800 896 3650

[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

This organization helps educate and support people who care for loved ones with chronic illness, disability, or the frailties of old age. It has an online library, workshops, and other resources.

**National Institute on Aging Information Center**

800 222 2225

[www.nia.nih.gov](http://www.nia.nih.gov)

This government Web-site offers a wide range of information on health, aging, and NIA-sponsored research.

**NIH Senior Health**

[www.nihseniorhealth.gov](http://www.nihseniorhealth.gov)

This Web site features health and wellness information for older adults on a variety of topics.

**National Resource Center on Supportive Housing and Home Modifications**

213 740 1364

[www.homemods.org](http://www.homemods.org)

This Web site promotes aging in place and independent living. It provides resources about home modifications.

**The National Academy of Elder Law Attorneys**

[www.naela.com](http://www.naela.com)

This Web site focuses on the legal needs of older people, providing educational resources. In addition, it can help the caregiver and elder law attorneys in their area.

**The Simon Foundation for Continence**

800 237 4666

[www.simonfoundation.org](http://www.simonfoundation.org)

This group helps people who have problems with incontinence, as well as their caregivers and healthcare providers. Books, pamphlets, tapes, self-help groups, and other resources are available.

**Well Spouse Association**

800 838 0879

[www.wellspouse.org](http://www.wellspouse.org)

Well Spouse is a membership group that supports the wives, husbands, and partners of the ill or disabled.