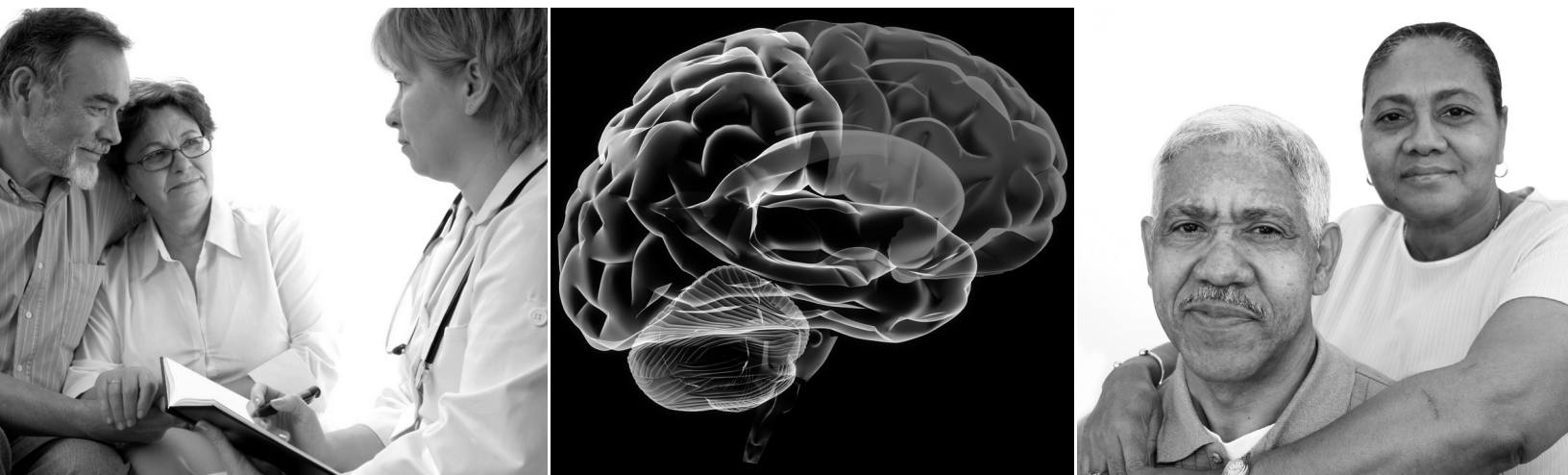


# Memory Matters

Screening Approaches to Increase Early Detection and Treatment of Alzheimer's Disease and Related Dementias, and Recommendations for National Policy



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Alzheimer's Foundation of America

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**The Alzheimer's Foundation of America (AFA)** is a 501(c)(3) national nonprofit organization headquartered in New York that focuses on providing optimal care to individuals with Alzheimer's disease and related illnesses, and their families. AFA is made up of more than 950 member organizations that offer hands-on programs and services to meet the educational, emotional, practical and social needs of families affected by Alzheimer's disease and related illnesses. AFA's services include a toll-free hot line, counseling, educational materials, a free caregiver magazine and professional training. One of its major focal points is early detection of Alzheimer's disease and related dementias, and appropriate intervention for those with the disease and their families; the highlight of these efforts is AFA's annual National Memory Screening Day. Eric J. Hall is AFA's president and founding CEO and oversees all policies related to screening advocacy and National Memory Screening Day. For more information, call (toll-free) 866-AFA-8484 or visit [www.alzfdn.org](http://www.alzfdn.org).

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Many of the statements and themes in this report were developed by the AFA Memory Screening Advisory Board. The AFA Memory Screening Advisory Board is composed of academicians and health care specialists who are leaders in the fields of memory assessment, dementia screening and Alzheimer's disease; have published numerous influential articles in the field; and have particular expertise in the subject of screening tests and their development. The board's mission is to provide consultation and recommendations to AFA for the management of projects related to helping to identify and treat individuals with memory problems, Alzheimer's disease or other dementias, including AFA's annual National Memory Screening Day. AFA thanks the members of the advisory board for their contributions:

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## EXECUTIVE SUMMARY

Most persons with dementia remain undiagnosed by their primary care providers, and families often fail to recognize the significance of early cognitive symptoms. In response, there has been a growing interest in screenings for memory problems. The proposed answer is that screening for memory dysfunction, Alzheimer's disease and other dementias is important, but raises pragmatic, ethical as well as theoretical considerations that need to be addressed before general screening practices can be widely implemented. Screenings are occurring throughout the nation by local, independent organizations, often with minimal guidance or technical assistance like that provided by national organizations such as the Alzheimer's Foundation of America (AFA) to groups participating in its screening initiative. To refine the screening process in general, the screening of at-risk populations for dementia should become a cornerstone for early treatment or prevention of cognitive decline. Prospective prevention research will not be performed in a timely manner to confirm the value of screening so policymakers must propose the best possible option as a comprehensive approach to cognitive health. Multiple types of screening interventions have been described in the medical literature, including person-to-person, telephone and computer-based. Screening is not a diagnosis, but can help lead to the referral of appropriate individuals for further evaluation or to the promotion of cognitive wellness. Screening should not produce adverse outcomes and published screening instruments can be completed in as little as five minutes. Screening is a safe, cost-efficient intervention that can reassure the healthy individual, promotes successful aging and, when indicated, directs individuals to appropriate clinical resources. Currently, there is no national strategy on dementia screening in particular and dementia in general, a public health problem related to an at-risk population on the threshold of a boom. It is irresponsible to leave the disease undetected to the extent it is now when there are safe tools available to increase earlier detection. There are several policy recommendations that, if implemented, would assist clinical efforts at early diagnosis and treatment for dementia, and promotion of cognitive wellness.

## WHY SCREEN FOR MEMORY PROBLEMS?

One of the main arguments in favor of memory screening is that there are serious deficiencies in the healthcare system's ability to recognize dementia. A 2006 editorial in the Journal of the American Geriatric Society estimated that missed diagnoses are greater than 25 percent of the dementia cases and may be as high as 90 percent.<sup>1</sup> Not surprisingly, individuals with mild dementia are more likely to go unrecognized by physicians than persons with moderate to severe dementia<sup>2</sup>; however, most researchers agree that most available medications are best given earlier in the disease when the individual has mild symptoms.<sup>3-4</sup> In addition, while close friends and family can play an important role in detection of dementia, many elderly live alone and have limited contact with distant relatives or friends.

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<sup>1</sup> Freund B. Office-based evaluation of the older driver. J Am Geriatr Soc. 2006 Dec;54(12):1943-4.

<sup>2</sup> Borson S, Scanlan JM, Watanabe J, Tu Sp, Lessig M. Improving identification of cognitive impairment in primary care. Int. J Geriatr Psychiatry. 2006 Apr;21(4):349-55.

<sup>3</sup> Hogan DB, Bailey P, Black S, et al. Diagnosis and treatment of dementia: 4. Approach to management of mild to moderate dementia. CMAJ 2008 Oct 7;179(8):787-93.

<sup>4</sup> Doody RS, Stevens JC, Beck C, et al. Practice parameter: management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology. 2001 May 8;56(9):1154-66.

There are additional barriers<sup>5</sup> to early detection<sup>6</sup> of dementia:

- Individuals are often unaware, deny or minimize the severity of symptoms, or are concerned about stigma.
- Access to quality care is a key issue for all individuals with dementia and for those of minority racial and ethnic backgrounds in particular.
- Clinician evaluation may be time consuming and not well reimbursed.
- Many, especially minority populations, believe that memory loss and cognitive decline are a normal part of aging.

For racial and ethnic minorities, the barriers to early detection are often magnified. One survey found that African-American and Hispanic caregivers of people with Alzheimer's disease are significantly more likely than caregivers of other races to consider the disease a normal part of the aging process and dismiss its symptoms as part of getting older.<sup>7</sup> According to the survey, African-American and Hispanic caregivers were significantly more likely (37 percent versus 33 percent) than caregivers of other races (23 percent) to believe that Alzheimer's disease is a normal part of the aging process. About one-third (33 percent) of overall respondents reported that their loved one's concern about stigma delayed diagnosis, while about a quarter (26 percent) indicated that their own concern about stigma was a reason for the delay. African-American caregivers were significantly more concerned about stigma (36 percent) than Hispanic (22 percent) and other race (18 percent) caregivers. Other reasons for the delay in diagnosis included not wanting to face the possibility of something being wrong, fear of the responsibility of caregiving, not being offered a memory screening and resistance to visiting a doctor.

Memory screening has been considered a low priority issue by health policy planners for several reasons. The lack of curative therapy coupled with the high level of stigma associated with the disease diminished the medical communities' interest in screening.<sup>8-9</sup> Several past consensus panels of experts have recommended screening individuals with risk factors or symptoms for dementia; however, none have explained how those individuals will self-identify and self-refer.<sup>10-11</sup> The U.S. Preventive Services Task Force (USPSTF), a federally funded independent panel of experts, has not endorsed or rejected screening of asymptomatic individuals. The lack of research about the efficacy of generalized screening was the major obstacle to promoting this intervention.<sup>12-13</sup> A similar predicament caused the USPSTF to not recommend screening for domestic or family violence.<sup>14</sup>

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<sup>5</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

<sup>6</sup> Knopman D, Donohue JA, Guterman EM. Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *J Am Geriatr Soc*. 2000 Mar;48(3):300-4.

<sup>7</sup> ICAN2: Investigating Caregivers' Attitudes and Needs. Harris Interactive for the Alzheimer's Foundation of America. February 9, 2007, [www.alzfdn.org](http://www.alzfdn.org).

<sup>8</sup> Brodaty H, Clarke J, Ganguli M, Grek A, et al. Screening for cognitive impairment in general practice: toward a consensus. *Alzheimer Dis Assoc Disord*. 1998 Mar;12(1):1-13.

<sup>9</sup> Knopman DS, DeKosky ST, Cummings JL, et al. Practice parameter: diagnosis of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2001 May 8;56(9):1143-53.

<sup>10</sup> Berg AO, Allan JD, Frame P, et al. Screening for dementia: Recommendation and rationale. *Ann Intern Med*. 2003 Jun 3;138(11):925-6.

<sup>11</sup> Burns A, Lawlor B, Craig S. *Assessment scales in old age psychiatry*. London: Martin Dunitz Ltd, 1999.

<sup>12</sup> Boustani M, Peterson B, Harris R, et al. Screening for dementia. Systematic Evidence Review. Number 20. Prepared for Agency for Healthcare Research and Quality. U.S. Department of Health and Human Services. Submitted by RTI International. June 2003.

In addition, the definition of effective treatment for dementia has been controversial. Many researchers have embraced the silver bullet concept for Alzheimer's disease where a specific pathology is identified and specific definitive treatment initiated. After three decades of intense research, with more than 47,000 cited publications in the National Institutes of Health PubMed listings, the silver bullet has not yet been found.<sup>15-16</sup>

## WHAT IS DEMENTIA?

Dementia is a general term that describes a group of symptoms—such as loss of memory, judgment, language, complex motor skills and other intellectual function—caused by the permanent damage or death of the brain's nerve cells, or neurons, over a prolonged period. One or more of several diseases, including Alzheimer's disease, can cause dementia. Alzheimer's disease is the most common cause of dementia, representing about 60 percent of all dementias identified at clinical assessment. According to the National Institute on Aging, recent estimates of how many people in the United States currently have Alzheimer's disease differ, with numbers ranging from 2.4 million to 4.5 million, depending on how Alzheimer's disease is measured.<sup>17</sup>

The other most common causes of dementia are vascular dementia, caused by stroke or blockage of blood supply, and dementia with Lewy bodies. Other types include alcoholic dementia, caused by sustained use of alcohol; post concussive dementia, caused by head injury; frontotemporal dementia; Lewy Body dementia; and many other uncommon diseases.

The incidence of dementia doubles approximately every five years in individuals between the ages of 65 and 95 and by some estimates may reach nearly 50 percent by age 85.<sup>18</sup> Alzheimer's disease is the most common cause of dementia among people aged 65 and older. Alzheimer's disease is not a normal part of aging; however, age is the greatest known risk factor. And with the older population on the threshold of a boom, dementia is an especially significant issue.<sup>19</sup> A 2005 U.S. Census Bureau report on aging in the United States notes that the population age 65 and older in 2030 is expected to be twice as large as in 2000, growing from 35 million to 72 million and representing nearly 20 percent of the United States population at the latter date.<sup>20</sup> According to the latest government statistics, Alzheimer's disease is now the sixth leading cause of death in the United States, rising one notch from seventh place in 2005, while the number of deaths from other chronic conditions, including diabetes, declined in 2006.

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<sup>13</sup> Boustani M, Peterson B, Handon L, et al. Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med.* 2003 Jun 3;138(11):927-37.

<sup>14</sup> U.S. Preventive Services Task Force. Screening for family and intimate partner violence: recommendation statement. *Ann Fam Med.* 2004 Mar-Apr;2(2): 156-60.

<sup>15</sup> DeKosky ST, Marek K. Looking backward to move forward: early detection of neurodegenerative disorders. *Science* 2003 Oct 31;302(5646):830-4.

<sup>16</sup> Cumming JL. Alzheimer's disease. *N Engl J Med.* 2004 Jul 1;351(1):56-67.

<sup>17</sup> Rodgers AB. Alzheimer's disease: unraveling the mystery. National Institute on Aging. National Institutes of Health. U.S. Department of Health and Human Services. NIH Publication Number: 08-3782. September 2008.

<sup>18</sup> Evans DA, Funkenstein HH, Albert MS, et al. Prevalence of Alzheimer's disease in a community population of older persons. Higher than previously reported. *JAMA* 1989 Nov 10;262(18):2551-6.

<sup>19</sup> Rodgers AB. Alzheimer's disease: unraveling the mystery. National Institute on Aging. National Institutes of Health. U.S. Department of Health and Human Services. NIH Publication Number: 08-3782. September 2008.

<sup>20</sup> Wan H, Sengupta M, Velkoff VA, DeBarros KA. 65+ in the United States. 2005 U.S. Census Bureau, Current Population Reports. P23-209. U.S. Government Printing Office. Washington, DC, 2005.

The clinical symptoms and the progression of dementia vary, depending on the type of disease causing it, and the location and number of damaged brain cells. Some types progress slowly over years, while others may result in the sudden loss of intellectual function. The uncertainty of the point of onset of dementia is one of the basic reasons that a screening system is needed; with a variable course, early dementia can be difficult for primary care providers to detect. There are now many widely accepted management interventions that are not properly applied because the presence of the disease is missed. Because of the difficulty in recognizing dementia, along with the perceived value of recognition, many scientists and clinicians have sought to develop screening tests for this problem.<sup>21</sup>

Experienced clinicians can accurately diagnose the probable cause of dementia 90 percent of the time.<sup>22</sup> Accurate diagnosis is critical. However, definitive diagnosis requires a post mortem examination of the brain. Based on post mortem examination, mixed dementia (most often a combination of Alzheimer's disease and vascular dementia) may be the most common brain disorder.<sup>23</sup>

### **ALZHEIMER'S DISEASE**

Alzheimer's disease is a progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes. These neurons, which produce the brain chemical, or neurotransmitter, acetylcholine, break connections with other nerve cells and ultimately die. For example, short-term memory fails when Alzheimer's disease first destroys nerve cells in the hippocampus, and language skills and judgment decline when neurons die in the cerebral cortex.

Two types of abnormal lesions clog the brains of individuals with Alzheimer's disease: beta-amyloid plaques—sticky clumps of protein fragments and cellular material that form outside and around neurons; and neurofibrillary tangles—insoluble twisted fibers composed largely of the protein tau that build up inside nerve cells. Although these structures are hallmarks of the disease, scientists are unclear whether they cause it or a byproduct of it.

Origin of the term Alzheimer's disease dates back to 1906 when Dr. Alois Alzheimer, a German physician, presented a case history before a medical meeting of a 51-year-old woman who suffered from a rare brain disorder. A brain autopsy identified the plaques and tangles that today characterize Alzheimer's disease.

Clinicians can now diagnose "probable" Alzheimer's disease with up to 90 percent accuracy. But it can only be confirmed by an autopsy, during which pathologists look for the disease's characteristic plaques and tangles in brain tissue. Clinicians diagnose "probable" Alzheimer's disease by taking a complete medical history and conducting lab tests, a physical exam, brain scans and neuropsychological tests that gauge memory, attention, language skills and problem-solving abilities. Proper diagnosis of Alzheimer's disease is critical since there are dozens of other causes of dementia that could exhibit the same symptoms.

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<sup>21</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? It is important to screen for evidence of dementia! *Alzheimer's & Dementia*. 2007;3:75-80.

<sup>22</sup> Ranginwala NA, Hynan LS, Weiner MF, White CL 3rd. Clinical criteria for the diagnosis of Alzheimer disease: still good after all these years. *Am J Geriatr Psychiatry*. 2008 May;16(5):384-8.

<sup>23</sup> Schneider JA, Arvanitakis Z, Bang W, Bennett DA. Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology* 2007 Dec 11;69(24):2197-204.

Some conditions that cause symptoms of dementia, such as hormone imbalance, vitamin deficiency and infections, can be reversed. For irreversible dementias, including Alzheimer's disease, treatment options vary depending on the disease. Obtaining a proper diagnosis involves consulting with a healthcare professional expert in dementia, communicating symptoms and undergoing extensive testing. Diagnostic tools include a complete medical history; blood, urine or other medical tests; neuropsychological tests that measure memory, problem solving, attention and language; and brain scans.

Individuals with clinically diagnosed dementia have clear cognitive loss in two or more intellectual domains, such as amnesia (loss of memory) and aphasia (inability to communicate effectively), but almost all individuals with Alzheimer's disease demonstrate short-term memory impairment.

#### **MILD COGNITIVE IMPAIRMENT**

Recently, there have been increasing discussions about what follows normal function but precedes dementia, a concept now widely referred to as mild cognitive impairment, or MCI. While not formally defined for clinicians, MCI is characterized as an early clinical stage of diseases that leads to dementia.

Although MCI is of considerable academic and research interest, the core issue in primary care is early detection of Alzheimer's disease and related disorders, because the benefits are considered to be substantial. From a purely pragmatic perspective, primary care providers are not likely to have the time to know when an individual crosses the line from having MCI to having mild dementia, so the provider's focus should simply be on detecting early dementia.

A variety of biomarkers are proposed for diagnosing pre-symptomatic or early stage dementia, including genetic markers, brain imaging, cerebral spinal fluid (CSF) and molecular pathology. Each type of dementia is characterized by different pathologic, or structural, changes in the brain.<sup>24</sup> However, the presence of a biomarker does not necessarily confirm dementia or the extent of one or more dementia-related brain illnesses.<sup>25</sup> For example, while amyloid deposition is common in the brains of individuals with dementia, some cognitively intact elders may have substantial deposits of this potentially toxic substance within their brains at death. Neurofibrillary tangles, filamentous collections within individual brain cells, are better related to cognitive impairment, but some individuals with dementia have limited numbers of these tangles within their brains and normal older individuals may have modest numbers of them. Synuclein-related pathology, a molecular change that is intrinsic to Lewy body dementia, is difficult to quantify, and this molecule is present in some brains of normal elders. Vascular brain pathology is poorly quantified with available techniques; however, vascular pathology, such as silent strokes or white matter damage, is extremely common in the brains of older subjects.

Again, it is important to note that many individuals have more than one disease in their brain at time of death. This complicates the creation of a single, specific, sensitive test using blood, spinal fluid or brain imaging to predict the risk for dementia. Future testing will be expensive, and clinicians will be more likely to employ molecular, genetic or radiological screening on at-risk individuals or those showing some evidence of cognitive decline. CSF values for Tau and amyloid may help with

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<sup>24</sup> DeKosky ST, Marek K. Looking backward to move forward: early detection of neurodegenerative disorders. *Science* 2003 Oct 31;302(5646):830-4.

<sup>25</sup> Sonnen JA, Montine KS, Quinn JF, et al. Biomarkers for cognitive impairment and dementia in elderly people. *Lancet Neurol.* 2008 Aug;7(8):704-14

distinguishing different types of dementia. Each intervention may produce valuable information, but these expensive procedures will not serve as a first step in the diagnostic cascade for dementia.

Cognitive screening is a simple, direct, cost-effective way to identify individuals at risk for dementia. Although some available brain imaging methodology may identify at-risk individuals, detailed neuropsychological evaluation remains the diagnostic “gold standard.”<sup>26–27–28</sup>

## WHAT IS MEMORY SCREENING AND IS IT EFFECTIVE?

A memory screening is a simple and safe evaluation tool that assesses memory and other intellectual functions and indicates whether additional testing is necessary. Memory screening can be done in a medical environment (e.g. dementia clinic, physician’s office) or in a community setting (e.g. senior center, pharmacy).

The main arguments against memory screening are the unsubstantiated assertions that there are many potential adverse consequences.<sup>29</sup> However, **screening is neither a diagnostic or case finding process.** Screening tests in general simply help determine whether diagnostic tests should be considered. A “positive” result from a memory screening should never be interpreted as a diagnosis of Alzheimer’s disease or a related illness or other illnesses—no more than a “positive” mammogram means an individual has breast cancer.

Screening for memory problems in general and dementia in particular has been conducted for years by local organizations throughout the United States. A general four-step methodology is apparent: 1) marketing and identification of a target group, 2) screening instrument selection and use, 3) follow-up advice for screened persons, and 4) quality assurance for the screening process. Screenings are advertised and participants are enrolled based on the organization’s goals. Multiple screening instruments are available to assess for cognitive decline.<sup>30–31</sup> The length of the screening test ranges from less than five minutes for the Brief Alzheimer’s Screen (BAS) to approximately 15 minutes for the Mini-Mental Status Examination (MMSE).<sup>32–33</sup> A broad range of statistically validated instruments, such as the GPCOG, Mini-Cog and MIS (the tools suggested by the AFA Memory Screening Advisory Board for use during National Memory Screening Day), are available with acceptable levels of sensitivity (probability of true positives) and specificity (probability of true negatives) as well as interrater or rate-rerate reliability.<sup>34–35</sup>

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<sup>26</sup> Den Heijer T, Geerlings MI, Hoebeek FE, et al., “Use of hippocampal and amygdalar volumes on magnetic resonance imaging to predict dementia in cognitively intact elderly people. *Arch Gen Psychiatry*. 2006 Jan;63(1):57-62.

<sup>27</sup> Fleisher AS, Houston WS, Eyler LT, et al. Identification of Alzheimer disease risk by functional magnetic resonance imaging. *Arch Neurol*. 2005 Dec;62(12):1881-8.

<sup>28</sup> van der Flier WM, Scheltens P. Use of laboratory and imaging investigations in dementia. *J Neurol Neurosurg Psychiatry*. 2005 Dec;76 Suppl 5:v45-52.

<sup>29</sup> Ashford JW, Borson S, O’Hara R, et al. Should older adults be screened for dementia? It is important to screen for evidence of dementia! *Alzheimer’s & Dementia*. 2007;3:75-80.

<sup>30</sup> Burns A, Lawlor B, Craig S. *Assessment scales in old age psychiatry*. London: Martin Dunitz Ltd, 1999.

<sup>31</sup> Ashford JW. Screening for Memory Disorder, Dementia, and Alzheimer’s disease. *Aging Health*. 2008 4(4):399-432.

<sup>32</sup> Mendiondo MS, Ashford JW, Kryscio RJ, Schmitt FA. Designing a Brief Alzheimer Screen (BAS). *J Alzheimers Dis*. 2003 Oct;5(5):391-8.

<sup>33</sup> Folstein MF, Folstein SE, McHugh PR. “Mini-mental state.” A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975 Nov;12(3):189-98.

<sup>34</sup> Brodaty H, Clarke J, Ganguli M, Grek A, et al. Screening for cognitive impairment in general practice: toward a consensus. *Alzheimer Disease and Associated Disorders* 1998;12(1):1-13.



Age is the biggest risk factor for Alzheimer's disease. Based on the fact that the incidence of dementia doubles every five years between 65 and 95, some experts recommend that annual memory screening is beneficial for everyone 75 and older, and for people 65 and older with a family history or other risk factors.<sup>36</sup> Other important risk factors are genotype and concurrent medical conditions.

Several distinct methodologies include face-to-face screening, telephone-based screening and computer-based screening of at-risk persons. Many dementia screening tests have been developed and studied in numerous populations, using both prospective and retrospective analyses, and have been recommended for consideration.<sup>37-38-39-40-41-42-43</sup>

Again, none of these screening methodologies produce a diagnosis of dementia, but rather indicate whether persons who exceed normal limits should be referred for further evaluation. Individuals who fall into the MCI group can undergo re-screening at regular intervals or proceed for further medical evaluation if not followed by their clinicians.<sup>44-45-46</sup> Most methods should incorporate face-to-face counseling and family support for individuals with positive results.<sup>47-48</sup>

Several screens have adequate sensitivity and specificity to serve as routine, cost-worthy evaluations. In fact, validated memory screening instruments demonstrate 80 percent to 90 percent or higher sensitivity and specificity in reviewed studies<sup>49</sup>—similar to other established screening tests such as a mammography<sup>50</sup> and Pap smear.<sup>51</sup>

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<sup>35</sup> Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London: Martin Dunitz Ltd, 1999.

<sup>36</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? It is important to screen for evidence of dementia! *Alzheimer's & Dementia*. 2007;3:75-80.

<sup>37</sup> Borson S, Scanlan JM, Watanabe J, et al. Simplifying detection of cognitive impairment: comparison of the Mini-Cog and Mini-Mental State Examination in a multiethnic sample. *J Am Geriatr Soc*. 2005 May;53(5):871-4.

<sup>38</sup> Brodaty H, Pond D, Kemp NM, Luscombe G, et al. The GPCOG: a new screening test for dementia designed for general practice. *J Am Geriatr Soc*. 2002 Mar;50(3):530-4.

<sup>39</sup> Buschke H, Kuslansky G, Katz M, et al. Screening for dementia with the memory impairment screen. *Neurology*. 1999 Jan 15;52(2):231-8.

<sup>40</sup> Mendiondo MS, Ashford JW, Kryscio RJ, Schmitt FA. Designing a Brief Alzheimer Screen (BAS). *J Alzheimers Dis*. 2003 Oct;5(5):391-8.

<sup>41</sup> Shankle WR, Romney AK, Hara J, et al. Methods to improve the detection of mild cognitive impairment. *Proc Natl Acad Sci U S A*. 2005 Mar 29;102(13):4919-24.

<sup>42</sup> Ashford JW. Screening for Memory Disorder, Dementia, and Alzheimer's disease. *Aging Health*. 2008 4(4):399-432.

<sup>43</sup> Milne A, Culverwell A, Guss R, et al. Screening for dementia in primary care: a review of the use, efficacy and quality of measures. *Int Psychogeriatr*. 2008 Oct;20(5):911-26.

<sup>44</sup> Hogan DB, McKeith IG. Of MCI and dementia: improving diagnosis and treatment. *Neurology*. 2001 May 8;56(9):1131-2.

<sup>45</sup> Dubois B, Albert ML. Amnesic MCI or prodromal Alzheimer's disease? *Lancet Neurol*. 2004;3:246-48.

<sup>46</sup> Kalbe E, Kessler J, Calabrese P, et al. DemTect: a new, sensitive cognitive screening test to support the diagnosis of mild cognitive impairment and early dementia. *Int J Geriatr Psychiatry* 2004 Feb;19(2):136-43.

<sup>47</sup> Bosie L, Camicioli R, Morgan DL, et al. Diagnosing dementia: perspectives of primary care physicians. *Gerontologist* 1999 Aug;39(4):457-64.

<sup>48</sup> Brodaty H, Clarke J, Ganguli M, Grek A, et al. Screening for cognitive impairment in general practice: toward a consensus. *Alzheimer Disease and Associated Disorders* 1998;12(1):1-13.

<sup>49</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

<sup>50</sup> National Cancer Institute. Breast Cancer Screening Modalities.

<http://www.nci.nih.gov/cancertopics/pdq/screening/breast/HealthProfessional/page5>.

<sup>51</sup> Kulasingam SL, Hughes JP, Kiviat NB, et al. Evaluation of human papillomavirus testing in primary screening for cervical abnormalities: comparison of sensitivity, specificity and frequency of referral. *JAMA*. 2002 Oct 9;288(14):1749-57.

Screening tests may be short cognitive tools administered to individuals, high-sensitivity questions asked of individuals themselves, questions asked of family members or some combination of all of these approaches.<sup>52</sup> Several comparative reviews on the application of screening tests for Alzheimer's disease and other dementias are available.<sup>53-54</sup> The qualifications of the healthcare professional depend upon the screening instrument used, but professionals such as social workers and registered nurses, and sometimes trained office staff, can perform most brief screening tests.<sup>55</sup> When individuals make such screening results available to their primary care providers, the providers have the opportunity to discuss the findings with them during an office visit.

Rather than a standardized screening, some propose more "cognitive surveillance" by individuals and primary care providers, and public awareness programs based on "warning signs" of Alzheimer's disease. Such "warning signs" have not been validated and are not promoted as screening instruments; however, concern has been raised that individuals experiencing cognitive deficits and their families may treat warning sign lists as a screening tool.<sup>56</sup> Although warning signs are publicized by several national organizations, including AFA, they are not a substitute for a structured screening or consultation with a primary care provider.

#### **THE ALZHEIMER'S FOUNDATION OF AMERICA'S NATIONAL MEMORY SCREENING DAY**

Memory screenings are one of the major focal points of the Alzheimer's Foundation of America's (AFA) national initiatives. Since 2003, AFA has sponsored National Memory Screening Day (NMSD) annually in collaboration with community organizations to promote early detection of memory problems as well as Alzheimer's disease and related illnesses, and encourage appropriate intervention. It has been held each November to coincide with National Alzheimer's Disease Awareness Month. On November 18, 2008, qualified healthcare professionals at nearly 2,200 sites nationwide offered free confidential memory screenings to an estimated 50,000 participants, as well as follow-up resources and educational materials about dementia and successful aging. In 2009, AFA will hold National Memory Screening Day on November 17.

Qualified healthcare professionals—including social workers, pharmacists, physician assistants, nurse practitioners and doctors—provide the screenings. The face-to-face screening takes place in a private setting in such venues as Alzheimer's agencies, senior centers, long-term care facilities, doctors' offices and pharmacies; only the individual being tested and the healthcare professional are present. The screening usually takes five to ten minutes on average and consists of a series of questions and/or tasks designed to test memory, language skills, thinking ability and other intellectual functions. Screening tools include the GPCOG, Mini-Cog and MIS.

A memory screening is not used to diagnose any particular illness and does not replace consultation with a qualified physician or other healthcare professional. The person who administers the screening reviews the results with the person screened, and suggests that those with abnormal scores and those with normal scores but who still have concerns follow up with a physician or other healthcare professional for more extensive testing. The person who was screened receives the screening results to bring to his or her healthcare professional. Screening sites also provide information about successful aging, including the benefits of proper diet, physical exercise, mental stimulation, socialization and stress management.

<sup>52</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? *Alzheimer's & Dementia*. 2006;2:76-85.

<sup>53</sup> Shulman KI, Herrmann N, Brodaty H, et al. IPA survey of brief cognitive screening instruments. *Int Psychogeriatr*. 2006 Jun;18(2):281-94.

<sup>54</sup> Lorentz WJ, Scanlan JM, Borson S. Brief screening tests for dementia. *Can J Psychiatry*. 2002 Oct;47(8):723-33.

<sup>55</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

<sup>56</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

It is widely recognized that physicians do not suspect dementia often enough, missing at least half the cases of mild and moderate dementia.<sup>57</sup> The likelihood of recognition of dementia by physicians is poor until it is at least moderately advanced. There is ample evidence that screening can improve case identification,<sup>58–59</sup> leading to the suggestion that community screening could double the number of individuals eventually diagnosed with dementia.<sup>60–61–62</sup> The implementation of screening programs in the community healthcare system can rectify this failure of current diagnostic practices.

## WHAT IF THE SCREEN IS POSITIVE?

As was previously stated, dementia is not diagnosed by a simple screening intervention. Persons who screen positive or who still have concerns after being tested at local screening sites during National Memory Screening Day are referred to their primary care providers for follow-up, and are encouraged to bring with them the results of the testing. Approximately 16 percent of individuals scored positive during National Memory Screening Day in 2007.<sup>63</sup> Based on studies of other community-based screenings, up to 60 percent of individuals with positive screens seek follow-up care.<sup>64</sup> The percentage of expected positive screens depends upon the age and other demographics of the screening population, the screening location and multiple other variables.

Another argument against screening is that a positive screening result requires clinicians to initiate an expensive diagnostic process. Researchers who have looked at the question of whether to screen for dementia<sup>65</sup> have commented on the issue of positive screens:

A brief screen frequently provides useful information about a patient's cognitive state to a clinician. Further screening does not obligate clinicians to undertake a lengthy, expensive workup—it merely obligates them to take appropriate steps to determine whether a positive screen is likely to be true or false. The second step after an initial screen can be as simple as an expanded clinical history and a few questions asked of family members.<sup>66–67</sup> Once a

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<sup>57</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? *Alzheimer's & Dementia*. 2006;2:76-85.

<sup>58</sup> Borson S, Scanlan JM, Watanabe J, et al. Improving identification of cognitive impairment in primary care. *Int J Geriatr Psychiatry*. 2006 Apr;21(4):349-55.

<sup>59</sup> Boustani M, Callahan CM, Unverzagt FW, et al. Implementing a screening and diagnosis program for dementia in primary care. *J Gen Intern Med*. 2005 Jul;20(7):572-7.

<sup>60</sup> DeKosky ST, McConnell SS, Branche C, et al. Guidelines for the development of community-based screening programs for cognitive impairment in older people. *Alzheimer Insights*. 2001;7:3.

<sup>61</sup> Clark CM, DeCarli C, Mungas D, et al. Earlier onset of Alzheimer disease symptoms in Latino individuals compared with Anglo individuals. *Arch Neurol*. 2005 May;62(5):774-8.

<sup>62</sup> Tractenberg RE, Aisen PS, Chuang YL. One-trial 10-item free-recall performance in Taiwanese elderly and near-elderly: A potential screen for cognitive decline. *Am J Alzheimers Dis Other Demen*. 2005 Jul-Aug;20(4):239-47.

<sup>63</sup> National Memory Screening Day 2007 site survey, Alzheimer's Foundation of America.

<sup>64</sup> Lawrence J, Davidoff D, Katt-Lloyd D, et al. A pilot program of improved methods for community-based screening for dementia. *Am J Geriatr Psychiatry* 2001 Summer;9(3):205-11.

<sup>65</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? *Alzheimer's & Dementia*. 2006;2:76-85.

<sup>66</sup> Galvin JE, Roe CM, Powlishta KK, et al. The AD8: a brief informant interview to detect dementia. *Neurology*. 2005 Aug 23;65(4):559-64.

<sup>67</sup> Jorm AF. The Informant Questionnaire on cognitive decline in the elderly (IQCODE): a review. *Int Psychogeriatr*. 2004 Sep;16(3):275-93.

positive screen is validated, there are ample recommendations available to guide physicians in pursuing an appropriate diagnostic evaluation.<sup>68-69-70-71</sup>

Recognition of impairment benefits the individual with the impairment, the caregiver, the family and society.<sup>72</sup> For the affected individual, identification of early stage dementia allows early aggressive use of most available treatments. The person can be offered support groups and other services to diminish the psychological impact of the disorder. Most individuals, regardless of their degree of impairment, tend to experience a sense of relief after receiving the diagnosis.<sup>73</sup> Moreover, the total medical care for this cognitively impaired individual can be adjusted to meet his or her needs. Issues such as patient education, self-medication, compliance and hospital care can be addressed to meet the needs of a person with mild dementia who is at risk for common complications such as delirium and depression. The early identification of dementia supports individual patient rights and self-determination. Most mildly impaired individuals are capable of charting the future course of their care and making substantial decisions on issues like end-of-life care, resuscitation, disposition of wealth, etc. Informing individuals about abnormal screening results does not produce hardship or harm to the individual or family caregiver.<sup>74-75-76-77-78</sup>

Unfortunately, the USPSTF suggested in its 2003 report that positive results from memory screening increase the risk of suicide—although its report citations did not support such a suggestion. The report on its screening recommendation for cognitive impairment erroneously raised the issue of self-harm by inaccurately citing one publication that did not involve screening and a second publication that discussed euthanasia.<sup>79</sup> The USPSTF recommendation is scheduled to be revisited in the late fall of 2008.

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<sup>68</sup> Ashford JW , Schmitt F , Kumar V . Diagnosis of Alzheimer's disease . In: Kumar V , Eisdorfer C editor. Advances in the diagnosis and treatment of Alzheimer's disease . New York: Springer Publishing Company; 1998;p. 111–151 .

<sup>69</sup> Cummings JL , Frank JC , Cherry D , et al. Guidelines for managing Alzheimer's disease: part I. Assessment. *Am Fam Physician*. 2002 Jun;65(11):2263–72.

<sup>70</sup> Khachaturian ZS . Diagnosis of Alzheimer's disease: two decades of progress. *J Alzheimers Dis* . 2006;9(3 Suppl):409-15.

<sup>71</sup> Knopman DS, DeKosky ST, Cummings JL, et al. Practice parameter: diagnosis of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2001 May 8;56(9):1143-53.

<sup>72</sup> deVugt ME, Jolles J, van Osch L, et al. Cognitive functioning in spousal caregivers of dementia patients: findings from the prospective MAASBED study. *Age Ageing* 2006 Mar;35(2):160-6.

<sup>73</sup> Carpenter BD, Xiong C, Porensky EK, et al. Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *J Am Geriatr Soc*. 2008 Mar;56(3):405-12.

<sup>74</sup> Lantz MS. Telling the patient the diagnosis of Alzheimer's disease: is truth-telling always best? *Clinical Geriatrics* 2004;12(4):22-25.

<sup>75</sup> Turnbull Q, Wolf AM, Holroyd S. Attitudes of elderly subjects toward "truth telling" for the diagnosis of Alzheimer's disease. *J Geriatr Psychiatry Neurol*. 2003 Jun;16(2):90-3.

<sup>76</sup> Post ST, Whitehouse PJ. Fairhill guidelines on ethics of the care of people with Alzheimer's disease: a clinical summary. Center for Biomedical Ethics, Case Western Reserve University and the Alzheimer's Association. *J Am Geriatr Soc*. 1995 Dec;43(12):1423-9.

<sup>77</sup> Johnson H, Bouman WP, Pinner G. On telling the truth in Alzheimer's disease: a pilot study of current practice and attitudes. *Int Psychogeriatr*. 2000 Jun;12(2):221-9.

<sup>78</sup> Maguire CP, Kirby M, Coen R, et al. Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *BMJ*. 1996 Aug;313(7056):529-30.

<sup>79</sup> Boustani M, Peterson B, Harris R, et al. Screening for dementia. Systematic Evidence Review. Number 20. Prepared for Agency for Healthcare Research and Quality. U.S. Department of Health and Human Services. Submitted by RTI International. June 2003.

While early recognition can bring relief, the burden of a dementia diagnosis on the individuals and family caregivers is enormous. In order to be successful, interventions for both those diagnosed and caregivers must be comprehensive and able to serve the needs of people from all ethnic and racial backgrounds. Caregivers of diverse ethnic and racial backgrounds were found to have a better quality of life when issues such as depression, burden, self-care and social support were adequately addressed through a structured intervention than those who did not have access to such an intervention.<sup>80</sup>

In addition, access to quality care is a key issue for all individuals with dementia and for those of minority racial and ethnic backgrounds in particular. Issues of stigma and mistrust as well as language and communication barriers may be magnified in certain groups. Training curricula should seek to examine and understand racial and ethnic health disparities that interfere with maximum quality of care.<sup>81</sup>

About one-third of elders live by themselves and these individuals are at risk for accidents, injuries, exploitation and other adverse outcomes. Early identification allows safeguards and home assistance to assure continued maximization of care in the home environment. Family caregivers derive multiple benefits from early identification. Early identification may reduce the burden of later life decision-making on issues like resuscitation, disposition of wealth, long-term care, etc. as families can solicit the opinion of their loved ones while they are still competent.

Screening and early identification may benefit society by protecting individuals and reducing costs of healthcare. Unrecognized dementia can increase the likelihood of avoidable complications such as delirium, adverse drug reactions, noncompliance, etc. These complications can reduce the autonomy of the individual with dementia. Enhancing compliance and protecting those with dementia have obvious financial benefits to the healthcare system. Adverse outcomes from screening programs are rarely reported in published peer-reviewed literature or experienced by community providers. Published studies on screening for community-based elders demonstrate effectiveness and acceptance.<sup>82–83–84</sup> Screened individuals and families have reported high satisfaction based on studies of experiences during AFA's National Memory Screening Day.<sup>85</sup>

The benefits are clear. Individuals with dementia can receive available therapy when the disease is identified and diagnosed. Most available treatments for Alzheimer's disease and other forms of dementia are most helpful in the early stages of illness. Early identification allows optimal therapy with available and emerging medications. A person's overall healthcare management can be adjusted to incorporate treatment strategies that accommodate a person with cognitive impairment. Home-based support systems can be adjusted to maximize home placement for this person;

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<sup>80</sup> Belle, SH, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann Intern Med.* 2006 Nov 21;145(10):727-38.

<sup>81</sup> Smith WR, Betancourt JR, Wynia MK, et al. Recommendations for teaching about racial and ethnic disparities in health and health care. *Ann Intern Med.* 2007 Nov 6;147(9):654-65.

<sup>82</sup> Lawrence J, Davidoff D, Katt-Lloyd D, et al. A pilot program of improved methods for community-based screening for dementia. *Am J Geriatr Psychiatry* 2001 Summer;9(3):205-11.

<sup>83</sup> Lantz MS. Telling the patient the diagnosis of Alzheimer's disease: is truth-telling always best? *Clinical Geriatrics* 2004;12(4):22-25.

<sup>84</sup> Turnbull Q, Wolf AM, Holroyd S. Attitudes of elderly subjects toward "truth telling" for the diagnosis of Alzheimer's disease. *J Geriatr Psychiatry Neurol.* 2003 Jun;16(2):90-3.

<sup>85</sup> Memory Screening: Who Attends and Why—A Survey of Participants at National Memory Screening Day, The MetLife Mature Market Institute, Alzheimer's Foundation of America, and The Center for Productive Aging at Towson University, at <http://www.alzfdn.org/surveys/survey1.pdf>.

delayed institutionalization provides cost savings to families and society.<sup>86</sup> Safeguards can be taken to prevent avoidable complications such as falls and wandering, as well as delirium during hospitalization. Advanced directives can be discussed that incorporate the wishes of the individual and reduces the burden of surrogate decision making for the family.

## WHAT IF THE SCREEN IS NEGATIVE?

For persons with a normal screen, memory screening provides a valuable opportunity to promote cognitive wellness and successful aging similar to efforts underway in other nations, such as Japan.<sup>87</sup> A simple, direct cognitive wellness message can be presented to these individuals. The emotional boost from a normal dementia screen can be used as an opportunity to discuss basic preventive interventions such as compliance with anti-hypertensives, responsible drinking, intellectual stimulation and other recommendations that may further protect a person's cognitive function.<sup>88-89</sup> Guidance on cognitive wellness for middle aged or older persons is available online at [www.alzbrain.org](http://www.alzbrain.org).

## IS THERE ADEQUATE FOLLOW-UP?

One of the issues raised about community-based memory screening is that some participants will neglect to follow up on the recommendations resulting from the testing. It is a concern when an individual with a positive screen fails to get further diagnostic assessment, but compliance with medical recommendations is a widespread problem<sup>90</sup> not only related to screening tests. Compliance issues represent one of the points in which modern medicine needs broad-based improvement that appears to be difficult to address within an overburdened healthcare system.<sup>91</sup>

The opposite issue, that an individual with a negative screen might see this result as permanent freedom from worry about dementia, is also a concern and a misunderstanding. A negative screening result only suggests that the immediate concern about dementia can be reduced. Such a response should not be considered a harm of screening, but an area for consumer education in which the quality of the whole screening system could be improved.<sup>92</sup>

Some argue that memory screenings should only take place in a clinical setting, where individuals with a positive screen will have immediate access to further diagnostic testing. In addition, some point out that the medical community is not equipped to process the results of mass memory screenings. However, even when a memory screening is conducted in a physician's office,

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<sup>86</sup> Mittelman MS, Ferris SH, Shulman E, et al. A family intervention to delay nursing home placement of patients with Alzheimer's disease. A randomized controlled trial. *JAMA* 1996 Dec 4;276(21):1725-31.

<sup>87</sup> Fujishiro H, Umegaki H, Suzuki Y, et al. [Awareness of dementia in older adults attending dementia-prevention programs in community healthcare centers.] *Nippon Ronen Igakkai Zasshi*. 2005 May;42(3):340-5.

<sup>88</sup> Rowe JW, Kahn RL. *Successful aging*. New York: Pantheon Books, Random House Inc. 1998.

<sup>89</sup> Shulman KI, Herrmann N, Brodaty H, et al. IPA survey of brief cognitive screening instruments. *Int Psychogeriatr*. 2006 Jun;18(2):281-94.

<sup>90</sup> See [www.alzbrain.org](http://www.alzbrain.org) for more information about compliance.

<sup>91</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? *Alzheimer's & Dementia*. 2006;2:76-85.

<sup>92</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? It is important to screen for evidence of dementia! *Alzheimer's & Dementia*. 2007;3:75-80.

abnormal results do not necessarily lead to treatment. Authors of a recent article in the *Journal of General Internal Medicine* found that of 524 adults screened in a doctor's office, only one in five who screened positive was referred to a specialist or after further evaluation received a diagnosis or prescription for medication.<sup>93</sup>

Lack of time is likely one reason for so little physician follow-up. This issue affects individuals with a variety of chronic illnesses and needs to be addressed in a broader context. Rather than dismiss memory screening policy due to a lack of time, policy efforts should be focused on increasing provider training and offering better reimbursement practices.

Too often primary care providers wait to hear from their patients about memory concerns before initiating memory screening tests. This method is inadequate because individuals with dementia often lack the self-awareness necessary to recognize that they have a memory problem. Those who do bring up memory problems are frequently the "worried well."

In addition, most people are not inclined to discuss memory concerns with their healthcare providers. A survey conducted during AFA's 2007 National Memory Screening Day found that 68 percent of respondents had concerns about their memory. However, while more than 44 percent had visited their primary care physician within the last six months, fewer than one in four of those with self-identified memory problems had discussed the issue with their physician.<sup>94</sup> Similar results among family members were found in a survey conducted on behalf of the Alzheimer's Disease Screening Discussion Group.<sup>95</sup> Primary care providers might be more likely to recommend further evaluation if individuals presented their abnormal memory screening results from events like National Memory Screening Day. Community screenings such as National Memory Screening Day generally educate participants about questions to ask their healthcare providers and empower them to begin a dialogue.

Aside from issues regarding clinical follow-up, memory screening may motivate people to adopt healthy lifestyle practices. An abnormal memory screening result is similar to a high blood pressure result. Although people are aware that they should exercise and watch their diet, many do not until they find out their blood pressure is elevated. In the same way, an abnormal memory screening finding can prompt people to make lifestyle changes, such as doing crossword puzzles and other cognitive stimulation, eating a heart-healthy diet and doing physical exercise.

## **COST-EFFECTIVENESS OF MEMORY SCREENING<sup>96</sup>**

One consideration for determining whether a screening test is appropriate is its costs and benefits. A mathematical calculation of "cost-worthiness" will provide a direct assessment of whether a

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<sup>93</sup> Borson S, Scanlan J, Hummel J, et al. Implementing routine cognitive screening of older adults in primary care: process and impact on physician behavior. *J Gen Intern Med.* 2007 Jun;22(6):811-7. Epub 2007 Apr 20. Erratum in: *J Gen Intern Med.* 2007 Aug;22(8):1224.

<sup>94</sup> Powers RE, Hall E, Ashford JW, Howard G. Self reported features of 2178 respondents undergoing memory screening during national memory screening day in 2007 as sponsored by the Alzheimer's foundation of America. 2008 ICAD Poster Session. June 30, 2008.

<sup>95</sup> Alzheimer's Disease 2008: Current Attitudes and Perceptions Survey, Harris Interactive Survey on behalf of the Alzheimer's Disease Screening Discussion Group, released September 24, 2008.

<sup>96</sup> This section is adapted from Ashford JW, Kraemer HC, Tinklenberg JR, et al. Statistical and pharmacoeconomic issues for Alzheimer's screening. *Alzheimer's & Dementia* 2007;3:126.

screening test should be implemented. To calculate cost-worthiness (\$W), the following factors should be considered:

- ✓ I = incidence (new occurrences each year, by age, in a population)
- ✓ Benefits and Costs:
  - \$B = benefit of a true positive diagnosis. For example: saving \$50,000 in nursing home costs for one year (after treatment cost deduction).
  - \$C = cost of a false positive diagnosis. For example: \$500 for further evaluation, in addition to the time and the stress of suspecting dementia.
  - True negative = real peace of mind (priceless)
  - False negative = false peace of mind (no price)
- ✓ Se = sensitivity of test (for a specific severity) = True positive / I
- ✓ Sp = specificity of test (in a normal population) = True negative / (1-I)
- ✓ \$T = cost of test, time to take (Subject, Tester)

The calculation would be  $\$W = (\$B \times I \times Se) - (\$C \times (1 - I) \times (1 - Sp)) - \$T$ . If \$W is greater than zero, then the test is cost-worthy.

As an example using conservative estimations, consider the following:

- ✓ I = incidence of Alzheimer's disease (increase from 1/1000 per year at age 62, doubling every 5 years);
- ✓ Se = 0.9;
- ✓ Sp = 0.9 (tests of less than five minutes appear to be able to reach this level);
- ✓ \$B = vary linearly from \$25,000 in a 50-year-old patient (considering the value of a six-month delay of nursing home placement with timely medical treatment) to \$0 in a centenarian patient;
- ✓ \$C = a false positive is estimated to require a \$500 clinic visit to disprove the dementia suspicion.

Even with conservative estimates, a cost for a clinician screening for dementia of \$25 per year is justified for individuals from 75 years of age until older than 95. Better or less expensive tests or more efficient clinic visits could lead to recommendations as low as 55 years of age, and more valuable treatments would similarly reduce the age for recommending broad application of screening tests.

The cost related to a false-negative screen is a delay in diagnosis and treatment, which is no different than the current condition. The costs of a false-positive screen include a referral of a normal individual for further testing, the value of the individual's time, the cost of additional testing (estimated at around \$500), and if misdiagnosed, the current high cost of untoward results of misdiagnosis, medication side effects and uninformed practice.

The benefits of a true-positive screen may be intangible, and include peace of mind, receiving medication that may help delay the onset or progression of symptoms, and the ability to do advance planning. As was stated previously, early diagnosis delays, rather than hastens, institutionalization.

There are several false considerations that have been brought up as arguments against memory screening in general—namely that it can be a problem for an individual attempting to obtain health and long-term care insurance or a new job, and it may result in loss of the person's driver's license. However, it is important not to confuse good clinical practice with questions of policy. The harms



cited are not harms of screening, but of dementia itself. Insurance companies conduct their own screening procedures to qualify applicants for benefit plans, and many individuals with dementia should not drive for safety reasons. Screening only helps to uncover dementia and cannot be blamed for its existence or its effects.<sup>97</sup>

## **TREATMENT FOR ALZHEIMER’S DISEASE—IS IT EFFECTIVE ENOUGH TO WARRANT SCREENING AND EARLY DETECTION?**

Five prescription drugs are approved by the U.S. Food and Drug Administration to treat the symptoms of Alzheimer’s disease: Razadyne (galantamine, previously known as Reminyl), Exelon (rivastigmine), Aricept (donepezil) and Cognex (tacrine) are a class of medications called cholinesterase inhibitors, which are approved to treat mild to moderate Alzheimer’s disease; Aricept has been approved for the severe stage of Alzheimer’s disease as well. Namenda (memantine) is an N-methyl D-aspartate (NMDA) antagonist, approved to treat moderate to severe Alzheimer’s disease.

Most medications for Alzheimer’s disease are most effective when taken early in the disease, although available treatments are useful only for slowing the progression of symptoms—not modifying the disease outcome.

Although based on studies considered less reliable in design than randomized controlled trials, data from pharmaceutical companies and pharmacy databases have suggested that cholinesterase inhibitors slow the rate of Alzheimer’s disease progression and delay nursing home placement.<sup>98–99–100</sup> Many studies have shown the benefits of the treatments on biologic (brain scans), psychological (cognitive testing and behavioral testing) and social (activities of daily living or ADL) measurements.<sup>101–102</sup> Although all studies addressing this issue to date suffer from design limitations, their results are consistent with known clinical effects of drug therapy from randomized placebo-controlled trials. Further, numerous studies of several cholinesterase inhibitors and memantine have shown clinically significant, positive effects in individuals who already have Alzheimer’s disease, with very few exceptions.<sup>103–104</sup>

Some, including the USPSTF, debate the drugs’ ability to meaningfully improve quality of life for a substantial length of time. The USPSTF believes medication for Alzheimer’s disease offers limited

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<sup>97</sup> Ashford WA, Borson S. Letter to the Editor. *JAMA*. 2008;299(10):132-33.

<sup>98</sup> Beusterien KM, Thomas, SK, Gause D, et al. Impact of Rivastigmine use on the risk of nursing home placement in a US sample. *CNS Drugs*. 2004;18(15):1143-8.

<sup>99</sup> Geldmacher DS, Provenzano G, McRae T, et al. Donepezil is associated with delayed nursing home placement in patients with Alzheimer’s disease. *J Am Geriatr Soc*. 2003 Jul;51(7):937-44.

<sup>100</sup> Knopman D, Schneider L, Davis K, et al. Long-term tacrine (Cognex) treatment: effects on nursing home placement and mortality, Tacrine Study Group. *Neurology*. 1996 Jul;47(1):166-77.

<sup>101</sup> Fillit HM, Doody RS, Binaso K, et al. Recommendations for best practices in the treatment of Alzheimer’s disease in managed care. *Am J Geriatr Pharmacother*. 2006;4 Suppl A:S9–S24.

<sup>102</sup> Geldmacher DS, Frolich L, Doody RS, et al. Realistic expectations for treatment success in Alzheimer’s disease. *J Nutr Health Aging*. 2006 Sep-Oct;10(5):417–29.

<sup>103</sup> Courtney C, Farrell D, Gray R, et al. Long-term donepezil treatment in 565 patients with Alzheimer’s disease (AD2000): randomised double-blind trial. *Lancet*. 2004 Jun 26;363(9427):2105-15.

<sup>104</sup> Holmes C, Burns A, Passmore P, et al. AD2000: design and conclusions. *Lancet* 2004 Oct 2-8;364(9441):1213-14: author reply 1216-17.

benefits.<sup>105–106</sup> The USPSTF states that although evidence shows that several medications can slow the progression of Alzheimer’s disease for a short time, the drugs do not help people remain independent.

Other studies show that medications can have a significant impact on individuals with the disease and their families by improving their quality of life from six months to two years.<sup>107</sup> Beyond specific clinical outcomes, the value of general supportive care for individuals with dementia and their families are outcomes that are being studied, and these outcomes must be included in the evaluation of the criteria for judging screening tests. Several studies have shown better outcomes for caregivers of individuals undergoing treatment, and these outcomes add further value to memory screening.<sup>108</sup>

## **WHAT IS THE NATIONAL POLICY ON MEMORY SCREENING?**

Presently, there is no national policy on dementia screening. Despite the acceptable accuracy of screens as well as the availability of medications for early to severe stages of the disease, there is no public health policy on assessing for dementia.

The present Medicare screening and prevention program does not include cognitive function. However, the Centers for Medicare & Medicaid Services (CMS) did decide in 2005 to include screening for cognitive impairment within the scope of its Initial Preventive Physical Exam (IPPE), commonly known as the “Welcome to Medicare” exam. The final rule specifically recognizes that “review of the individual’s functional ability and level of safety” would include an assessment of the role cognitive impairment may play in affecting an individual’s ability to perform activities of daily living.

A national system of dementia screening will require several years for development and implementation. It will require a flexible array of services and instruments. A policy executed today would only be fully available in the field several years from now. For the present and near future, local and national organizations are left to create their own programs.

Scientists and researchers are trained to accept treatment strategies that incorporate evidence-based practices. Although this conceptual model is the gold standard, this strategy has significant limitations that are rarely emphasized by the scientific community. Mass scale public health interventions are tested over a multi-decade period. Researchers are generally preoccupied with conclusive scientific data and the promotion of research. In contrast, public systems must use a pragmatic approach, i.e. a “best possible solution.”

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<sup>105</sup> Boustani M, Peterson B, Harris R, et al. Screening for dementia. Systematic Evidence Review. Number 20. Prepared for Agency for Healthcare Research and Quality. U.S. Department of Health and Human Services. Submitted by RTI International. June 2003.

<sup>106</sup> Boustani M, Peterson B, Handon L, et al. Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med.* 2003 Jun 3;138(11):927-37.

<sup>107</sup> Wallin AK, Andreasen N, Eriksson S, et al. Donepezil in Alzheimer’s disease: what to expect after 3 years of treatment in a routine clinical setting. *Dement Geriatr Cogn Disord.* 2007;23(3):150–60.

<sup>108</sup> Ashford JW, Borson S, O’Hara R, et al. Should older adults be screened for dementia? *Alzheimer’s & Dementia.* 2006;2:76-85.

## **IS THE PRIMARY CARE NETWORK CAPABLE OF EVALUATING PATIENTS WITH DEMENTIA?**

Although there are published treatment guidelines for the management of dementia, clinical competency issues have not been addressed for the primary care provider. The primary care provider will carry the burden of assessment and management because of the large numbers of people who require treatment. Competency guidelines and studies of service availabilities have not been widely performed. Anecdotal information provided to AFA and its member organizations suggests that many caregivers struggle to identify local primary care providers capable of assessing and managing persons with dementia. The AFA position on clinical care holds that all citizens are entitled to adequate evaluation by competent healthcare providers who understand basic management strategies for key aspects of dementia. Possible gaps in the healthcare system should be studied by responsible federal agencies and addressed by uniform education of all healthcare providers who manage persons with dementia. AFA supports a message of empowerment to families of persons with dementia. Caregivers and those with dementia are entitled to adequate medical and psychosocial services in order to continue their valuable role and service to America. Dementia screening should be included in routine screening assessments performed under Medicare, and participating providers should be expected to demonstrate basic competency in the area of dementia management.

### **AFA RECOMMENDATIONS**

AFA respectfully recommends that Congress and the Administration work collaboratively to adopt the following changes in national policy regarding dementia screening:

- ✓ Congress should establish a consensus panel to guide implementation of a screening initiative and craft recommendations on screening, using members that include a broad range of consumers as well as public health officials, scientists and other experts.
- ✓ National leadership should recognize the role early intervention plays in the success of available medical, psychological and social interventions for dementia. The value of early recognition extends beyond the opportunity for treatment to improving patient autonomy, adjusting healthcare services and supporting family caregivers.
- ✓ Dementia screening should be used as an opportunity to promote cognitive wellness.
- ✓ CMS should provide clear guidance to providers and beneficiaries regarding: (1) the circumstances under which screening for cognitive impairment should be conducted; and (2) the extent of Medicare's coverage for services provided in the context of the IPPE or any medically necessary follow-up examination. Such an initiative can be seamlessly incorporated into the agency's broader efforts to inform beneficiaries and providers about the IPPE.<sup>109</sup> Ideally, CMS should cover a memory screening for all new Medicare beneficiaries.

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<sup>109</sup> Failure to effectively communicate this information will have severe consequences for affected Medicare beneficiaries. Unrecognized dementia can increase the likelihood of avoidable complications such as delirium, adverse drug reactions, and noncompliance with a prescribed medication regimen. These complications reduce the autonomy of affected individuals, thereby impeding their ability to perform activities of daily living and compromising their safety. Such an outcome would be inconsistent with the relevant American Academy of Neurology practice guideline for physicians, which states: "Patients with mild cognitive impairment should be recognized and monitored for cognitive and functional decline due to their increased risk for subsequent dementia." Similarly, the U.S. Preventive Health Services Task Force has concluded that while "current evidence does not support routine screening of patients in whom cognitive

Participating providers should be expected to demonstrate basic competency in the area of dementia management.

- ✓ Policymakers should encourage medical schools to include in their curriculum screening, diagnosis and treatment for memory problems in general, and Alzheimer's disease and related dementias specifically. Such curricula should also seek to train students on dementia-related racial and ethnic health disparities.
- ✓ Federal medical school loan incentives should be created to encourage entry into the geriatric field.
- ✓ Policymakers should acknowledge the importance of basic science research; however, the country needs a balanced program that combines basic research with preventive strategies and chronic disease management.
- ✓ Policymakers should request a review by the Institute of Medicine to examine current research programs and provide a timetable for when an Alzheimer's disease "cure" is likely to be developed and what it will look like.
- ✓ The National Institute on Aging (NIA) should fund research to compare existing memory screening tools to identify those that are most useful.
- ✓ NIA should fund research to help develop a more effective method of case-finding for dementia and for earlier detection in particular.

The absence of prospective data on the effectiveness of screening has limited the willingness of experts to promote a specific plan of action for screening. A consensus panel that includes a range of consumer advocates as well as public health officials, scientists and other experts can define programmatic issues such as age at which screening should be initiated, frequency of screening, successful aging information, types of expected counseling available, methods of caring for persons who exhibit age-associated memory impairment or MCI, and other key issues.

The screening process provides an opportunity to disseminate material on successful aging and cognitive wellness. Our nation needs a specific set of recommendations to promote intellectual health and overall risk mitigation in aging individuals. Sufficient data exists to craft these guidelines for both consumers and primary care providers.<sup>110-111</sup> AFA and affiliated organizations presently disseminate information that is based on peer-reviewed, published literature. These guidelines can be amended and improved over time; however, our nation needs a starting point for this wellness program. This policy should be crafted by a range of consumer advocates as well as public health officials, scientists and other experts. Congress should initiate this process to promote risk mitigation and earlier detection.

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impairment is **not** otherwise suspected, clinicians should assess cognitive function whenever cognitive impairment or deterioration **is** suspected, based on direct observation, patient report, or concerns raised by family members, friends, or caretakers." (Emphasis added)

<sup>110</sup> Burke D, Hickie I, Breakspear M, Gotz J. Possibilities for the prevention and treatment of cognitive impairment and dementia. *Br J Psychiatry*. 2007 May;190:371-2.

<sup>111</sup> Korczyn AD, Vakhpova V. The prevention of the dementia epidemic. *J Neurol Sci*. 2007 Jun 15;257(1-2):2-4.