

policybrief

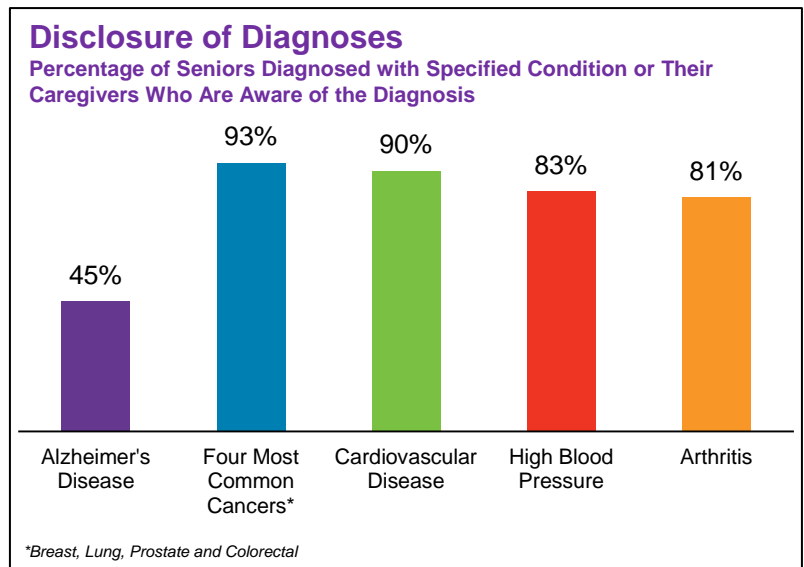
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Early Detection and Diagnosis of Alzheimer's Disease

Quality care for Alzheimer's disease and other dementias starts with an early, documented diagnosis, including disclosure of the diagnosis. However, among individuals living with Alzheimer's and other dementias, evidence indicates about half have not been diagnosed. And of those who have been diagnosed, less than half are aware of their diagnosis. Only 45 percent of adults age 65 and older diagnosed with Alzheimer's, or their caregivers, are aware of the diagnosis.¹ Among individuals diagnosed with Alzheimer's, only 33 percent are aware of the diagnosis.¹ These data are comparable to baseline data from *Healthy People 2020*, the nation's 10-year public health agenda, that indicate approximately 35 percent of Medicare beneficiaries age 65 and older diagnosed with dementia, or their caregivers, were aware of the diagnosis.²

To address this challenge, *Healthy People 2020* includes the objective to "increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis."² To make progress on this objective, actions include assuring the public and health care providers know the early warning signs of Alzheimer's; educating health care providers on early detection and diagnosis, including patient/family communications and documentation in medical records; and assessing cognition during the Medicare Annual Wellness Visit (AWV). These actions, among others, provide a foundation for the delivery of quality dementia care.



Benefits and barriers for early detection and diagnosis

Alzheimer's disease, the most common cause of dementia, is a disabling chronic condition characterized by symptoms such as increased confusion, memory loss and impaired judgment.¹ These symptoms impede daily activities and the management of comorbid conditions, and can lead to functional decline, significant caregiver burden and long-term disability. Although Alzheimer's is not a normal part of aging, age is the biggest risk factor: only an estimated 4 percent of Alzheimer's cases occur among those under the age of 65; of those 85 years and older, 32 percent have the disease.¹ With the aging of the Baby Boom Generation, an increasing number of Americans will

move into the age range where they will be at higher risk of developing Alzheimer's and other dementias and could benefit from increased efforts at promoting early detection and diagnosis.

Benefits of early detection and diagnosis

Early detection and diagnosis offers a number of benefits to help affected individuals and their families. Early detection and diagnosis allows people to access available treatments, build a care team, participate in support services, and enroll in clinical trials. People who know they have the disease and their caregivers can create advance health directives and make financial and legal arrangements before cognition further declines. They can also address safety issues and seek counseling on how to cope with behavioral changes associated with disease progression.¹

Early detection can also help health care providers deliver better care. Early detection can help physicians better manage a patient's comorbid conditions and avoid prescribing medications that may worsen cognition or function.³ And because early warning signs such as memory problems, confusion, personality changes and trouble with judgment^{4,5} may be attributable to other sources, early detection of cognitive changes allows physicians to identify and treat reversible conditions that mimic cognitive impairment and dementia such as depression or vitamin deficiency.¹

Furthermore, early detection and diagnosis of Alzheimer's and other dementias may help to reduce unmet needs of affected individuals who are more likely to experience disability. Among Medicare beneficiaries who report being aware of their diagnosis, 57 percent required assistance with three or more activities of daily living (ADLs) and 59 percent required assistance with three or more instrumental activities of daily living (IADLs).¹ Data from the 2011 Behavioral Risk Factor Surveillance System (BRFSS) found those with self-reported confusion or memory loss – often referred to as subjective cognitive decline – and functional difficulties were more likely to report frequent poor health, limited activity due to poor

U.S. Preventive Services Task Force

The U.S. Preventive Services Task Force, a group of national experts who develop recommendations on clinical preventive services and evidence-based medicine, has concluded there is "insufficient evidence" to recommend for or against routine screening for cognitive impairment in asymptomatic older adults. However, the Task Force stated that "clinicians should remain alert to early signs or symptoms of cognitive impairment and evaluate as appropriate." The Task Force also recognized cognitive impairment as a serious public health issue and encouraged consumers experiencing memory problems to speak with a their health care providers.

Final Recommendation Statement: Cognitive Impairment in Older Adults: Screening. U.S. Preventive Services Task Force. 2014.

physical or mental health, and a need for more assistance.⁶

Barriers to early detection and diagnosis

For early detection to occur – and subsequent diagnosis and disclosure awareness – patients and physicians must overcome several barriers. Patients face barriers such as low public awareness of the early signs of Alzheimer's, including notable differences in diverse populations;^{7,8} perceived emotional distress of Alzheimer's and other dementias on family members;⁹ and misperceptions about Alzheimer's and other dementias.^{10,11} For example, a recent survey of 12 countries found 59 percent of respondents incorrectly believed that Alzheimer's is a typical part of aging, and 40 percent believed that Alzheimer's is not fatal.¹² These barriers can lead to stigma, delays in seeking medical assistance or reluctance to communicate with health care providers. Data from the 2012 BRFSS showed only 23 percent of adults age 45 and older who reported subjective cognitive decline in the previous 12 months had talked with a health care provider about it.¹³

Physicians face barriers such as low recognition of the signs of cognitive impairment; a lack of education or training on dementia care; concerns about stigma and the usefulness of an early diagnosis; lack of time; and

difficulty talking about dementia or disclosing a diagnosis.^{1,14,15,16} Contributing to these challenges are low rates of documentation of diagnoses in patients' medical records. Less than half of those with Alzheimer's and dementia diagnoses have it documented in their medical records.^{14,17,18} Research also indicates low rates of documentation for mild cognitive impairment, even if doctors recognize and diagnose it.¹⁵

Detection/assessment of cognitive change

Experts agree establishing a cognitive baseline in a medical setting can assist health care providers with identifying changes in cognition that merit further evaluation.¹⁹ Consistent with this, detection of possible cognitive impairment is a mandatory element of the Medicare Annual Wellness Visit (AWV).²⁰ As previously noted, because early signs and symptoms of cognitive impairment and dementia may be characteristic of other health conditions, these routine, brief cognitive assessments are an important way for physicians to detect notable change over time that could indicate underlying pathology.

The National Institute on Aging (NIA),²¹ the Gerontological Society of America (GSA)²² and the Alzheimer's Association¹⁹ have developed evidence-based guidelines to advise health care providers on how to detect cognitive impairment in primary care settings, including during the Medicare AWV. Although expert groups have not recommended a single preferred instrument, there is consensus that tools for the detection of cognitive impairment should be short, easy to administer, and validated for use in primary care settings.^{19,21,22} If cognitive impairment is detected, health care providers can then refer patients for comprehensive diagnostic evaluations.

In addition to employing a brief assessment tool for detection, these guidelines recommend physicians incorporate informant interviews and self-reports. A growing body of evidence suggests subjective cognitive decline (SCD) may be a harbinger of subsequent cognitive impairment or dementia, including Alzheimer's. Studies have shown SCD to be

associated with increased risk of MCI or dementia;²³ significant decline in episodic memory;²⁴ early Alzheimer's pathology such as the buildup of beta-amyloid;²⁵ and memory decline in people who carry the apolipoprotein E (APOE)-e4 gene,²⁶ a genetic risk factor for Alzheimer's. As research continues, health care providers may be able to employ SCD as a clinical complement to other cognitive detection tools.

What can be done?

Early detection and diagnosis of Alzheimer's disease and other dementias helps affected individuals achieve better quality care by identifying cognitive impairment as early as possible. As with other chronic conditions, early identification and management of Alzheimer's and other dementias helps people better understand and anticipate care needs as they arise. Because of the progressive nature of the disease on functioning, the best opportunity for individuals to benefit from available treatments, express their wishes, and plan for the future is in the early stages. The following public policies can help promote early detection and diagnosis, and ultimately support the health outcomes of affected individuals.

➤ Raise public awareness about the signs and symptoms of Alzheimer's disease and other dementias – and the importance of early detection and diagnosis. Educating the public about Alzheimer's disease and other dementias and early detection can increase understanding about what cognitive impairment looks like, dispel myths and encourage individuals to talk with their health care providers. Federal, state and public health agencies can share information with the public on the early warning signs and the importance of talking with a health care provider when experiencing memory problems. Outreach should include faith-based groups and diverse communities, and be translated to languages appropriate for local audiences. Large employers can be encouraged to participate in the Alzheimer's Workplace Alliance® (AWA), which aims to raise awareness about Alzheimer's disease and the importance of early detection while

providing help to those who are balancing work and caregiving responsibilities.²⁷

- Promote participation in the Medicare Annual Wellness Visit (AWV). The Medicare AWV provides an excellent opportunity for physicians to discuss healthy aging with patients, including risk factors for cognitive decline and guidance on lifestyle and behavioral changes that can support brain health.²⁸ Public health, aging and health professionals' organizations can educate the public on the importance of this annual health visit by providing information on what it entails in easy-to-read, language-appropriate materials. They can also educate physicians on how to detect cognitive impairment and use validated cognitive assessment tools and quick references such as the Alzheimer's Association Cognitive Assessment Toolkit,²⁹ a guide for detecting cognitive impairment during the Medicare AWV.
- Educate health care providers. State agencies and provider groups should share information with physicians about early detection and diagnosis, including the importance of disclosing a diagnosis and medical record documentation. For example, the New York State Department of Health sent a "Dear Colleague" letter to all primary care providers in the state³⁰ to convey the benefits of early detection, validated cognitive assessment tools, and indications for referral for further evaluation. State agencies can also partner with medical associations to develop and post a "tool box" on their web sites that includes information about Alzheimer's disease and other dementias, community resources and continuing education courses³¹ that can help health care professionals improve their ability to recognize the early warning signs and provide appropriate care for affected individuals.
- Collect data on early detection and cognition. While the Medicare AWV requires "detection of cognitive impairment," there is currently no way to track if physicians are actually doing it. Medical associations, consumer health groups, and public health entities can partner to periodically survey

health care providers in their states to find out how often physicians discuss cognitive health during the AWV and what tools they use with patients who have symptoms suggestive of cognitive impairment. The surveys would inform efforts to enhance use of the AWV in increasing early detection. State public health agencies can also adopt the Cognitive Module in their annual BRFSS surveys to capture state-specific data on cognitive decline (including discussions with health care providers), and use this information to inform actions for interventions.

- Support research on outcomes of early detection. Additional research is needed to evaluate outcomes of early detection for cognitive impairment, specifically the impact detection has on patient and caregiver decision-making and societal outcomes.
- Pass the HOPE for Alzheimer's Act. One reason doctors do not disclose an Alzheimer's diagnosis is because of the insufficient time and resources available to provide support at the time of diagnosis.¹ The HOPE for Alzheimer's Act (S. 857/H.R. 1559) would provide Medicare coverage for comprehensive care planning services and medical record documentation of both the diagnosis and the care planning. It would also require the U.S. Department of Health and Human Services to conduct provider outreach about the new benefit, identify barriers beneficiaries face in accessing care planning services and make recommendations to eliminate them.

Conclusion

Detecting cognitive impairment, diagnosing Alzheimer's disease and other dementias, and disclosing that diagnosis to the individual are necessary elements to ensuring those with the disease and their families have the opportunity to access available treatments, build a care team, participate in support services, enroll in clinical trials, and plan for the future. Policies to promote early detection and diagnosis – among the public and health care providers – can ensure those opportunities are available.

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