

KICKSTART

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THE GSA K A E R TOOLKIT FOR PRIMARY CARE TEAMS

**Supporting Conversations About Brain Health,
Timely Detection of Cognitive Impairment,
and Accurate Diagnosis of Dementia**

FALL 2020 EDITION



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Preface to the Fall 2020 Edition

The Gerontological Society of America (GSA) first made the GSA KAER Toolkit publicly available in 2017. The Fall 2020 edition was developed to accommodate changes to clinical evidence and the availability of new educational resources since its initial release. The content of this updated version has been abridged and the design has been modified for electronic use while preserving the key approaches for implementing the KAER Model. All content and design updates were made to enhance the toolkit's usefulness for primary care teams, medical educators, and medical students, among others. The GSA KAER Toolkit, along with materials related to its implementation, is a living document that will be updated periodically. Visit the GSA KAER home page (geron.org/kaer) regularly to access the latest KAER resources.

Acknowledgments

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Terminology

In this toolkit, the terms "person" or "individual living with dementia" are prioritized over "patient." The purpose of these word choices is to remind readers that individuals and families can live fully with dementia, without stigma and misperceptions.

The terms "family," "family member," "friend," and "caregiver" are used interchangeably to mean any relative, partner, friend, or neighbor who has a significant relationship with the person experiencing or living with symptoms of dementia. The term "knowledgeable informant" refers to instances in which a family member or friend is able to offer useful information to the primary care team to inform the clinical history.

The term "dementia" is an umbrella term that refers to a wide range of medical conditions caused by abnormal brain changes, with Alzheimer's disease being the most common cause of dementia (Alzheimer's Association, 2020). These changes can cause a decline in thinking and problem-solving skills, also known as cognitive function, and interfere with daily activities. The changes can also affect behavior, feelings, and relationships.

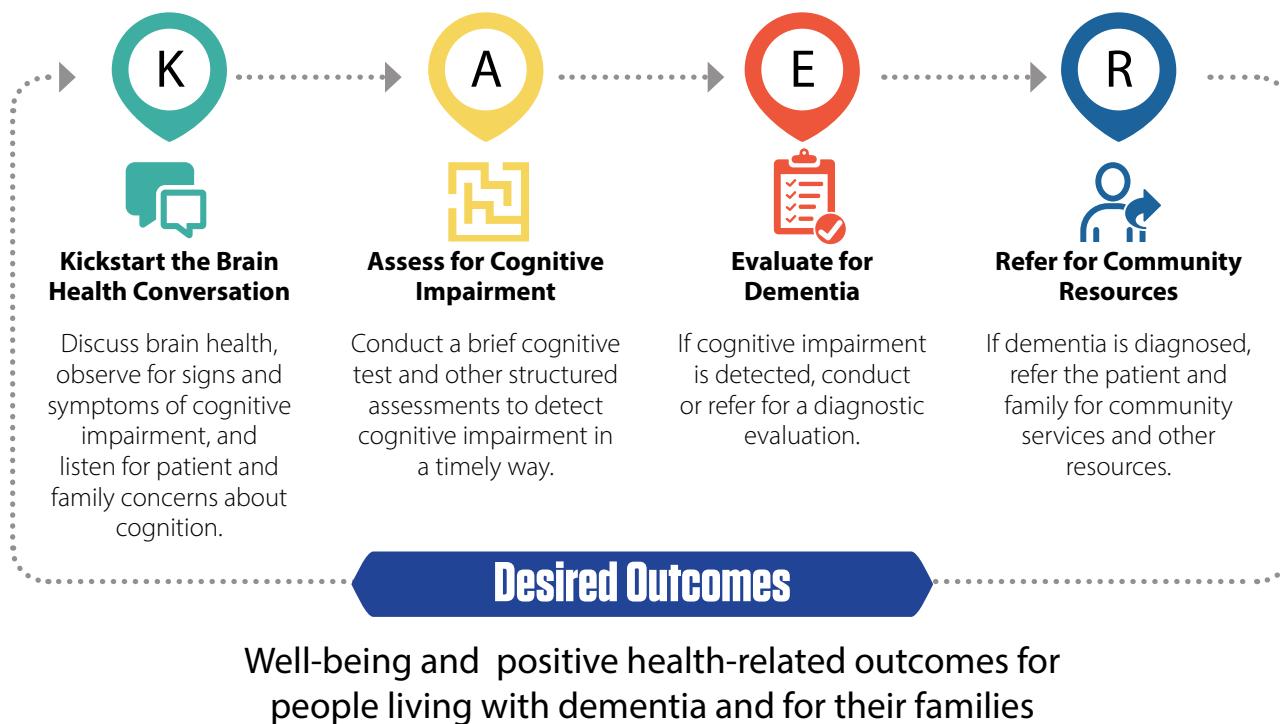
Introduction to the KAER Toolkit

Background on the KAER Model

In 2015, GSA released a report on the detection of cognitive impairment and diagnosis of dementia (GSA, 2015). The report, which was developed by the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis (GSA Workgroup), underscored the value of detecting cognitive impairment and providing timely diagnostic evaluations for older adults. The report emphasized that various members of the primary care team, including physicians, physician assistants, nurses, and nurse practitioners, along with their office staff, play critical roles in preventive care, diagnosis, and follow-up for individuals with dementia and their families.

The GSA Workgroup created a model that identifies four steps to achieve greater awareness of cognition and brain health in older adults, increase detection of cognitive impairment, initiate earlier diagnostic evaluation, and make referrals for educational and supportive community services for people with dementia. The four steps—Kickstart, Assess, Evaluate, and Refer (KAER)—are intended to improve health-related outcomes and well-being for people living with dementia and their families (Figure 1).

Figure 1. The KAER Model





Scope and Intended Uses of the GSA KAER Toolkit

The toolkit is intended as a supportive document of practical approaches, educational resources, and validated clinical tools to help primary care teams implement the KAER Model in their own initiatives related to brain health and timely detection of cognitive impairment. The content of the toolkit and selection of tools was developed with primary care teams as the principal audience. Medical educators and medical students may also find its contents useful. GSA recognizes that health care professionals outside the primary care setting also play a valuable role in detecting cognitive impairment (Chodosh et al., 2019).

This toolkit is divided into four sections to reflect each step of the KAER Model. The scope of information is directed to busy primary care teams in the following ways:

- Illustrations of early warning signs are provided through examples that primarily focus on memory problems. GSA recognizes that cognitive issues are broader than memory concerns alone and that functional impairment is also an important consideration.
- Information on the different types of dementia is brief. GSA recognizes that making a differential diagnosis is challenging and should involve a partnership between primary care teams and specialists who have expertise in this area of health care.

Primary care teams have varying degrees of familiarity with dementia-related clinical processes and may operate in different types of structures, organizations, and geographic regions. As such, care team members who are considering using the KAER Model in their clinical workflows may find certain steps to be more relevant than others and are encouraged to adopt processes that make sense within their clinical context.

New approaches and tools are continually being researched and tested in the field. Users of the toolkit are encouraged to consider new validated tools as they become available, especially those that can better address gender, racial, ethnic, cultural, and language-related diversity; low literacy; sensory impairments; and intellectual disabilities.

Ways to Get Paid for Delivering KAER-Based Quality Patient Care

Each step of the KAER Model promotes clinical processes that represent a basic standard of care for individuals living with dementia. By appropriately documenting visit notes in the electronic health record, health care providers should be able to bill for these processes. Some of the information needed for billing may already be recorded in the patient's history. A team-based approach to completing elements of specific visits (e.g., involving medical assistants in the Medicare Annual Wellness Visit) will help to obtain appropriate reimbursement.

Using CPT Codes for Detection, Evaluation, Diagnosis and Care Planning

Components of the coding process are the selection of diagnosis codes from the *International Classification of Diseases, Tenth Revision, Clinical Modification* (ICD-10) and the selection of the proper Current Procedural Terminology (CPT) codes and Healthcare Common Procedure Coding System (HCPCS) codes.

The use of an ICD-10 code is a prerequisite for using CPT or HCPCS codes. Most CPT or HCPCS codes can be used in conjunction with an ICD-10 code for any geriatric syndrome. While health care providers are encouraged to use specific dementia-related diagnostic codes when completing KAER-related processes, it also may be appropriate to use additional codes that represent risk factors for dementia such as diabetes and hypertension, as well as comorbid conditions including falls and major depression.

The exception is the CPT code 99483 for care planning, which can only be used with an ICD-10 code related to dementia or mild cognitive impairment. Options for ICD-10 codes are presented in Table 1 on the next page. CPT code 99483 provides reimbursement to physicians and other eligible billing practitioners for a comprehensive clinical visit that results in a written care plan. More details about [CPT 99483](#) are available from the Alzheimer's Association.



Table 1. Commonly Used ICD-10 Codes for Dementia and Mild Cognitive Impairment

Code	Description
G30.0	Dementia Alzheimer's disease with early onset
G30.1	Dementia Alzheimer's disease with late onset
G30.9	Dementia Alzheimer's disease, unspecified
F01.50	Vascular dementia without behavioral disturbance
F01.51	Vascular dementia with behavioral disturbance
F02.80	Dementia in other diseases classified elsewhere without behavioral disturbance
F02.81	Dementia in other diseases classified elsewhere with behavioral disturbance
F03.90	Unspecified dementia without behavioral disturbance
F03.91	Unspecified dementia with behavioral disturbance
G31.01	Pick's disease
G31.09	Other frontotemporal dementia
G31.83	Dementia with Lewy bodies
G31.84	Mild cognitive impairment, so stated
G31.85	Corticobasal degeneration

CPT Codes for the Ongoing Care of Persons with Cognitive Impairment or Dementia

Although CPT 99483 is specific to evaluating and treating dementia, and should be used in the appropriate circumstances, there are other ways to be compensated for ongoing care for patients already diagnosed with cognitive impairment or dementia. The Centers for Medicare & Medicaid Services (CMS) is making significant modifications to how physicians will be compensated through CPT codes as of January 1, 2021, so the codes described below may undergo changes.

Prolonged Service Codes with Direct Patient Contact:

- CPT code 99354, Prolonged E/M in the office or other outpatient setting requiring direct patient contact beyond the usual service, first hour
- CPT code 99355, Each additional 30 minutes, list separately in addition to code for prolonged service

These codes are added to the E/M codes 99212 to 99214, or 99202 to 99205 usual office visit codes. This is helpful when a patient has multiple comorbidities along with cognitive impairment. In this way, time spent managing their medical issues is compensated, as is time spent with family members and social workers. Time spent must be documented.



Prolonged Services Without Direct Face-to-Face Patient Contact:

- CPT code 99358, Prolonged E/M before and/or after direct patient care, first hour
- CPT code 99355, Each additional 30 minutes, list separately in addition to code for prolonged service

These codes are useful for work done before and after patient care. For example, telephone discussions with family members not present during face-to-face time, time consulting with other physicians or professionals (e.g., social work, physical therapy), and time reviewing records. These codes help reimburse for time that had previously not been compensated. Time spent must be documented.

Supervisory Codes:

- G0180 Care Plan Certification, initial
- G0179 Care Plan Re-Certification, valid if care is ongoing. This can be billed every 60 days.

If a patient is referred for skilled home care, usually requiring a visiting nurse in addition to physical therapy or occupational therapy, these codes will cover the time spent by the physician signing orders, as well as discussing and supervising care.

Both codes are also valid for ongoing hospice care if health care providers add the required GV/GW modifiers.

Advance Care Planning Codes:

- CPT code 99497 Advance Care Planning Up to 30 minutes
- CPT code 99498 Additional 30 minutes

Because cognitive impairment and dementia are progressive, it is crucial to have the patients express their wishes about whom they want to represent them and what they desire for end-of-life care before they lose the ability to articulate their preferences. These codes involve any discussion of Power of Attorney for Health Care, Advance Directives, Portable Medical Orders (POLST) forms, and/or the completion of these forms. If these codes are used contemporaneously with the Annual Wellness Visit, add 33 modifier (preventive services) as Medicare then pays the full covered amount without involving the secondary insurance.

Telehealth Visits

During the coronavirus pandemic, CMS has significantly expanded telehealth for Medicare beneficiaries. Table 2 summarizes the three main types of virtual services physicians and other professionals can provide to Medicare beneficiaries. Medicare telehealth visits can now be billed at the same rate as regular in-person visits. Within the category of Medicare telehealth visits, CMS and some private payers are allowing audio-only telephone calls to be billed in the same way as in-person visits and these visits are being paid retroactive to March 1, 2020.

In addition, certain telemedicine services have been expanded to both new and established patients, whereas previously those services were limited to patients who had an established relationship with the practitioner (Centers for Medicare & Medicaid Services, 2020). While regulations on telehealth will continue to evolve, the primary care team can explore how to further optimize dementia assessment, diagnosis, and care management through telehealth visits.

Table 2. Overview of Telehealth Visits

Type of Telehealth Visit	Requirements	Payment
Medicare telehealth visits	Must use an interactive audio and video telecommunications system that permits real-time communication between the distant site and the patient at home	May be billed at same rate as regular, in-person visits
Audio-only telephone calls	<ul style="list-style-type: none"> Can be used for new or established patients Document verbal consent and why in-person or audio video encounter was not possible These are patient (or caregiver) initiated encounters 	<ul style="list-style-type: none"> 99441: Medical discussion of 5–10 minutes duration 99442: Medical discussion of 11–20 minutes duration 99443: Medical discussion of 21–30 minutes duration
Virtual check-ins	<ul style="list-style-type: none"> Intended for brief, patient-initiated technology-based communications (5–7 minutes of discussion) Practitioner may respond to the patient's concern by telephone, audio/video, secure text messaging, email, or use of a patient portal 	<ul style="list-style-type: none"> May be billed as communication technology modalities, such as telephone (HCPCS code G2012) Separate captured video or images can be sent to a physician (HCPCS code G2010)
E-visits	Patient-initiated online evaluation and management conducted via a patient portal	May be billed using CPT codes 99421–99423 and HCPCS codes G2061–G2063, as applicable

Source: Centers for Medicare & Medicaid Services, 2020.

Quality Measures

In addition to coding, health care practices should consider how KAER-related clinical processes align with the clinical quality measures in federal programs such as the Merit-based Incentive Payment System (MIPS) and payment models such as Primary Care First. As an example, clinicians meeting [eligibility criteria](#) to participate in MIPS for performance year 2020 (January 1–December 31) can submit data on certain dementia process measures, summarized in Table 3. To access MIPS measures lists beyond the 2020 performance year, consult the [CMS Quality Payment Program website](#).

Table 3: Quality Measures That Align With KAER-Related Processes

Measure Name	Measure Description
Dementia: Cognitive Assessment	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least once within a 12-month period
Dementia: Functional Status Assessment	Percentage of patients with dementia for whom an assessment of functional status was performed at least once in the last 12 months
Dementia Associated Behavioral and Psychiatric Symptoms Screening and Management	Percentage of patients with dementia for whom there was a documented screening for behavioral and psychiatric symptoms, including depression, and for whom, if symptoms screening was positive, there was also documentation of recommendations for management in the last 12 months
Dementia: Safety Concern Screening and Follow-Up for Patients with Dementia	Percentage of patients with dementia or their caregiver(s) for whom there was a documented safety concerns screening in two domains of risk: 1) dangerousness to self or others and 2) environmental risks; and if safety concerns screening was positive in the last 12 months, there was documentation of mitigation recommendations, including but not limited to referral to other resources
Dementia: Education and Support of Caregivers for Patients with Dementia	Percentage of patients with dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND were referred to additional resources for support in the last 12 months

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Kickstart the Brain Health Conversation



Section Takeaways

After reviewing this section, primary care teams will know how to:

- Assess for sensory impairment.
- Comfortably initiate one or a series of brain health-focused conversations.
- Describe modifiable risk factors for dementia.
- Ask individuals about their memory and cognition.
- Actively listen for concerns expressed by patients and their families about memory and cognition.
- Have members of the health care team and office staff observe patients for signs and symptoms of cognitive impairment.
- Understand various ways that the primary care team can begin to identify indicators of cognitive impairment.

Overview

The objectives of Step 1 of the KAER Model—K for Kickstart—are to increase people's awareness of the importance of brain health and to assist the primary care team, including office staff, in detecting signs and symptoms of cognitive impairment that may lead to further evaluation.

A combination of approaches to detect cognitive impairment is useful, and methods described in this section may be used along with those in the next section of the KAER Model—A for Assess. If the primary concern is using a brief cognitive test or other structured assessment instruments, then toolkit users may opt to move ahead to [Step 2](#). It is essential to select and then routinely use one or more of the approaches described in Step 1 and/or Step 2.

None of the approaches detailed in this section should be considered diagnostic; if use of these approaches confirms the presence of signs and symptoms of cognitive impairment, practitioners should conduct a diagnostic evaluation or refer individuals for further evaluation (see [Step 3](#) in the toolkit—E for Evaluate).

All the tools and procedures are appropriate for use by primary care providers, and some can also be used by other primary care team members and office staff. Moreover, such assessments are consistent with the Annual Wellness Visit requirement for detection of cognitive impairment (U.S. Department of Health and Human Services, 2010).

Approaches to Implement

1 Address any sensory loss and apply effective communication strategies.

Individuals, especially older adults, may have sensory loss such as hearing or vision loss that can interfere with effective communication in primary care visits. Individuals with dual sensory loss are at increased risk for dementia (Hwang et al., 2020). Consider screening for these prior to initiating a brain health–focused conversation.

The [Hearing Handicap Inventory for the Elderly](#) is a widely recommended brief screening test for hearing loss.

To assess for vision loss, consider asking a single question from the [American Community Survey](#): “Are you blind or do you have serious difficulty seeing even when wearing glasses?” (U.S. Census Bureau, 2017).

If hearing or vision loss is detected, the [Addressing Sensory Loss Checklist](#) can provide strategies to help with effective communication.

The [one-page summary](#) of tips based on GSA’s *Communicating with Older Adults: An Evidence-Based Review of What Really Works*, is also a helpful resource.

2 Raise the topic of brain health and continue the conversation over subsequent visits.

The topic of brain health as an important aspect of overall health should be addressed with patients during any office visit, including the Annual Wellness Visit. If patients are scheduled for their Annual Wellness Visit, primary care teams should consider communicating about the purpose of the visit and have them [complete a list of medical history information to bring to the appointment](#).

Raising the topic of brain health will help normalize attention to it, encourage individuals to be more aware of changes to their cognition or other brain health–related changes, and create an environment where patients may feel more comfortable sharing their concerns. Many people are reluctant to express such concerns because of fear and stigma often associated with dementia.

Frank yet sensitive conversation about brain aging can be initiated using key messages (Table K-1) based on the Institute of Medicine’s [Cognitive Aging: Progress in Understanding and Opportunities for Action](#). Another useful resource is a video from the Alzheimer’s Association, [Visit 1: Assessing Cognition and Recommending Follow-Up](#), illustrating how these messages can be effectively used during a visit.

Table K-1. Key Messages About Brain Aging

The brain ages, just like other parts of the body.
Cognitive aging is not a disease. It is a natural, lifelong process that occurs in every individual.
Cognitive aging is different for every individual.
Some cognitive functions improve with age.
People can take steps to protect their cognitive health.

Source: Adapted from the Institute of Medicine, 2015.

Even if individuals do not express concerns, health care team members can use a brain health conversation to share important information about how medications can affect the brain, the connection between a healthy heart and a healthy brain, and lifestyle habits that can support a healthy body and brain. A variety of print and web-based resources on brain health-related topics are readily available, in English and Spanish, to share with patients (Table K-2). These resources can be offered during a single visit, or, ideally over the course of multiple visits to allow opportunity for additional dialogue about each topic.

Table K-2. Resources on Brain Health for Patients

Topic	Resource	Developer
The relationship between brain health and factors such as smoking, alcohol, cholesterol, and blood pressure	<ul style="list-style-type: none"> Brain Health as You Age (printable file) Salud cerebral con el paso de los años (printable file) Talking About Brain Health & Aging (English-only printable file) 	Administration for Community Living
How medications to treat certain conditions may affect brain function	Medicine, Age, and Your Brain (English-only printable file)	Administration for Community Living, National Institutes of Health, Centers for Disease Control and Prevention
The connection between a healthy heart and a healthy brain; lifestyle changes to reduce risk of stroke, heart disease, and dementia in later life	<ul style="list-style-type: none"> Steps to Manage Risk webpage High Blood Pressure (webpage) Presión arterial alta (webpage) 	National Institute of Neurological Disorders and Stroke; National Heart, Lung, and Blood Institute
The difference between normal, healthy aging and dementia	The Truth About Aging and Dementia (webpage)	Centers for Disease Control and Prevention
Information on key lifestyle habits for a healthy body and brain, including dietary approaches	10 Ways to Love Your Brain (webpage)	Alzheimer's Association
Physical exercise, food and nutrition, medical health, sleep and relaxation, mental fitness, and social interaction are foundational to brain health	Six Pillars of Brain Health (webpage)	Cleveland Clinic
Actions that individuals, communities, and policymakers can take to promote healthy brain behaviors	How to Sustain Brain Healthy Behaviors: Applying Lessons of Public Health and Science to Drive Change Report (Spanish); Summary; Infographic (Spanish, French, Chinese, and Arabic)	The Global Council on Brain Health



In addition, health care teams can use brain health-related discussions to encourage patients to adopt lifestyle changes that can potentially improve their brain health. The evidence base for risk factors is quickly evolving. Recent clinical studies have confirmed that treating high blood pressure with medication can reduce risk of dementia and Alzheimer's disease (SPRINT MIND, 2019; Ding et al., 2020). There is also a global study underway examining the protective effects of a multi-pronged intervention consisting of physical exercise, a healthy diet, cognitive stimulation, and self-monitoring of heart health risk factors on cognitive function (Kivipelto, 2020; U.S. POINTER, 2020).

According to the Lancet Commission, an interdisciplinary, international group of experts, there are [12 potentially modifiable risk factors](#) that vary according to a person's stage of life and may contribute to an estimated 40% of dementia cases (Livingston et al., 2020).

Notably, the data examined by the Lancet Commission demonstrates association between these risk factors and dementia but does not prove causation. For example, individuals ages 65 years and older who have depression may be at higher risk of dementia; however, it is not clear whether their depression contributes to causing dementia because there is also evidence that the changes in the brain early in dementia cause depression (Science Media Centre, 2020).

In December 2021, the National Alzheimer's Plan added a new goal: Accelerate Action to Promote Healthy Aging and Reduce risk Factors for Alzheimer's Disease and Related Dementias (ADRD). The update calls for clear strategies to achieve this goal, including additional research, strengthening the public health infrastructure, and turning risk reduction research findings into clinical practice.

USAAgainstAlzheimer's has developed the [Clinician Guide on Risk Reduction, Primary Prevention Recommendations to Reduce the Risk of Cognitive Decline](#), which provides recommendations and implementation strategies across six topics: neurovascular risk management, physical activity, sleep, nutrition, social isolation, and cognitive stimulation. These recommendations are a first step for clinicians to address brain health with patients and potentially help them prevent cognitive decline. The recommendations are mindful of social determinants of health, account for cultural differences, and are designed for general accessibility. This toolkit includes infographics and a clinician guide, both in English and Spanish.

The [Global Council on Brain Health's](#) report, *How to Sustain Brain Healthy Behaviors: Applying Lessons of Public Health and Science to Drive Change* addresses actions that individuals, communities, and policymakers can take to promote healthy brain behaviors. The Council also makes available several resources that accompany the report in their [resource library](#).

When talking about risk factors with patients, it may be helpful to describe how lifestyle changes may make the brain more vulnerable or more resilient over time; however, it is important not to give the impression that getting dementia is their own "fault" (Science Media Centre 2020).

3 Ask about memory and cognition.

Ask patients whether they have concerns about their memory or cognition or have noticed changes in their memory or cognition since their last office visit or over a specified time period.

Options for wording include the following:

- "Are you worried about your memory?"
- "Have you noticed any changes in your memory that concern you?"
- "During the past few months, have you had increasing problems with your memory?"

The first and second questions ask about concerns that individuals may have, whereas the second and third questions ask about changes they may have noticed. Both topics are important, and asking one question about each topic may be the preferred option.

The focus on memory in all three questions reflects the way many people speak about changes in their cognition, even though other cognitive functions, such as attention, executive function, language, and spatial orientation, can also decline. Members of the care team may opt to ask about memory and at least one other cognition-related function (e.g., following a familiar recipe or getting lost in a familiar place).

4 Listen for people's concerns about memory and cognition.

Listen for and acknowledge people's concerns about memory and cognition. Thoughtful responses to their tentatively expressed concerns can help them to overcome reluctance to talk about the problem. A brief cognitive test for assessment (Step 2, [Approach 1](#) in the toolkit) can be introduced.

As an example, [Assessing Cognition and Recommending Follow-Up](#) shows a staged interaction in which a physician responds to a patient's very tentative expression of concern about her memory. In a friendly, conversational tone, the physician acknowledges the concern and encourages the patient to share more about her experience with memory problems.

UsAgainstAlzheimer's has developed a memory questionnaire, [BrainGuide](#), that may be useful for patients who are concerned about their brain health, that of a loved one, or if they are an Alzheimer's caregiver, it provides the tools needed for move forward confidentially. It takes about 10 minutes to complete and upon finishing, patients will be directed to a page with relevant resources that can help them better understand Alzheimer's, their brain health, and recommendations on next steps.

5 Listen for family concerns about people's memory and cognition.

More than one third of patients ages 65 years and older are routinely accompanied by a family member, close friend, or neighbor to their primary care visits; these older individuals, on average, are sicker and more likely to have dementia than those who are not routinely accompanied to their primary care visits (Wolff & Roter, 2008).

Family members and others may offer valuable insights about a person's cognition-related behaviors such as (U.S. Department of Veterans Affairs, 2020):

- Asking the same question repeatedly.
- Becoming lost in familiar places.
- Not being able to follow directions.
- Getting very confused about time, people, and places.
- Having difficulty with self-care, nutrition, bathing, or safety.

During the visit, health care team members may turn to the family member, friend, or neighbor and ask, "Have you noticed changes in your relative's (or friend's) memory?" Some family members and friends may be reluctant to talk about such changes in front of the individual because they do not want to upset or embarrass their friend or relative. For this reason, when speaking with a family member, close friend, or neighbor about the individual's cognition, consider asking the patient, "Do you mind if I ask your [family member, friend, neighbor] about your memory?"

In follow-up visits, a validated questionnaire can be completed by family members and other knowledgeable informants (as described in Step 2, [Approach 2](#)). The results of the questionnaire can be used to help determine whether a diagnostic evaluation is needed.

6 Observe for signs and symptoms of cognitive impairment.

Look for observable signs and symptoms, as listed in Figure K-3, that would suggest patients are experiencing a change in functions and abilities and that further evaluation is needed. The emphasis on change reflects the core requirement for a decline in memory and other cognitive functions to justify a diagnosis of dementia.

Figure K-3. Identification of Symptoms That Might Indicate Dementia

Does the person have increased difficulty with any of the activities listed below? Positive findings in any of these areas generally indicate the need for further assessment for the presence of dementia.

- Learning and retaining new information.** *For example,* is more repetitive; has more trouble remembering recent conversations, events, appointments; more frequently misplaces objects.
- Solving problems and handling complex tasks.** *For example,* struggles to perform tasks such as tracking monthly bills or solving a simple math problem; has more trouble following a complex train of thought.
- Reasoning ability.** *For example,* is unable to respond with a reasonable plan to problems at work or home, such as knowing what to do if the bathroom flooded; shows uncharacteristic disregard for rules of social conduct.
- Spatial ability and orientation.** *For example,* has trouble driving, organizing objects around the house, or finding his or her way around familiar places.
- Language.** *For example,* has increasing difficulty finding the words to express what he or she wants to say and has increasing difficulty following conversations.
- Behavior.** *For example,* appears more passive and less responsive; is more irritable than usual; is more suspicious than usual; misinterprets visual or auditory stimuli.

Source: Adapted from Agency for Healthcare Research and Quality, 1996.

Additional signs and symptoms may especially be observable to members of the clinical team or office staff before, during, or after a patient's medical appointment (National Chronic Care Consortium & Alzheimer's Association, 2003). For example, those employed at the primary care practice may note that the patient:

- Fails to appear for scheduled appointments or comes at the wrong time or on the wrong day.
- Is a poor historian.
- Defers to a family member to answer questions directed to the patient.
- Repeatedly and apparently unintentionally fails to follow instructions (e.g., changing medications).

Health care teams that have been caring for a patient over a period of years may notice changes in the individual's cognitive functioning and abilities that might not be noticed in a patient being seen for the first time. The whole primary care team can contribute to these observations. Indeed, some signs (e.g., the patient repeatedly fails to appear for scheduled appointments) may be more readily noticed by office staff than members of the clinical team.

7 Add a question about memory or cognition to health risk questionnaires.

Consider adding a question about memory or cognition as part of an assessment or questionnaire that is already in use at the practice for collecting patient information prior to or during regular visits. For new patients, this can be part of the general admission procedure and can be included in the electronic health record to be monitored in future visits. Examples of questions to use include:

- “Are you worried about your memory?” (Maslow & Fortinsky, 2018)
- “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” (Cordell et al., 2013)

The second question has been tested and approved by the Centers for Disease Control and Prevention (CDC) for use in a national survey (National Association of Chronic Disease Directors, 2018). Because reference to a concrete time request such as 12 months may make patients nervous, especially if they are already having trouble in managing their time and schedule, consider softening this question to “lately”, “recently”, or “frequently.”

8 Use electronic health records to flag potential indicators of cognitive impairment.

Most medical records already include information about characteristics of patients, such as age, health conditions, and functional abilities that have been found to be associated with cognitive impairment and dementia. These include:

- Stroke
- Diabetes
- Depressive symptoms
- Falls
- Gait disorders
- Need for assistance with money management
- Need for assistance with medication administration
- Need for assistance with activities of daily living

Some of these factors, such as stroke, are known causes of cognitive impairment. Others, such as the need for assistance with medication administration, may be caused by cognitive impairment.

The primary care team can use information about these factors as flags to identify individuals who should receive a cognitive assessment and a diagnostic evaluation (Barnes et al., 2014; Hausdorff & Buchman, 2013; Stark et al., 2013). One way to do this is to create alerts in the electronic health record related to one or a combination of these indicators (Cordell et al., 2013).



KAER

2

Assess for Cognitive Impairment



Section Takeaways

After reviewing this section, primary care teams will know how to:

- Select a validated brief cognitive test to use in efforts to detect cognitive impairment.
- Encourage family members and other knowledgeable informants to share potential concerns.
- Encourage patients to share potential concerns.
- Define subjective cognitive decline.
- Involve medical assistants and other nonclinical team members in efforts to detect cognitive impairment.

Overview

The objective of KAER Step 2—A for Assess—is to help the primary care team detect cognitive impairment in patients and determine whether a diagnostic evaluation is needed. Care teams can accomplish this by using brief cognitive tests and other structured assessment instruments as described in this section. **These tests can be administered by a variety of team members, including medical assistants.**

In addition to brief cognitive tests, there are two other types of structured assessment instruments to detect cognitive impairment:

- Brief informant questionnaires that elicit family members' perceptions about the patient's cognition.
- Brief self-report questionnaires to obtain the patient's perceptions about his or her own cognition.

All three types of assessment instruments can be used during a patient visit, including initial and subsequent Annual Wellness Visits. Clinicians should bear in mind that **there is no gold standard test for detecting cognitive impairment** and that these tests are not designed for rendering a diagnosis (see Step 3 of the toolkit—E for Evaluate—for approaches within the diagnostic evaluation process.)



Approaches to Implement

1 Use a validated, brief cognitive test to detect cognitive impairment.

The primary care team can use brief cognitive screening tests to determine whether an individual should receive a full diagnostic evaluation.

Several instruments are available to screen for cognitive impairment (Table A-1). Health care providers can select the one that care team members feel most comfortable integrating into clinical practice. Among the factors to consider when selecting a cognitive screening instrument are the existing clinical structure, workflow, and patient population. Practices may also wish to consider the criteria previously used by the National Institute on Aging and Alzheimer's Association (Cordell et al., 2013). These key questions are constructive when selecting a cognitive screening test:

- Can it be administered in fewer than 5 minutes?
- Can it be used clinically free of charge?
- Has it been validated in the community or primary care setting?

The Mini-Cog® meets these criteria and would be a good choice for primary care teams wishing to prioritize among available tools. The Clock Drawing Test, which can be administered as part of or separate from the Mini-Cog®, can be useful to assess executive function. It can be very good as a quick screening to see if more detailed assessment is needed.

The Montreal Cognitive Assessment (MoCA) and the Saint Louis University Mental Status (SLUMS) examination, while requiring more time to administer, are popular instruments among primary care teams and dementia experts because of their high reliability and ability to adjust for level of education. Of note, a variety of team members without psychometric and cognitive training, including nurses and medical assistants, can be trained to use these instruments.

Table A-1 on the next page summarizes features of each instrument; screening time will vary accordingly to the patient's functional and cognitive status, and educational level. Use of the MoCA will involve paying licensing fees and meeting training requirements.

Table A-1. Brief Cognitive Screening Tests

Name of Test	Distinguishing Features	Number of Items	Time to Administer*	Supporting Studies
Mini-Cog®	<ul style="list-style-type: none"> Good sensitivity Easy to administer and interpret Does not adjust for education level Available in English, Spanish, and other languages† 	Not applicable; 3-word recall and clock-drawing test	3–5 minutes	Holsinger et al., 2012
Clock Drawing Test	Can be rapidly administered to identify structural impairment	Not applicable	Not applicable	Wolf-Klein et al., 1989
The Montreal Cognitive Assessment (MoCA) questionnaire	<ul style="list-style-type: none"> Good sensitivity Adjusts for education level Assesses for executive function 	12	10 minutes	Galvin, 2018
The Saint Louis University Mental Status (SLUMS) exam	<ul style="list-style-type: none"> Good sensitivity Adjusts for education level Assesses for executive function Available in English, Spanish, and other languages† 	11	7 minutes	Feliciano et al., 2013
A Short Test of Mental Status (STMS) questionnaire	<ul style="list-style-type: none"> Good sensitivity and specificity Does not adjust for education level Assesses for executive function 	8	5 minutes	Kokmen et al., 1991

* Timing is approximate and will depend on the patient's functional status.

† Links to English version only.

2 Use a validated, brief questionnaire to obtain perceptions of family members or other knowledgeable informants.

Use of a brief, structured questionnaire can help the health care team obtain the perceptions of a family member or other knowledgeable informant about any changes to cognition and function, as well as any neuropsychiatric symptoms, that the patient may be experiencing. Although not diagnostic in nature, these can be helpful tools for increasing accuracy of information collected before undertaking a more comprehensive evaluation.

As with the brief cognitive tests, there are several informant-based instruments that can produce reliable data to help determine whether a diagnostic evaluation is needed (Table A-2). The Ascertain Dementia 8-Item Informant Questionnaire (AD8) discriminates normal and abnormal cognitive function. It yields a score from 0 to 8 based on the number of positive responses to eight 'Yes/No' questions. These questions cover whether or not an individual repeats him or herself (memory), has reduced interest in hobbies and activities (apathy), has trouble with judgment (executive), has trouble operating appliances (executive), forgets the month or year (orientation), has trouble with finances (executive), forgets appointments (memory), or experiences daily problems with memory or thinking (general) (Galvin et al., 2005). The AD8 is sensitive to the earliest signs of cognitive impairment as reported by a knowledgeable informant (e.g., family member or close friend) or the individual (Galvin et al. 2005; Galvin et al. 2006). For more information on the AD8 as a self-report questionnaire, please see discussion under Step 2, [Approach 3](#).

The Informant-based Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) rating scale is distinct from the AD8 questionnaire in that it can provide insight about the severity of neuropsychiatric symptoms that a person with dementia may experience in an observable way (e.g., dementia-related psychosis, aggression). Because the test asks about symptoms observed in the past two weeks, it does not require long-term recall on the part of the family member or knowledgeable informant. In contrast, the Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE or IQ Code 16) screening tool asks the family member or knowledgeable informant to reflect on any changes that may have occurred in the person in the last ten years.

Table A-2. Family and Informant Questionnaires for Detecting Signs of Dementia

Name of Questionnaire	Distinguishing Features	Number Questions	Response Categories	Length of Time Addressed	Time to Administer*	Supporting Studies
The Ascertain Dementia 8-Item Informant Questionnaire (AD8)	<ul style="list-style-type: none"> Reliably differentiates cognitive function among individuals with and without dementia Brief to administer Well-researched 	8	3	Several years	3 minutes	Galvin et al., 2005
Informant-based Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) rating scale	Collects information on observable neuropsychiatric symptoms unlike other informant-based tests	25	3	2 weeks	20 minutes	Reisberg et al., 1996 Reisberg et al., 2014
The Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE or IQ Code 16) screening tool	<ul style="list-style-type: none"> May not be able to detect mild cognitive impairment and prodromal forms of dementia Information from the IQCODE and the Mini-Mental State Examination can be combined to aid in assessing for dementia 	16	5	10 years	10–15 minutes	Jorm, 1994 Jorm, 2004 Razavi et al., 2014



③ Use a brief, validated self-report questionnaire to obtain individuals' perceptions of their own cognition.

Some individuals may have subjective cognitive decline (SCD), the self-reported experience of worsening or more frequent confusion or memory loss. Although 1 in 9 people ages 45 years and older experience SCD, fewer than half discuss it with their health care teams (National Association of Chronic Disease Directors, 2018). An [infographic](#) from the CDC is helpful for explaining SCD to patients.

The Alzheimer's Association offers a [patient-facing worksheet](#) and a [worksheet for family members and other informants](#), based on its widely disseminated [10 Warning Signs of Alzheimer's](#) that can help begin to guide individuals on how to observe symptoms.

To elicit patient concerns and identify SCD; a member of the health care team can ask individuals to use a self-report questionnaire. This may be especially important when a person does not have a family member or friend to provide reliable information about changes that may have occurred to the person's cognitive status.

There is no standardized way to measure SCD, however the authors of an international study on available measures for SCD made recommendations regarding tool selection (Rabin et al., 2015). SCD measures should:

- Correspond to the target patient population
- Be simple and easy to understand
- Avoid combining multiple health constructs (e.g., items related to cognition and health status)
- Inquire about cognitive issues that individuals may frequently experience in everyday life
- Emphasize specific cognitive items rather than general items

Some research studies suggest that the Ascertain Dementia 8-Item Informant Questionnaire (AD8), which is also used as an informant-based tool (see discussion under Step 2, [Approach 2](#)), may be better than other self-report questionnaires at capturing self-reported symptoms of cognitive decline for three reasons (Galvin et al., 2007):

- Questions are neutral in tone and present everyday functional activities in a nonthreatening fashion.
- Questions do not attribute cause to any change in ability; therefore, the AD8 is less likely to provoke anxiety about whether change is due to aging or disease in the respondent.
- Individuals are not asked to offer complaints but simply to rate whether a change in their ability to complete the tasks has occurred.

While research on the AD8 suggests the tool is more accurate in detecting subtle signs of cognitive decline when used by the informant rather than the individual (Dong et al., 2013), AD8 self-ratings provide useful information about cognitive ability and are especially valuable for increasing understanding about people's own perceptions about cognitive changes. Table A-3 summarizes the key features of the AD8 as a self-report instrument.

Table A-3. Features of Tools for Self-Reporting of Cognitive Decline

Name of Tool	Key Features	Number of Questions	Response Categories	Length of Time Addressed	Time to Administer*	Evidence of Validation
The Ascertain Dementia 8-Item Informant Questionnaire (AD8)	Less likely to provoke anxiety because questions do not address change in ability	8	3	Several years	3 minutes	Galvin et al., 2007

4 Have office staff participate in the primary care team's efforts to detect cognitive impairment in a timely way.

With some training, office staff can assist the care team in detecting cognitive impairment in patients (Maslow & Fortinsky, 2018). For example, they can ask patients whether they have noticed changes in their memory; office staff also can be alert for signs, as discussed in Step 1, [Approach 6](#), such as missing scheduled appointments or coming in on the wrong day. In addition, office staff can administer and score brief cognitive tests as described in the Case Study.

Findings from the brief cognitive test can be integrated into the electronic health record to prompt the primary care team to follow up. The primary care team can then determine whether patients should receive further cognitive assessment or a diagnostic evaluation.

Case Study: Medical Assistants Administer the Mini-Cog® With High Reliability in Four Primary Care Clinics

Setting: The University of Washington Physicians Neighborhood Clinics, four university-affiliated primary care clinics

Method: Twenty-six medical assistants (MAs) were trained in administration of the Mini-Cog®, gave and scored it after completing vital signs (noting the reason the patient was not screened, if applicable), and recorded the result in the electronic health record for review and further decision making by the physician. MAs were instructed not to discuss screening results with the patient and to refer any questions about the process to the patient's physician. Scoring of the Mini-Cog® by MAs was highly reliable (96% concordance with research scoring).

Results: MAs successfully screened 70% of all eligible patients who made at least one clinic visit during the intervention period; 18% screened positive. Mini-Cog® screening was associated with increased dementia diagnoses, specialist referrals, and prescribing of cognitive-enhancing medications. There were no complaints about workflow interruption.

Source: Borson et al., 2007.

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3

Evaluate for Dementia



Section Takeaways

After reviewing this section, primary care teams will know how to:

- Clearly explain the goals of the diagnostic process to patients and their families.
- Implement the key steps of the diagnostic process in clinical practice and/or be comfortable referring to the appropriate specialist.
- Identify diagnostic criteria for various potential causes of dementia.
- Appropriately document a diagnosis.
- Make disclosure of a diagnosis in a sensitive, person-centered way.

Overview

Many people who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed, and fewer than half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records report being told of their diagnosis (Alzheimer's Association, 2020).

If any member of the care team detects the presence of cognitive impairment in a patient, **at a minimum, reversible physiological causes of cognitive impairment need to be ruled out by ordering the appropriate guideline-recommended laboratory tests** (e.g., thyroid or vitamin B12 deficiency) (GSA, 2015).

If reversible physiologic causes are ruled out, then proceeding with a diagnostic evaluation may be appropriate. Step 3 of this toolkit—E for Evaluate—presents approaches, tools, and relevant clinical practice guidelines that may be helpful to the health care team in conducting a diagnostic evaluation, documenting the diagnosis, and disclosing it to the individual and family. The section also presents several available tools to help increase the individual and family members understanding about the importance of undergoing a diagnostic evaluation after cognitive impairment is detected.

There is no one-size-fits-all approach to the diagnostic evaluation process for primary care teams. Some primary care teams may already have procedures in place for conducting diagnostic evaluations, whereas others may need to develop a plan. The approaches and tools in this step are intended to provide information and options that will help care teams formulate new procedures or evaluate and perhaps improve the team's existing procedures for conducting diagnostic evaluations for dementia, as well as documenting and disclosing dementia diagnoses.

If the primary care team is unable to conduct a diagnostic evaluation, then patients with suspected cognitive impairment should be referred to a clinician or team specializing in dementia (e.g., geriatrician, neurologist, geriatric psychiatrist, neuropsychologist, nurse practitioner with geropsychiatric expertise, memory disorders clinic) (GSA, 2015).

Approaches to Implement

1 Support individuals and family members in understanding the importance of the diagnostic evaluation.

Primary care teams should support individuals and their families through the diagnostic journey by setting appropriate expectations, addressing misconceptions, and conveying information about the benefits of completing the process in an accessible way, free of jargon and judgment.

In addition, as described in [In Brief for Healthcare Professionals](#), primary care teams may want to convey to patients prior to their visit that the team's goal is to help them improve their health, delay their symptoms, and allow them to continue doing activities they enjoy.

This type of communication is crucial because patients and their families may fail to follow through on the primary care team's recommendation. Lack of follow-up may occur because of fear or shame about the possibility of a confirmed dementia diagnosis, reluctance to have others know about the diagnosis, and worry about consequences such as loss of the individual's driver's license, rejection for health or long-term care insurance, or refused admission to an assisted living facility or other senior residence.

Table E-1 shows some English- and Spanish-language resources that can be shared with individuals about the benefits of a timely diagnosis. The resource from Alzheimer's and Dementia Alliance of Wisconsin may be the most comprehensive resource to use with English-speaking individuals.

Table E-1. Resources for the Public About Early Recognition of Dementia

Name of Resource	Authoring Organization	Format
Early, Accurate Diagnosis Is Key	Alzheimer's and Dementia Alliance of Wisconsin	Website
Why Get Checked? ¿Por qué debe usted chequearse?	Alzheimer's Association	Website





2 Conduct a diagnostic evaluation or refer to a specialist.

A diagnostic evaluation for dementia is intended to determine whether a person with cognitive impairment has dementia or a non-dementia condition that is causing the cognitive impairment. Dementia is a syndrome characterized by cognitive and functional impairments. Specific criteria for a diagnosis of dementia come from various sources.

If the primary care team is unable to conduct a diagnostic evaluation, then patients with suspected cognitive impairment should be referred to a clinician or team of specialists with expertise in dementia.

The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) does not use the term "dementia." Instead, DSM-5 uses the term "neurocognitive disorder" to minimize the stigma associated with dementia. The criteria for neurocognitive disorder require impairment in one or more of six cognitive domains: complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition. The DSM-5 criteria require that the cognitive impairments must constitute a decline from a previous level of functioning, are serious enough to interfere with independent functioning, and do not occur solely in the course of delirium (American Psychiatric Association, 2013).

The eight recommended components of diagnostic evaluation for dementia include:

- Medical history
- Cognitive and mental status testing
- Functional assessment
- Physical and neurological examination
- Neuropsychological testing
- Laboratory tests
- Neuroimaging
- Specialist referral

The 2015 GSA Workgroup summarized each of these components based on six clinical guidance documents that were mainly intended for primary care (American Academy of Neurology, 2013; American Geriatrics Society, 2011; American Psychological Association, 2012; Galvin & Sadowsky, 2012; Geldmacher & Kerwin, 2013; Group Health Cooperative, 2012). More recent guidance documents by the American Academy of Neurology (Petersen, 2018) and the Alzheimer's Association (Fazio, 2018) affirm these components, which are summarized on the next page in Figure E-1.

Figure E-1. Components of a Diagnostic Evaluation for Dementia

Medical History

A medical history can be obtained through a clinical interview with the patient and at least one additional informant. It is important to gather information about the onset, course, and nature of memory and other cognitive impairments and any associated behavioral, medical, or psychological issues, including comorbid medical conditions, alcohol and other substance use, vision and hearing problems, and depression. The primary care team should also ask about recent illnesses, falls, head injury, prescription and over-the-counter medications, unintentional weight loss, and family history of dementia.

Cognitive and Mental Status Testing

Primary care teams may wish to use several assessment tools to evaluate patients for depression, cognition, and function. It is best to conduct cognitive testing using validated assessment instruments that measure multiple cognitive domains. Recommended instruments include the Mini-Cog® and the Montreal Cognitive Assessment (MoCA). Please see Table A-1 under Step 2, Approach 1 for a full list of recommended brief cognitive screening tests.

The Mini-Mental State Examination (MMSE) (Folstein et al., 1975) is a well-accepted and commonly used tool among healthcare professionals. The MMSE is more appropriate for patients with established cognitive impairment and can be used to evaluate the speed of decline over time. Presently, the use of the MMSE is restricted by copyright and can involve fees. Thus, the MMSE is not shown in this toolkit.

Primary care teams may use validated instruments to test for delirium and depression, such as the [Confusion Assessment Method \(CAM\)](#), the [Patient Health Questionnaire-9 \(PHQ-9\)](#), the [Geriatric Depression Scale](#), and the [Center for Epidemiologic Studies-Depression \(CES-D\) Scale](#).

Functional Assessment

Functional impairment is usually assessed by asking the older adult and a family member or other informant about the patient's daily functioning daily functioning. Commonly used instruments include the [Katz Index of Independence in Activities of Daily Living \(ADL\)](#) (asks about bathing, dressing, toileting, transferring, continence, and feeding) (Katz et al., 1970); the [Instrumental Activities of Daily Living \(IADL\) Scale](#) (asks about using the telephone, shopping, food preparation, housekeeping, laundry, transportation, and ability to manage medications and finances (Lawton & Brody, 1969); and the [Functional Activities Questionnaire \(FAQ\)](#) (asks about writing checks and other financial management activities; working on a hobby; making a cup of coffee or a balanced meal; keeping track of current events; understanding TV, a book, or a magazine; remembering appointments and medications; and driving or using other transportation) (Pfeffer et al., 1982).

A diagnosis of dementia requires impairment in functioning that is sufficient to interfere with performance of daily activities. If the patient has cognitive impairment but not the required level of functional impairment, a diagnosis of dementia cannot be made.

Physical and Neurological Examination

A physical and neurological examination can be conducted to assess walking, gait, balance, coordination, speech and language, vision, hearing, focal weakness, extrapyramidal signs rigidity, tremor, or slowness of movement (bradykinesia), blood pressure, and heart and other vascular functions that affect blood flow to the brain.

Neuropsychological Testing

Neuropsychological testing is especially helpful in diagnosing mild and very early stage dementia and evaluating atypical presentations. It can provide comprehensive, objective

information about which cognitive functions are affected and establish a baseline for future reevaluations.

Laboratory Tests

Routine laboratory tests are used to rule out treatable causes for cognitive impairment. Suggested tests include the following:

- Complete blood cell count
- Serum B12
- Serum calcium
- Folate
- Glucose
- Serum Electrolytes
- Thyroid function tests
- Liver function tests
- Renal function tests

Neuroimaging

Recommendations for use of neuroimaging in the clinical diagnostic evaluation of dementia vary. Some sources say that structural neuroimaging with a non-contrast computed tomography (CT) or magnetic resonance imaging (MRI) scan should be included. Other sources say that neuroimaging should be limited to particular clinical situations—for example, when the history and/or physical and neurological examinations indicate a possible central nervous system lesion and for patients who have atypical symptoms or sudden onset of dementia symptoms that could indicate a tumor, subdural hematoma, or normal pressure hydrocephalus.

SPECT (single-photon emission computed tomography) and FDG-PET (fluorodeoxyglucose positron emission tomography) are not currently recommended for use in routine clinical diagnostic evaluations for dementia. Diagnostic practices vary in different medical settings, however, and these tests may be used in routine clinical dementia evaluations in some settings.

FDG-PET scans are currently approved by CMS for patients who meet specified criteria (Centers for Medicare & Medicaid Services, 2009): they must have a recently established diagnosis of dementia with cognitive decline documented for at least 6 months; meet diagnostic criteria for both Alzheimer's disease and frontotemporal dementia; and have already been evaluated for specific alternative degenerative diseases or causative factors. Medicare also covers FDG-PET in CMS-approved clinical trials that focus on the utility of FDG-PET in the diagnosis or treatment of mild cognitive impairment or early dementia.

Specialist Referral

In the future, Beta-amyloid PET and Tau PET imaging might also be incorporated into standard practice. There are ongoing clinical studies to demonstrate their value in increasing the accuracy of the diagnostic process and in improving patient management. Results from a multicenter study of more than 11,000 Medicare beneficiaries suggested that amyloid PET imaging can be impactful in both areas (Rabinovici et al., 2019).

Primary care teams should consider referral to a specialist, such as a neurologist, geriatric psychiatrist, neuropsychologist, geriatrician, nurse practitioner with geropsychiatric experience, or a memory disorders clinic in situations where there is

- diagnostic uncertainty following a standard diagnostic evaluation;
- an atypical presentation;
- onset of symptoms in patients younger than 60 years of age;
- a request for a second opinion by the older adult or a family member; or
- conflict among family members about the diagnosis.

3 Identify the cause (or causes) of diagnosed dementia.

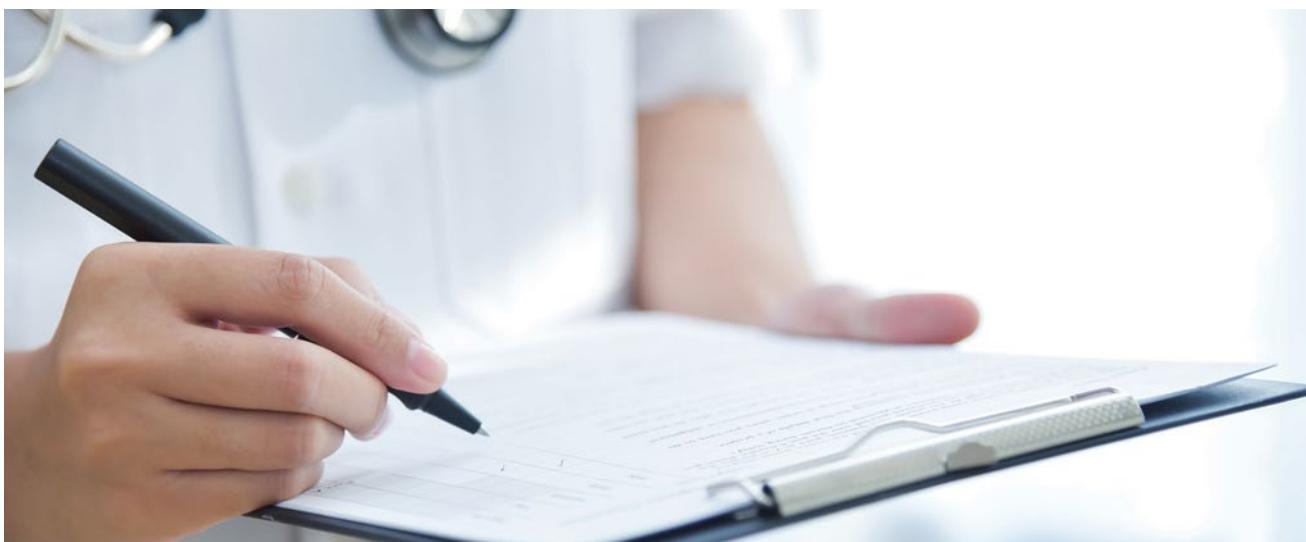
Once a person has been diagnosed with dementia, the next step is to identify its cause or causes so that the most appropriate therapies and support services can be initiated. Common causes of dementia include Alzheimer's disease, vascular conditions, Lewy body diseases, frontotemporal degeneration, and combinations of these and other conditions.

Until recently, the term "mixed dementia" was generally used for dementia caused by Alzheimer's disease and vascular conditions (Langa et al., 2004; Rahimi & Kovacs, 2014). There is growing recognition that more complex combinations of diseases and conditions often cause dementia, especially in older adults (Rahimi & Kovacs, 2014; Schneider et al., 2007; Sonnen et al., 2009). The implications of this in primary care are still unclear, and diagnostic criteria and procedures for clinical use related to mixed dementia are not available.

Providing an accurate diagnosis can be quite challenging and may require more than one visit and referral to a specialist. Table E-3 summarizes useful resources for developing or refining diagnostic procedures to identify the key features and pathology of different dementia types.

Table E-3. Comparison of Conditions and DSM-5 Diagnostic Criteria

Topic	Title	Format
Comparison table of various conditions that cause dementia, including usual course, presentation, risk factors, and imaging results	In Brief for Healthcare Professionals: Differentiating Dementias	2-page publication
Diagnostic criteria and codes for neurocognitive disorders, including dementia	DSM-5 (American Psychiatric Association, 2013) DSM-5 Coding Update For the latest updates, visit http://dsm.psychiatryonline.org	23-page publication



Dementia Caused by Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia. Current clinical criteria and procedures for the diagnosis of dementia caused by Alzheimer's disease (AD) were developed by the National Institute on Aging and the Alzheimer's Association Workgroup (McKhann et al., 2011). Table E-4 shows useful resources for clinical criteria and procedures for the diagnosis of AD.

Table E-4. Resources for Dementia Caused by Alzheimer's Disease

Topic	Title	Format
Clinical criteria and diagnostic procedures	The Diagnosis of Dementia Due to Alzheimer's Disease: Recommendations From the National Institute on Aging-Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease	Diagnostic criteria
A comprehensive quick-reference guide for clinicians that offers clinical criteria, assessment tools, and other information to support assessment, diagnosis, differential diagnosis, and ongoing management	<ul style="list-style-type: none"> • Alzheimer's Association—Alzheimer's Disease Pocketcard web version • Clinician Pocketcard app 	Free web- and smartphone-based applications

Dementia Caused by Vascular Conditions

Various vascular conditions can cause dementia, including stroke, multiple small strokes, white matter brain lesions, atherosclerosis, and micro bleeds. A review by Korczyn and colleagues (2012) cites several sources of clinical criteria for diagnosis of dementia caused by vascular conditions, including Chui and colleagues (1992) and Roman and colleagues (1993), but notes that there is no gold standard for this diagnosis. The review by Korczyn and colleagues (2012) concludes that "the occurrence of comorbid changes in the brain, the availability of multiple diagnostic criteria, and reliance on several imaging methods and different criteria for abnormality make diagnosis imprecise." With these caveats in mind, Table E-5 provides some useful resources.

Table E-5. Resources on Dementia Caused by Vascular Conditions

Topic	Title	Format
Diagnostic criteria for vascular dementia	NINDS – AIREN Criteria for the Diagnosis of Vascular Dementia (Roman et al., 1993)	Website
Summary of risk factors, course, differential diagnosis, and medications to use and avoid	A Healthcare Provider's Guide to Vascular Dementia (VaD)	5-page publication

Dementia Caused by Lewy Body Disease

Lewy body dementias are composed of two related disorders: dementia with Lewy bodies (DLB) and Parkinson's disease dementia. While there are no medical tests to diagnose Lewy body dementias with absolute certainty during life, specialists very familiar with the disease (e.g., neurologists, geriatrics psychiatrists, neuropsychologists) may accurately diagnose up to 90% of the time (Lewy Body Dementia Association, 2020). These specialists conduct their evaluation based on the patient's history, examination, and, potentially, blood tests or brain scans to exclude other causes of dementia, movement disorders, or behavioral problems.

The Lewy Body Dementia Association has several useful publications on diagnostic criteria and procedures for the disease that can be used to determine whether a referral to a specialist is indicated (Table E-6). The care team may consider using the Lewy Body Composite Risk Score after the completion of patient and caregiver interviews, a physical exam, and a neurological exam (Galvin, 2015).

Table E-6. Resources on Diagnostic Criteria for Lewy Body Dementia

Topic	Title	Format
Lewy Body Dementia Diagnostic Symptoms and 2017 Revised Diagnostic Criteria for Dementia with Lewy Bodies	Lewy Body Dementia Diagnostic Symptoms	2-page checklist
Instructions and validated rating scale to determine whether Lewy bodies are contributing pathology	Lewy Body Composite Risk Score (LBCRS)	2-page validated scale with instructions and 10 yes/no questions

Dementia Caused by Frontotemporal Degeneration

Frontotemporal degeneration includes three subtypes, each of which can cause dementia: behavioral variant frontotemporal dementia (bvFTD), semantic variant of primary progressive aphasia (svPPA), and nonfluent variant of primary progressive aphasia (nfvPPA). Neuropsychiatric symptoms are the most prominent symptoms of bvFTD, whereas difficulty with language and speech are the most prominent symptoms of svPPA and nfvPPA (Bott et al., 2014). Several published articles discuss diagnostic criteria for bvFTD (see Pijnenburg, 2011; Rascovsky et al., 2011) and primary progressive aphasia (Gorno-Tempini et al., 2011).

The Association for Frontotemporal Degeneration (AFTD) offers [resources for health care professionals](#) on diagnosing frontotemporal dementia, including a description of its key elements and references to diagnostic criteria. AFTD also makes available [resources for people newly diagnosed with frontotemporal degeneration](#) and their families.

4 Document the dementia diagnosis and identified causes.

Documentation of a dementia diagnosis in a patient's visit notes and problem list is essential to ensure continuous follow-up care. Primary care providers also need to include this information in the electronic health record to coordinate the care of individuals living with dementia who frequently transition across settings (Callahan et al., 2012; Callahan et al., 2015). Primary care teams should consider instituting routine documentation of dementia diagnoses and including relevant check boxes in the electronic health record.

5 Disclose the diagnosis and cause (or causes) to the individual in a person-centered way. When indicated—and with the appropriate permission—also disclose to the family or trusted friend in a person-centered manner.

Disclosing the diagnosis to the patient is crucial. If the individual does not have capacity to understand the information and/or share it, then the health care provider should seek the person's permission to involve a family member or trusted friend in the disclosure process as well. During the process, it is important to ask questions about what the individual knows and understands and to present the information in a way that avoids stigmatization.

According to several national surveys and studies, fewer than half of individuals diagnosed with dementia and their family members have a diagnosis disclosed to them (Alzheimer's Association, 2020; Bradford et al., 2011; U.S. Office of Disease Prevention and Health Promotion, 2016). Yet results from public surveys about Alzheimer's disease indicate that people have an interest in knowing the truth about their dementia-related symptoms or the symptoms of a family member. In an international survey, 85% of respondents stated that if they were exhibiting confusion and memory loss, they would want to see a doctor to determine if the cause of the symptoms was Alzheimer's disease; more than 94% stated they would want the same care if a family member were exhibiting the symptoms (Harvard School of Public Health & Alzheimer Europe, 2011). In a U.S.-based survey, most respondents expressed that they would be "very likely" (21%) or "somewhat likely" (31%) to proactively get a test or scan for early signs of Alzheimer's disease (Alliance for Aging Research, 2019).

A variety of online and print resources can assist the primary care team in delivering a diagnosis of dementia (Table E-7). As the care team adapts one or several of these resources for use in practice, the choice of words becomes critical to empowering patients and their family members—the language used should be simple, without jargon, and nonjudgmental.

Table E-7. Resources on How to Disclose a Diagnosis of Dementia

Topic	Title	Format
Video featuring a person-centered approach to disclosing a diagnosis	Delivering an Alzheimer's Disease Diagnosis	8-minute video
Video demonstrating best practices for making disclosure	Disclosing an Alzheimer's Diagnosis	10-minute video
Sample talking points to use with patients	Group Health Cooperative (2012) Dementia and Cognitive Impairment Diagnosis and Treatment Guideline	1-page summary document
Elements of making disclosure in a person-centered way as a process rather than a single event	Disclosing a Diagnosis of Dementia: Recommendations for a Person-Centered Approach	5-page peer-reviewed article

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4

Refer for Community Resources



Section Takeaways

After reviewing this section, primary care teams will know how to:

- Address the medical and psychosocial needs of people with dementia and their family caregivers by making referrals within the primary care team or extended care team in a standardized way.
- Address the medical and psychosocial needs of people with dementia and their family caregivers by making referrals to qualified local, regional, or national organizations in a standardized way.
- Support continuous education of patients and their families by making online and printed resources available prior to, during, and after office visits.
- Refer individuals with dementia and their families to clinical trials.

Overview

Offering follow-on assistance to individuals living with dementia and their families is crucial after disclosing a diagnosis. Individuals living with dementia are more likely to have other chronic conditions and have twice as many hospital stays per year than those without dementia (Alzheimer's Association, 2020). **A person living with dementia has many other health needs that need to be addressed** through referrals to professionals who have experience treating patients with dementia for their condition (e.g., hearing loss, arthritis, diabetes). Failure to attend to these needs will increase the apparent severity of a person's dementia.

A range of evidence-based psychosocial interventions can maintain or even improve quality of life for people with dementia and their families. For example, neuropsychiatric symptoms cause negative health outcomes in people with dementia (e.g., greater impairment in activities of daily living, accelerated mortality) (Karttunen et al., 2011; Murman et al., 2002) and increase family caregiver burden (Kales et al., 2015). Many interventions are available to help address the neuropsychiatric symptoms that these patients may experience. Someone on the primary care team should be knowledgeable about where such interventions are available in the local geographic area and be able to make a referral or provide the necessary contact information to patients or their families.

Step 4 of the KAER toolkit—R for Refer—provides approaches and resources to help primary care teams refer and connect people with dementia and their families to professionals, agencies, and organizations that provide supports and services related to dementia, as well as to clinical trials.

Approaches to Implement

① Refer patients with dementia to qualified internal staff to assess dementia-related needs and offer support.

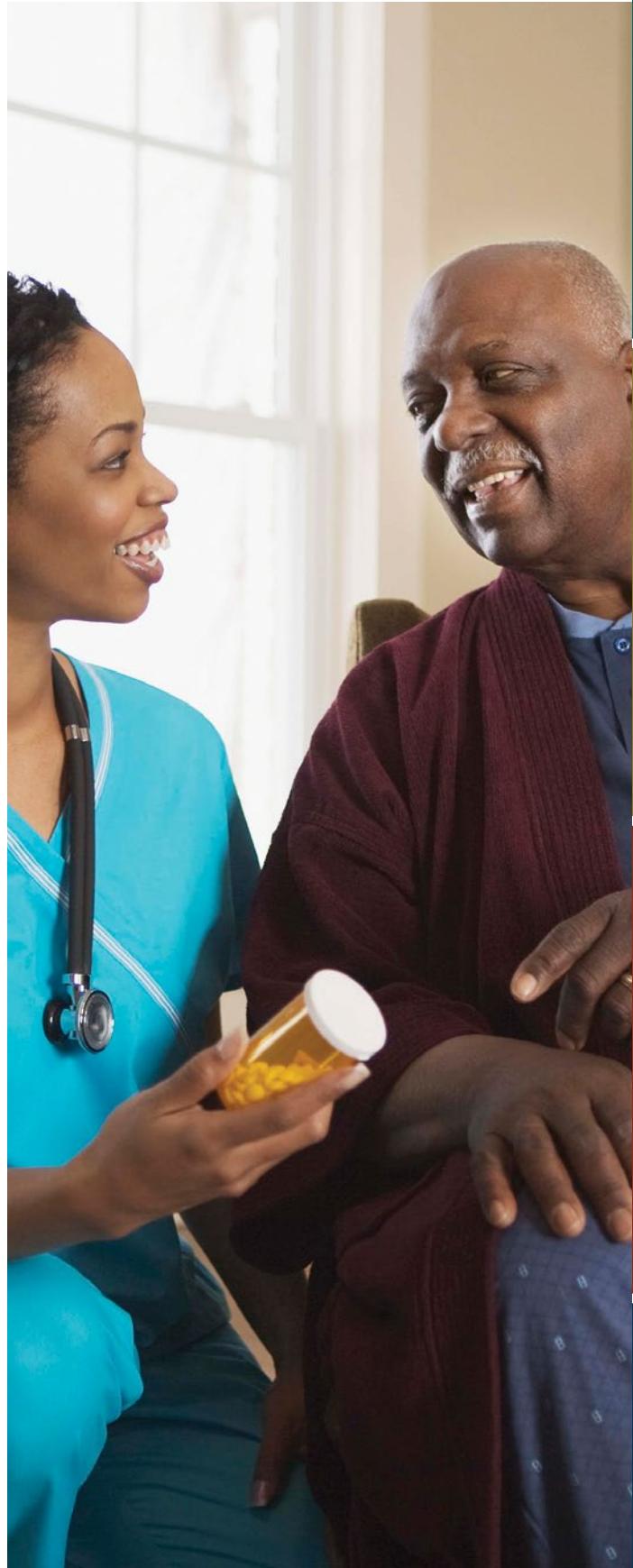
A member of the primary care team should refer individuals with dementia and their families to qualified professionals within the organization who can assist with identifying and addressing broader medical and psychosocial needs. If the health care organization has case managers, care managers, patient navigators, or others trained to assist primary care patients at high risk, then those staff can help with the needs assessment.

For example, if the person with dementia shows signs of sensory or motor loss, the case manager may ask the care team to conduct additional evaluations that could lead to a referral for rehabilitation services. As part of developing a holistic, person-centered care plan, the case manager may also recommend that the patient receive a nutritional evaluation and set up a plan to ensure the person with dementia will have regular, nutritious meals as the disease progresses. Of note, all the professionals involved in the internal referral (e.g., rehabilitation expert, nutritionist) must be aware of the special needs of individuals with dementia (Mittelman & Epstein, 2003).

The [GSA referral form](#), which can be customized to individual health care organizations, lists a variety of issues that can merit a referral and the types of professionals that would address these issues. The referral form also offers information about external organizations (page 3 of the referral form) that can assist with relevant needs and can be shared with patients.

② Refer patients with dementia to qualified community agencies and professionals to identify needs and access support.

When internal staff resources are limited, primary care teams should connect their patients and families to individuals or organizations that can help assess their needs. When doing so, it is important for the primary care team to verify that the external providers or organizations are knowledgeable about and qualified to assist with dementia-related needs (including nonmedical needs such as recreational, financial, and legal matters).





To ensure the information for each referral is standardized, the primary care team may wish to customize the [GSA referral form](#) for its own practice or organization. The form lists a variety of issues that can merit a referral and encourages documentation of the patient or health care proxy's authorization before making a referral.

In addition, the referral form offers information about external organizations that can be used to customize page 4 of the form to each patient. Ideally, a member of the care team would include the contact information for an expert who can assist with a specific issue and then serve as a gateway for the patient's next referral because individuals with dementia may have several competing needs for prioritization.

To avoid overwhelming people with dementia and their families with too much information, it is best to focus the materials offered to key resources. Another important aspect to ease the referral process is to ensure that any contact information shared is current.

Primary care teams can customize the referral form by

- including the contact information for the nearest [Area Agency on Aging, Aging and Disability Resource Centers](#), as well as contact information (ideally of specific individuals) for local or regional organizations offering dementia-specific supports. Of note, some Alzheimer's Association chapters and other Alzheimer's support organizations may help individuals living with other dementias (e.g., Lewy body dementias, frontotemporal dementia) access the appropriate services but that is not always the case. While services (and associated costs) will differ across communities and regions, certain Alzheimer's support organizations, including Alzheimer's Association chapters, tend to have similar programs.
- reviewing [Best Practice Caregiving](#), an online resource to identify nonpharmacological, evidence-based dementia caregiving programs and how to implement them into the health care organization. Filters can be applied to compare programs that meet the specific needs of the caregivers (e.g., the need to understand and manage symptoms of dementia or to improve health and wellness).
- adding specific community wellness centers, private agencies, and private organizations that



offer day programs and care management services for the benefit of people with dementia and their caregivers, such as the following:

- ▶ [SilverSneakers](#) offers free exercise classes for older adults with and without dementia on a Medicare Advantage Plan at gyms and community centers across the country.
- ▶ New York University Langone Health's [Alzheimer's Disease & Related Dementias Family Support Program](#) offers free recreational programs (e.g., memory café, music and dance therapy) specifically designed for people with early-stage dementia and caregivers to residents in the five boroughs of New York City.
- ▶ Alzheimer's Los Angeles, an Alzheimer's support organization, has a referral program, [ALZ Direct Connect](#), that primary care teams can use to refer a person with dementia, family member, or personal representative to the organization for help in identifying needs and finding appropriate services and other resources.

The services and resources in this list are useful examples when having discussions with people with dementia and their families on the types of services they may need. Alternative programs and strategies may need to be considered during the COVID-19 pandemic.

3 Conduct regular follow-up with patients and/or their families after making a referral.

After the primary care team makes the necessary referrals for the patient, regular points of follow-up should be established (e.g., after 2 weeks, after 1 month). This can be helpful for

- confirming that the professionals, agencies, or organizations are credible referral resources. A follow-up call will reveal whether these resources are getting in touch with the referred patients as requested and providing helpful services.
- refining the referral process. Patients and families may be able to provide useful feedback on which services they find most helpful.

- supporting patients and families in any outreach that they may need to do on their own. They may benefit from additional guidance on which resource to contact about their issue and the types of services to request.
- avoiding crisis situations. A 5-minute conversation may go a long way in helping patients or their family members to identify solutions that can prevent a worsening clinical or social scenario.

4 Provide information about clinical trials and encourage participation.

It is important to inform people that there are a variety of research opportunities that can benefit individuals with dementia. Both people with dementia and healthy individuals at risk for developing dementia may wish to sign up to participate.

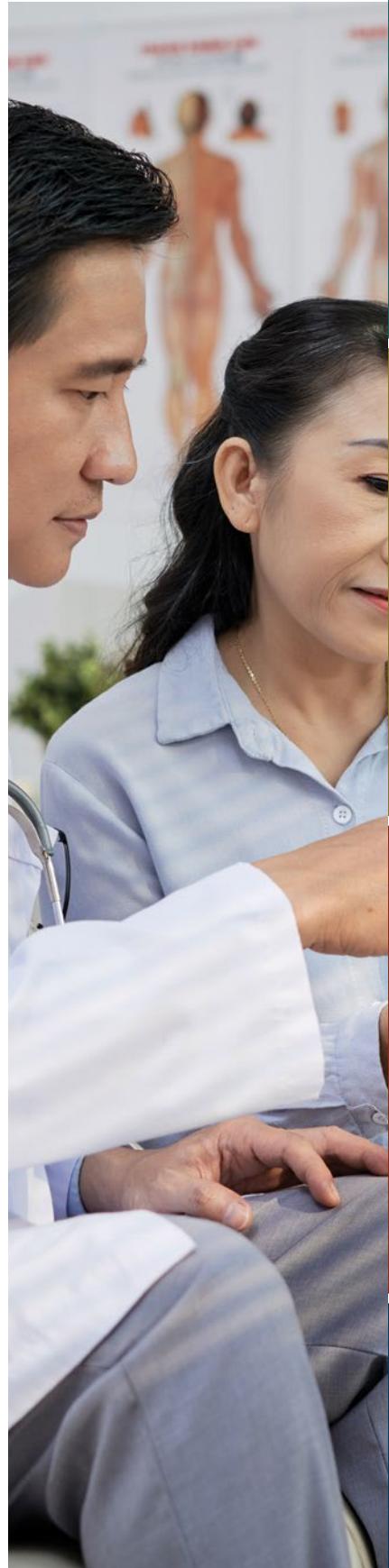
There are many kinds of research studies that may be of interest to people with dementia and their families. Some studies focus on testing new treatments for addressing the symptoms of dementia or slowing disease progression (both drug and nondrug trials). Others investigate ways to prevent the onset of disease through lifestyle interventions. There are also studies that seek to improve people's quality of life through psychosocial interventions.

Benefits of participation may include access to potential new treatments, access to medical care during the length of the study (often free of charge), the chance to play a more active role in one's own health care, and the ability to contribute to research that might benefit others (Alzheimer's Association, 2020).

Someone on the primary care team should be prepared to inform individuals about the benefits, risks, and options for participation in clinical trials by

- directly discussing options during an office visit, as part of care planning activities (CPT code 99483 may be applicable). To facilitate the discussion, the National Institute on Aging's 2-page [infographic](#) on clinical trial participation called Together We Make the Difference! Participate in Alzheimer's and Related Dementias Clinical Research can be shared.
- making an internal referral to a study coordinator, if one's organization is running a study that may be a good fit. Consider using the [GSA referral form](#) for this purpose.
- providing people and their families with the contact information for the National Institute on Aging's Alzheimer's Disease Education and Referral Center website, Find Alzheimer's Disease and Related Clinical Trials. It is a free resource that allows users to search for relevant clinical trials being conducted in their geographic area.

When discussing potential options with patients, it may be best to avoid negative phrases, such as "You don't qualify for this trial," that may be interpreted as a rejection. Instead, consider keeping the language positive: for example, "Let's find a trial that's a better fit."



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