



THE GERONTOLOGICAL SOCIETY OF AMERICA®



A 4-STEP PROCESS TO DETECTING  
COGNITIVE IMPAIRMENT AND  
EARLIER DIAGNOSIS OF DEMENTIA

Approaches and Tools for Primary Care Providers

Developed by the GSA Workgroup on  
Cognitive Impairment Detection  
and Earlier Diagnosis



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## THE KAER MODEL

In 2015, The Gerontological Society of America (GSA) released a report on 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, calls attention to three major points:

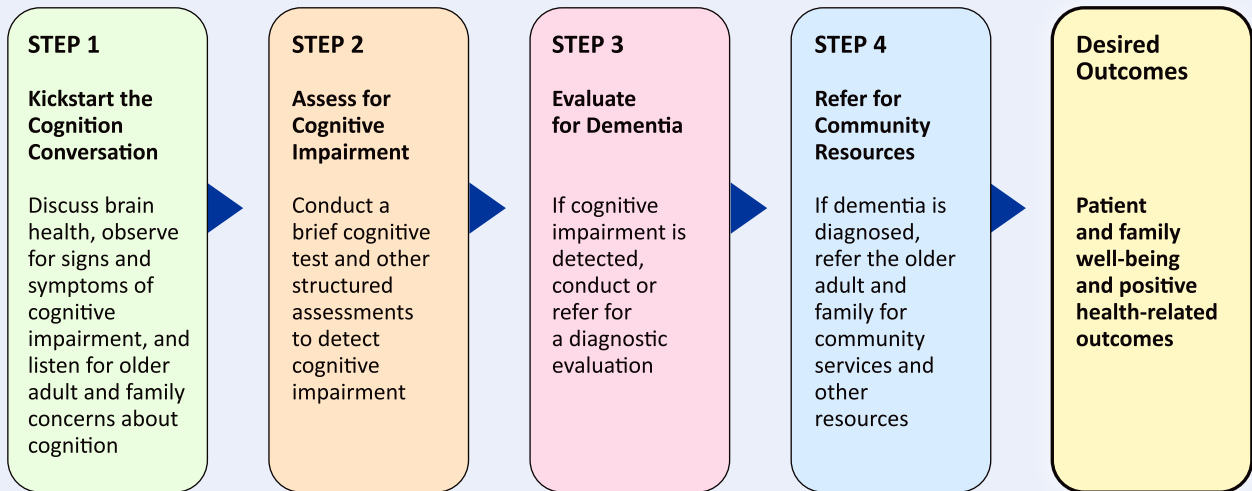
- Cognitive impairment in older adults is severely underdetected in the United States.
- If cognitive impairment is undetected, older adults who have the condition are unlikely to receive a diagnostic evaluation to determine the cause. Without a diagnostic evaluation, those who have dementia are unlikely to receive a diagnosis. Likewise, without a diagnostic evaluation, those who have treatable conditions that are either causing their cognitive impairment or exacerbating the cognitive impairment caused by their dementia are unlikely to receive treatments for these conditions.
- Without a diagnosis, older adults who have dementia and their families are unlikely to receive community-based educational, support, and skill-building services that often lead to improved health-related outcomes and well-being for the person with dementia as well as reduced stress, depression, and feelings of isolation and burden for family caregivers. Likewise, without a diagnosis, older adults with dementia are unlikely to benefit from post-diagnostic medical care that can help to mitigate the person's dementia-related symptoms and take into account the effects of the person's dementia in managing his or her other serious medical conditions (e.g., diabetes, congestive heart failure).

The GSA report emphasizes that primary care providers (PCPs), including physicians, physician assistants, and nurse practitioners, play critical roles in initiating conversations about brain health and cognition with their older adult patients, detecting cognitive impairment, conducting or referring for a diagnostic evaluation, and referring older adults with dementia and their families for help in accessing community-based services and other resources that will benefit them. This toolkit provides assessment instruments and other approaches and tools to help PCPs with these important functions.



The GSA Workgroup created a model that identifies four steps to achieve greater awareness of cognition in older adults, increased detection of cognitive impairment, earlier diagnostic evaluation, and referrals for educational and supportive community services for persons with dementia and their family caregivers. The four steps are ultimately intended to improve health-related outcomes and well-being for older adults with diagnosed dementia and their families. Figure 1 illustrates the KAER model.

**Figure 1. Steps in the KAER Model to Increase Cognitive Awareness, Detection of Cognitive Impairment, Diagnosis, and Post-Diagnostic Referrals and Medical Care**





## OBJECTIVES AND COMPONENTS OF THE TOOLKIT

PCPs, health plans, and health care systems vary greatly in the structure, organization, and the usual procedures of their primary care practices. The toolkit is intended to provide options so that PCPs, health plans, and health care systems will be able to select the approaches and tools that fit best with their existing primary care structure, organization, and procedures.

The toolkit has a section for each of the four steps in the KAER model:

1. **Kickstart** the cognition conversation
2. **Assess** for cognitive impairment
3. **Evaluate** for dementia
4. **Refer** for community resources

The four sections provide approaches and tools PCPs can use to implement the steps. Some of the tools are shown in the text, and other tools are included as appendices at the end of each section.

The KAER model focuses on the roles and functions of PCPs, but the GSA Workgroup recognizes that the knowledge and perceptions of older adults and their families affect what PCPs are able to accomplish in primary care office visits. An appendix to the fourth section of this toolkit (**Appendix R-6**) includes informational materials and tools that can help older adults and families be better prepared to engage in conversations about cognition with their PCP and understand and respond to their PCP's recommendations about obtaining a structured cognitive assessment, a diagnostic evaluation, and needed community services. These materials and tools include, for example, *Forgetfulness: Knowing When to Ask for Help*, a document developed by the National Institute on Aging (2016a) and the *Community Resource Finder*, an online tool developed by the Alzheimer's Association (n.d.-b) to help persons with dementia, families, and others identify needed services. Many other informational materials and tools for older adults and their families are listed in the appendix and can be easily downloaded and printed. Although PCPs are not responsible for providing these materials and tools, some PCPs, health plans, and health care systems may wish to inform their older adult patients and families about some of the materials and tools and may opt to have some of them available in the primary care office.





In general, the approaches and tools shown in this toolkit can be adapted by PCPs, health plans, and health care systems to fit their existing primary care structure, organization, and procedures. The exceptions are the brief cognitive tests and other structured assessments in KAER Step 2. These tests and other assessments have been validated in primary care settings, and changes made to them are likely to reduce their validity. Other tools and materials included in the toolkit should be considered templates that provide concepts, wording, and procedures that can be adapted by PCPs, health plans, and health care systems.

The approaches and tools included in the toolkit have been selected because they are appropriate for use in primary care settings. While the 2015 GSA report and this toolkit focus on PCPs and primary care, the GSA Workgroup recognizes that some older adults with cognitive impairment present first to another health care professional. Older adults also receive care in settings other than primary care, such as hospitals, emergency departments, nursing homes, assisted living facilities, and home and community-based care settings. Many of the tools and approaches included in the toolkit can be used as is or adapted for use by these other health care professionals and in care settings other than primary care.

An addendum to the KAER toolkit includes three clinical practice tools developed for Dementia Friendly America (2015, 2016a, 2016b), a Minnesota-based initiative to foster dementia friendly communities. The three clinical practice tools incorporate many of the same approaches and tools included in the KAER toolkit, but they encompass the broad continuum of dementia care delivered by an array of health care and other service providers in many care settings. In contrast, the KAER toolkit focuses primarily on dementia care provided by PCPs in primary care settings. The Dementia Friendly America clinical practice tools may be especially useful to PCPs, health plans, and health care systems in thinking about and designing systems of dementia care.

New approaches and tools to initiate conversations about brain health, detect and assess cognitive impairment, diagnose dementia, and provide post-diagnostic referrals are currently being developed and tested. As these new tools and materials become available, PCPs, health plans, and health care systems should adopt those that will work best in their primary care practices. In particular, the GSA Workgroup notes the need for evidence-based tools and approaches that more effectively accommodate racial, ethnic, cultural, and language-related diversity; low literacy; sensory impairments; and intellectual disabilities in older adults with cognitive impairment and dementia. As such tools become available, PCPs, health plans, and health care systems should consider adopting them.



## GENERAL TIPS FOR COMMUNICATING WITH OLDER ADULTS

A 2012 GSA publication, [Communicating With Older Adults: An Evidence-Based Review of What Really Works](#), provides information about communicating with older adults in general. A one-page summary of tips from the document can be found in **Appendix 1**.

Many older adults have hearing impairments that can interfere with effective communication in primary care visits. Although PCPs are aware of this problem in some of their older patients, it may be missed in other patients. Use of a brief screening test, the Hearing Handicap Inventory for the Elderly, is widely recommended. The test can be found in **Appendix 2**.

## TERMS AND DEFINITIONS

In this toolkit, the terms *family*, *family member*, and *family caregiver* are used to mean any relative, partner, friend, or neighbor who has a significant relationship with and provides assistance for an older adult with one or more chronic or disabling conditions (adapted from Feinberg, Reinhard, Houser, & Choula, 2011).

The term *dementia* is used to mean a condition in which there is decline in memory and other cognitive functions, such as thinking, problem solving, and language, that is severe enough to interfere with daily activities. Dementia can be caused by Alzheimer's disease, vascular conditions, Lewy body disease, frontotemporal degeneration, and combinations of these and other diseases and conditions, including treatable conditions, such as depression and vitamin B12 deficiency.





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<b>Appendix 2</b>	<a href="#"><u>Hearing Handicap Inventory for the Elderly-Screening Version</u></a>



# Recommendations for Communicating With Older Adults

## General Tips for Improving Interactions With Older Adults

- 1 Recognize the tendency to stereotype older adults, then conduct your own assessment.
- 2 Avoid speech that might be seen as patronizing to an older person (“elderspeak”).

## General Tips for Improving Face-to-Face Communication With Older Adults

- 3 Monitor and control your nonverbal behavior.
- 4 Minimize background noise.
- 5 Face older adults when you speak with them, with your lips at the same level as theirs.
- 6 Pay close attention to sentence structure when conveying critical information.
- 7 Use visual aids such as pictures and diagrams to help clarify and reinforce comprehension of key points.
- 8 Ask open-ended questions and genuinely listen.

## Tips for Optimizing Interactions Between Health Care Professionals and Older Patients

- 9 Express understanding and compassion to help older patients manage fear and uncertainty related to the aging process and chronic diseases.
- 10 Ask questions about an older adult’s living situation and social contacts.
- 11 Include older adults in the conversation even if their companion is in the room.
- 12 Customize care by seeking information about older adults’ cultural beliefs and values pertaining to illness and death.
- 13 Engage in shared decision making.
- 14 Strike an appropriate balance between respecting patients’ autonomy and stimulating their active participation in health care.
- 15 Avoid ageist assumptions when providing information and recommendations about preventive care.
- 16 Providing information to patients is important, but how you give information to patients may be even more important.
- 17 Use direct, concrete, actionable language when talking to older adults.
- 18 Verify listener comprehension during a conversation.
- 19 Set specific goals for listener comprehension.
- 20 Incorporate both technical knowledge and emotional appeal when discussing treatment regimens with older patients.
- 21 To provide quality health care, focus on enhancing patient satisfaction.
- 22 Use humor and a direct communication style with caution when interacting with non-Western older patients.
- 23 Help Internet-savvy older adults with chronic diseases find reputable sources of online support.
- 24 If computers are used during face-to-face visits with older adults, consider switching to models that facilitate collaborative use.

## Tips for Communicating With Older Adults With Dementia

- 25 Maintain a positive communicative tone when speaking with an older adult with dementia.
- 26 Avoid speaking slowly to older adults with dementia.
- 27 Pose different types of questions to patients with dementia according to conversational goals.
- 28 When communicating with older adults with dementia, simplify sentences by using right-branching sentences.
- 29 Use verbatim repetition or paraphrase sentences to facilitate comprehension in older adults with dementia.





## Hearing Handicap Inventory for the Elderly (HHIE-S)

ITEM	YES (4 pts)	SOMETIMES (2 pts)	NO (0 pts)
Does a hearing problem cause you to feel embarrassed when you meet new people?			
Does a hearing problem cause you to feel frustrated when talking to members of your family?			
Do you have difficulty hearing when someone speaks in a whisper?			
Do you feel handicapped by a hearing problem?			
Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbors?			
Does a hearing problem cause you to attend religious services less often than you would like?			
Does a hearing problem cause you to have arguments with family members?			
Does a hearing problem cause you difficulty when listening to TV or radio?			
Do you feel that any difficulty with your hearing limits or hampers your personal or social life?			
Does a hearing problem cause you difficulty when in a restaurant with relatives or friends?			
<b>RAW SCORE</b> _____ (sum of the points assigned each of the items)			
<b>INTERPRETING THE RAW SCORE</b>			
0 to 8 = 13% probability of hearing impairment (no handicap/no referral)			
10 to 24 = 50% probability of hearing impairment (mild-moderate handicap/refer)			
26 to 40 = 84% probability of hearing impairment (severe handicap/refer)			
Source: Ventry, I., Weinstein, B. (1983). Identification of elderly people with hearing problems. ©American Speech-Language-Hearing Association, July, 37–42. Reprinted with permission.			



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2. Ask about memory and cognition
3. Listen for older adults’ concerns about memory and cognition
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6. Add a question about memory or cognition to health risk questionnaires
7. Use information about health conditions and functioning from existing patient records
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## OVERVIEW

In its 2015 report, the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis recommends that:

- PCPs should initiate a conversation with their older adult patients and patients' families about brain health and changes in cognition that may occur with aging. PCPs should continue the conversation in subsequent visits and encourage their older adult patients to express any questions or concerns they may have about their cognition (GSA, 2015).
- PCPs should listen for and acknowledge any questions or concerns about cognition expressed by their older adult patients or family members. PCPs should use their clinical judgment and observational skills to identify signs and symptoms of cognitive impairment in their older adult patients (GSA, 2015).

The objectives of KAER Step 1 are to increase awareness among older adult patients about the importance of brain health and to assist PCPs in detecting signs and symptoms of cognitive impairment that should lead to further evaluation, including a brief cognitive test and other structured assessments (KAER Step 2) and a diagnostic evaluation (KAER Step 3), if indicated. Approach 1 includes tools and materials PCPs can use to increase awareness about brain health and aging. Approaches 2 to 7 include tools and procedures to help PCPs recognize signs and symptoms of cognitive impairment in their older adult patients. All the tools and procedures are intended for use by PCPs, and some can also be used by other primary care office staff.

***It is important to emphasize that none of these approaches is diagnostic.*** The approaches are intended to increase older adults' awareness of brain health and to assist PCPs in identifying older adults who have signs and symptoms of cognitive impairment and therefore should receive further evaluation.

All the approaches can be used in any PCP office visit, including initial and subsequent Annual Wellness Visits. The 2010 federal legislation that created the Annual Wellness Visit requires detection of any cognitive impairment and says that detection should be accomplished by "assessment of an individual's cognitive function by direct observation, with due consideration of information obtained by way of patient report, concerns raised by family members, friends, caretakers or others" (U.S. Department of Health and Human Services, 2010, p. 73613). All the tools and procedures shown in KAER Step 1 approaches 2 to 7 are consistent with the Annual Wellness Visit requirement for detection of cognitive impairment.



The brief cognitive tests and other structured assessment instruments described in KAER Step 2 also can be used to detect cognitive impairment. PCPs, health plans, and health care systems may choose to adopt any combination of the approaches and tools shown in Steps 1 and 2 to achieve the objective of detecting cognitive impairment. PCPs could, for example:

- Use one or more of the approaches in Step 1 to detect signs and symptoms of cognitive impairment and then recommend that older adults with such signs and symptoms receive a brief cognitive test and other structured assessments (KAER Step 2). Based on results of the cognitive test and other structured assessments, PCPs could then conduct or refer older adults with cognitive impairment for a diagnostic evaluation (KAER Step 3).
- Use one or more of the approaches in Step 1 to detect signs and symptoms of cognitive impairment and then conduct or refer older adults with such signs and symptoms for a diagnostic evaluation, thus skipping KAER Step 2.
- Use a brief cognitive test and other structured assessments (KAER Step 2) to determine which older adults should receive or be referred for a diagnostic evaluation, thus skipping KAER Step 1.

There is considerable disagreement about the best approach to detect cognitive impairment and determine which older adults should receive a diagnostic evaluation. Many clinician experts are convinced that the best approach is routine use of a brief cognitive test for all older adults, or older adults above a specified age, followed by provision or referral for a diagnostic evaluation for those whose scores on the brief cognitive test are consistent with possible dementia. In contrast, other clinician experts are convinced that the best approach is to observe for signs and symptoms of possible cognitive impairment, then provide a brief cognitive test and other structured assessments for only those older adults who are observed to have such signs and symptoms, and then conduct or refer for a diagnostic evaluation only those older adults whose test and other assessment scores are consistent with possible dementia. Disagreement about the best approach reflects differences in beliefs about a wide array of issues, including: the accuracy of cognitive impairment detection based on observed signs and symptoms versus a brief cognitive test; the willingness of older adults to take a brief cognitive test; the risk of over-identification of cognitive impairment based on a brief cognitive test; the risk of under-identification based on use of observed signs and symptoms alone; and recognition that some method or methods are needed to determine which older adults should receive a diagnostic evaluation in order to avoid the prohibitive cost of staff time and other resources that would be required to provide diagnostic evaluations for all older adults, most of whom do not have dementia.





## STEP 1 : KICKSTART

In this context, it is important to reiterate the findings of the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis that cognitive impairment in older adults is severely underdetected in the United States and that unless cognitive impairment is detected, older adults who have the condition are unlikely to receive a diagnostic evaluation to determine the cause of their cognitive impairment; those who have dementia are unlikely to receive a diagnosis; and those who have treatable conditions that are either causing or exacerbating their cognitive impairment are unlikely to receive treatments for the conditions. Therefore, despite ongoing disagreement about the best approach to detect cognitive impairment, it is essential for PCPs, health plans, and health care systems to select and then routinely use one or more of the approaches described in KAER Step 1 and/or Step 2.





## APPROACHES

### RAISE THE TOPIC OF BRAIN HEALTH.

PCPs can raise the topic of brain health during any office visit with an older adult, including an Annual Wellness Visit. By raising this topic, PCPs will communicate to their older adult patients that brain health and changes in memory and cognition that may occur in aging are important aspects of their overall health. Raising the topic will also help to normalize attention to cognition in primary care and encourage older adults to be aware of changes in their cognition and to tell their PCP about cognition-related concerns, if any. Many older adults are reluctant to express such concerns to their PCP, in part because of fear and stigma often associated with dementia. A frank yet sensitive introduction to the topic by the PCP is a highly appropriate first step to kickstart the cognition conversation. This approach can open the way for older adults to reveal any cognition-related concerns they may have.

#### Figure K-1. Key Messages for Older Adults 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.
- There are steps patients can take to protect their cognitive health.

Source: Institute of Medicine, 2015a.

A 2015 Institute of Medicine (IOM) report, *Cognitive Aging: Progress in Understanding and Opportunities for Action*, recommends that PCPs and other health care professionals should provide patients and families with information about brain health and aging. The related four-page document, [Cognitive Aging: An Action Guide for Health Care Providers \(Appendix K-1\)](#), suggests five key messages that PCPs could use in providing such information (Figure K-1) (IOM, 2015a).

IOM (2015b) also created a similar four-page document for older adults and their families, [Cognitive Aging: An Action Guide for Individuals and Families \(Appendix K-2\)](#).



Another source that may be useful for adult patients is a website, [“Brain Health: You Can Make a Difference!”](#) (**Appendix K-3**). The website was developed by the Administration for Community Living, the Centers for Disease Control and Prevention, and the National Institutes of Health (2014). It provides information about brain health and aging, including a [PowerPoint presentation](#) with slides on age-related changes in memory and learning and possible risks or threats to brain health (**Appendix K-4**). The slides are targeted to older adults and provide brief messages about brain health and aging that PCPs could adapt as they choose to talk with their older patients. The slides are available in Spanish on the same website. There is also a brief handout that some PCPs might want to download and give to patients as a reminder of the main points. The handout is available in English (**Appendix K-5**) and [Spanish](#) (**Appendix K-6**).



### ASK ABOUT MEMORY AND COGNITION.

PCPs can ask older adult patients whether they have concerns about their memory or cognition or have noticed changes in their memory or cognition since a previous office visit, if any, or over a specified time period.

Options for wording include the following:

- “Are you worried about your memory?”
- “Have you noticed a change in your memory that concerns you?”
- “During the past few months, have you had increasing problems with your memory?”

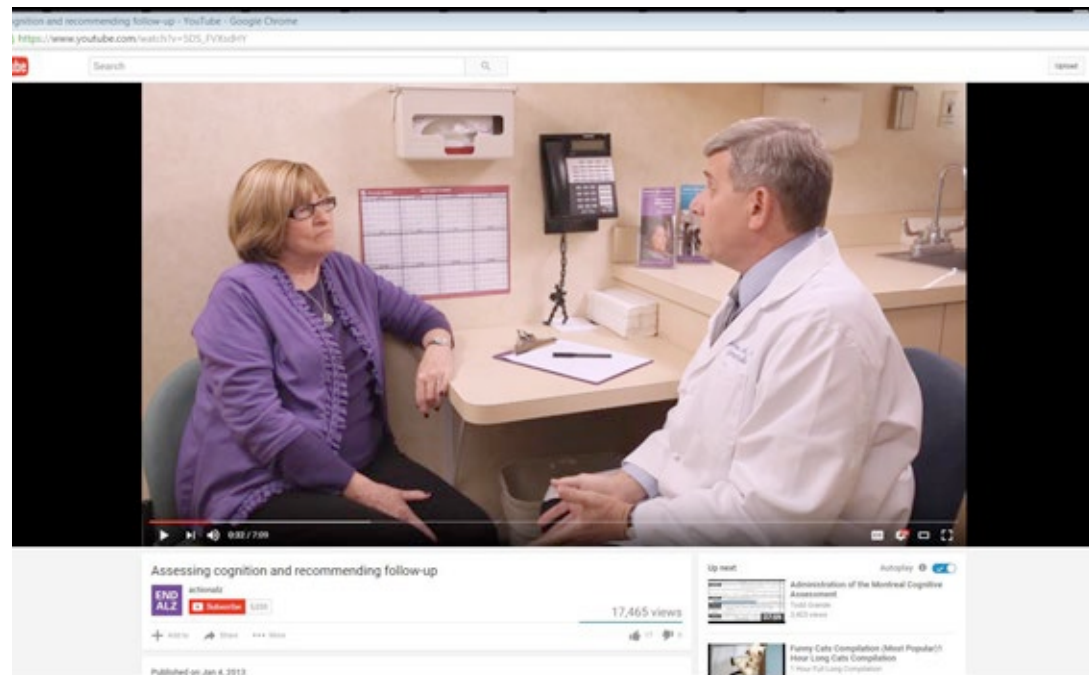
The first and second options ask about concerns the older adult may have, while the second and third options ask about changes the older adult may have noticed. Both topics are important, and PCPs may prefer to ask one question about each topic.

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 in older adults. PCPs may prefer to ask about memory and at least one other cognition-related function, such as following a familiar recipe or getting lost in a familiar place.



## LISTEN FOR OLDER ADULTS' CONCERNS ABOUT MEMORY AND COGNITION.

PCPs can listen for and acknowledge concerns about memory and cognition that are expressed by their older adult patients. The video, [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 (Alzheimer's Association, n.d.-a). In a conversational tone, he acknowledges her concern and encourages her to say more about the concern.



A PCP's thoughtful response to an older adult's tentatively expressed concerns about memory or cognition can help to overcome the older adult's reluctance to talk about the problem. As shown in the video, the PCP can then introduce the next step, in this case, a brief, cognitive test (Step 2 in the KAER process).





## LISTEN FOR FAMILY CONCERNS ABOUT THE OLDER ADULT'S MEMORY AND COGNITION.

PCPs can listen for and acknowledge concerns expressed by family members and others about the older adult's memory and cognition. More than one-third of adults aged 65 years and older are routinely accompanied by a family member, close friend, or neighbor to PCP visits, and these older adults are, on average, older, sicker, and more likely to have dementia than older adults who are not routinely accompanied to PCP visits (Wolff & Roter, 2008). PCPs can listen for comments and concerns expressed by these individuals about the older adult's memory and cognition. In addition or instead of commenting specifically about memory and cognition, some family members and others may mention cognition-related behaviors, such as:

- Asking the same question over and over again.
- 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 (U.S. Department of Veterans Affairs, 2011).

Some PCPs may choose to ask family members and others who accompany older adult patients to a PCP visit whether they have noticed changes in the older adult's memory or cognition. The question can be asked simply, in the course of PCP visit. For example, the PCP can 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 older adult because they do not want to upset or embarrass him or her. For this reason, PCPs who choose to ask the family member, close friend, or neighbor about the older adult's cognition in the older adult's presence could begin by asking the older adult, "Do you mind if I ask your [family member, friend, neighbor] about your memory?"

Note: Structured family questionnaires that ask the family member to respond to several specific questions about the older adult's memory, cognition, and cognition-related behaviors are shown in the next section of this toolkit (KAER Step 2).



## OBSERVE FOR SIGNS AND SYMPTOMS OF COGNITIVE IMPAIRMENT.

Figure K-2 shows signs and symptoms that PCPs can use as triggers to identify older adults who should receive further evaluation.

### Figure K-2. 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.
- \_\_\_\_\_ **Handling complex tasks.** For example, has more trouble following a complex train of thought, performing tasks that require many steps such as balancing a checkbook or cooking a meal.
- \_\_\_\_\_ **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 with finding the words to express what he or she wants to say and with 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: Agency for Healthcare Research and Quality, 1996.



Most of the symptoms listed in Figure K-2 refer to a change in functions and abilities (e.g., is more repetitive, has increasing difficulty). The emphasis on change reflects the core requirement for a decline in memory and other cognitive functions to justify a diagnosis of dementia. PCPs who have been caring for an older adult over a period of years may notice changes in the older adult's cognitive functions and abilities. This is not possible for a PCP who is seeing the older adult for the first time. Additional signs and symptoms that can be noticed in both new and ongoing patients include the following:

- The patient is a “poor historian.”
- The patient fails to appear for scheduled appointments or comes at the wrong time or on the wrong day.
- The patient repeatedly and apparently unintentionally fails to follow instructions, for example, changing medications.
- The patient defers to a family member to answer questions directed to the patient (National Chronic Care Consortium & Alzheimer's Association, 2003).

Some of the signs and symptoms listed above are most likely to be noticed by the PCP, for example, “The patient is a ‘poor historian,’” that is, the patient is unable to provide accurate information about his or her health and previous medical treatment, or “The patient repeatedly and apparently unintentionally fails to follow instructions, for example, changing medications.” Other signs and symptoms listed above may be noticed more often by other clinical and office staff, for example, “The patient fails to appear for scheduled appointments or comes at the wrong time or on the wrong day.”



## ADD A QUESTION ABOUT MEMORY OR COGNITION TO HEALTH RISK QUESTIONNAIRES.

Many PCPs, health plans, and health care systems have a health risk assessment or other questionnaire that older adults are asked to complete either before the PCP visit or in the office before meeting with the PCP. Some of these health risk assessments and patient questionnaires include a question about memory or other cognitive functions. The American College of Physicians has a Medicare Annual Wellness Visit and Other Preventive Visits letter and check list for physicians that includes the question, “Are you worried about your memory?” (American College of Physicians, n.d.) **(Appendix K-7)**.

The Alzheimer’s Association Medicare Detection of Cognitive Impairment Workgroup (Cordell et al., 2013) proposed another question that could be used in a health risk assessment or other patient questionnaire: “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” This question has been tested and approved for use in a national survey that includes older adults (Centers for Disease Control and Prevention, 2014).

PCPs, health plans, and health care systems that currently use a health risk assessment or other patient questionnaire that does not include a question about memory and/or other cognitive functions could add one of these questions to their assessment or questionnaire. A positive patient response to either question provides an easy way for PCPs to begin a conversation with the patient about cognitive changes and next steps to assess cognition.





## USE INFORMATION ABOUT HEALTH CONDITIONS AND FUNCTIONING FROM EXISTING PATIENT RECORDS.

Most PCPs, health plans, and health care systems already have information about characteristics of their older adult patients, such as age, health conditions, and functional abilities that have been found to be associated with cognitive impairment and dementia. Examples include stroke, diabetes, depressive symptoms, falls, gait disorders, and need for assistance with money management, medication administration, and activities of daily living. Some of these factors, such as stroke, are known causes of cognitive impairment. Others, such as need for assistance with medication administration, are caused by the cognitive impairment. Analyses of epidemiological and clinical data and experience indicate that information about these factors could be used as flags by PCPs, health plans, and health care systems to identify older adults who should receive a cognitive assessment and a diagnostic evaluation, if indicated (Barnes et al., 2014; Hausdorff & Buchman, 2013; Stark et al., 2013). PCPs, health plans, and health care systems with electronic health records could program in a notification to the PCP when one or a combination of the factors are present as an indicator of possible cognitive impairment (Cordell et al., 2013).

PCPs could also mention one or more of these factors, for example, recent falls or need for assistance with medication administration, as a way to engage older adults and family members in a conversation about the importance of further cognitive assessment.





## COMBINE APPROACHES.

PCPs, health plans, and health care systems may decide to combine two or more of the seven approaches above to achieve the objective of detecting cognitive impairment in older adult patients.

### Figure K-3. Dementia Warning Signs That Clinicians May Notice

#### Is your patient:

- Inattentive to appearance or unkempt, inappropriately dressed for weather, or disheveled?
- A “poor historian” or forgetful?

#### Does your patient:

- Fail to keep appointments or appear on the wrong day or wrong time for an appointment?
- Have unexplained weight loss, “failure to thrive,” or vague symptoms, e.g., dizziness, weakness?
- Repeatedly and apparently unintentionally fail to follow directions, e.g., not following through with medication changes?
- Defer to a caregiver or family member to answer questions?

#### Dementia warning signs that patients and caregivers may report:

- Asking the same questions over and over again.
- Becoming lost in familiar places.
- Not being able to follow directions.
- Getting very confused about time, people, and places.
- Problems with self-care, nutrition, bathing, or safety.

Source: U.S. Department of Veterans Affairs, 2016.

In its *Dementia Warning Signs*, the U.S. Department of Veterans Affairs (VA) (Figure K-3) combines three of these approaches: observing for signs and symptoms of cognitive impairment (approach 5), and listening for memory and cognition-related concerns that older adults and their family members may report (approaches 3 and 4). The VA states, “Use of the Dementia Warning Signs is recommended to prompt provider evaluation of cognition. Dementia Warning Signs are a set of ‘red flags’ or signs/symptoms that a clinician, a caregiver, or a patient may notice” ([U.S. Department of Veterans Affairs, 2016](#)) (Appendix K-8).



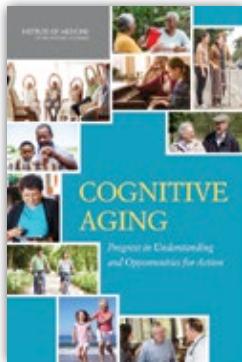
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# COGNITIVE AGING

An Action Guide for Health Care Providers



For the vast majority of adults, staying “mentally sharp” as they age is a high priority. Memory lapses may trigger fears of Alzheimer’s disease or other dementia-related diseases. At a time when the older population is rapidly growing in the United States, health care providers should be prepared to advise patients and their families about cognitive health.

There is a need for core competencies in cognitive aging for providers who see older adults, as well as more research on risk and preventive factors and potential interventions for cognitive aging. But there are resources available now to meet the increasing demand for information about cognitive health and aging. *Cognitive Aging: Progress in Understanding and Opportunities for Action*, a 2015 report from the Institute of Medicine (IOM), analyzes the best available evidence to help offer guidance for providers.

## Key messages for patients about cognitive aging

- **The brain ages, just like other parts of the body.** The brain is responsible for “cognition,” a term that describes mental functions including memory, decision making, processing speed, and learning. As the brain ages, these functions may change—a process called “cognitive aging.”
- **Cognitive aging is not a disease.** It is not the same as Alzheimer’s disease or other types of dementia. Cognitive aging is a natural, lifelong process that occurs in every individual.
- **Cognitive aging is different for every individual.** Some people may experience very few effects, while others may undergo changes that can affect cognitive abilities needed to carry out daily tasks, such as paying bills, driving, and following recipes.
- **Some cognitive functions improve with age.** Wisdom and knowledge often increase with age, and older adults report greater levels of happiness and satisfaction than their younger counterparts.
- **There are steps patients can take to protect their cognitive health.** Although aging is inevitable, it is possible to promote and support cognitive health and adapt to age-related changes in cognitive function.





## 3 steps patients can take to help protect their cognitive health

- 1 Be physically active.**
- 2 Reduce cardiovascular risk factors (including hypertension, diabetes, and smoking).**
- 3 Manage medications and health conditions that could affect cognition.**

### Other actions that may promote cognitive health include:

- Be socially and intellectually active, and continually seek opportunities to learn.
- Get adequate sleep and seek professional treatment for sleep disorders, if needed.
- Avoid delirium associated with hospitalization or certain medications.



## MONITORING MEDICATIONS WITH PATIENTS

Older adults take an average of 14 prescription drugs per year, putting them at heightened risk for adverse drug reactions, drug-drug interactions, and drug-disease interactions. Health care professionals, particularly primary care providers, play a critical role in monitoring medications and avoiding inappropriate use by older adults.

### Key messages for patients about medication management

- A complete medication review (including over-the-counter and herbal remedies) should be performed frequently, and especially during care transitions, such as post-surgery or hospital discharge.
- Over-the-counter medications (such as antihistamines, sedatives, and other medications that have strong anticholinergic activity), may have significant cognitive side effects, so their use should be carefully assessed.

#### Online resources for safe medication use in older adults:

- American Geriatrics Society Beers Criteria (including public education resources)
- American Geriatrics Society—What To Do and What to Ask Your Healthcare Provider If A Medication You Take is Listed in the Beers Criteria for Potentially Inappropriate Medications to Use in Older Adults
- National Institute on Aging—Safe Use of Medicines
- National Institutes of Health Senior Health—Taking Medications Safely
- Centers for Disease Control and Prevention—Adults and Older Adult Adverse Drug Events
- Food and Drug Administration—Medicines and You: A Guide for Older Adults
- Institute of Medicine—Preventing Medication Errors: Quality Chasm Series

## PREVENTING DELIRIUM

Delirium is a common and often preventable contributor to cognitive decline in older adults. Health care providers can play an important role in identifying patients at moderate to high risk for delirium, especially in pre-surgery, intensive care, and post-acute care settings. Common risk factors for delirium include age greater than 65 years, chronic cognitive impairment or dementia, current hip fracture, severe illness, multi-morbidity, depression, cerebrovascular disease, and alcohol abuse.

Delirium prevention has emerged as a priority in the prevention of cognitive decline following major illness, hospitalization, or surgery.



## RESOURCES FOR HEALTH CARE PROVIDERS

### Practice guidelines for health care professionals relevant to cognitive aging:

- American Psychological Association—Guidelines for the Evaluation of Dementia and Age-Related Cognitive Changes
- American Occupational Therapy Association—Cognition, Cognitive Rehabilitation, and Occupational Performance
- Royal Australian College of General Practitioners—Preventive Activities in Older Age
- American Association of Colleges of Nursing—Older Adult Care Competencies
- American Geriatrics Society—Clinical Practice Guideline for Postoperative Delirium in Older Adults
- American College of Surgeons—Best Practices Statement for Prevention and Treatment of Postoperative Delirium

### Cognitive assessment procedures and tools for use by health care providers:

- Alzheimer’s Association—Recommendations for Operationalizing the Detection of Cognitive Impairment During the Medicare Annual Wellness Visit in a Primary Care Setting
- Alzheimer’s Association—Health Care

### Professionals’ Cognitive Assessment Toolkit

- American Occupational Therapy Association—Occupational Therapy’s Role in Adult Cognitive Disorders
- American Psychological Association—Part III. Procedural Guidelines: Conducting Evaluations of Dementia and Age-Related Cognitive Change
- American Psychiatric Association—Diagnostic and Statistical Manual of Mental Disorders, 5th Ed.
- Hospital Elder Life Program
- National Institute on Aging—Assessing Cognitive Impairment in Older Adults: A Quick Guide for Primary Care Physicians

### Patient counseling and education about cognitive aging and related concerns:

- National Institute on Aging—Talking with Your Older Patient: A Clinician’s Handbook
- Alzheimer’s Association—10 Early Signs and Symptoms of Alzheimer’s
- American Psychological Association—Older Adults’ Health and Age-Related Changes: Reality Versus Myth
- Alzheimer’s Association—Brain Health

For more resources, visit  
[www.nas.edu/cognitiveaging](http://www.nas.edu/cognitiveaging)



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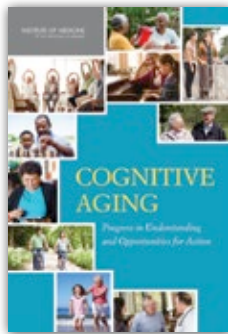
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# COGNITIVE AGING

An Action Guide for Individuals and Families



## What is cognitive aging?

**Like other organs, the human brain changes with age** in both its physical structures and its ability to carry out various functions. The brain is responsible for “cognition,” a term that includes memory, decision making, processing speed, wisdom, and learning. As a person ages, these functions may change—a process called “cognitive aging.”

**Cognitive aging is not a disease.** In fact, it is a process that occurs in every individual, beginning at birth and continuing throughout the life span. There is tremendous variability in how people’s cognition changes as they age. Some older adults may experience very few effects from cognitive aging, while in others the effects may be more pronounced. Furthermore, an individual’s cognitive function may vary from one day to another.

**Aging can affect the cognitive abilities needed to perform daily tasks,** such as paying bills, driving, following recipes, and adhering to medication schedules. It can challenge an older person’s ability to live independently, pursue favorite activities, and maintain a sense of identity. As a result, some older adults are reluctant to tell loved ones or care providers when they experience change in their cognitive function.

But **there are actions individuals and their families can take** to support and promote their cognitive health and to adapt to age-related cognitive changes. It is important to overcome stigma and misconceptions that might prevent older adults from seeking resources that can help promote their cognitive health and overall quality of life.

Cognitive aging is not the same as Alzheimer’s disease.

ALZHEIMER’S DISEASE	COGNITIVE AGING
Chronic neurodegenerative disease	<b>Part of aging</b>
Extensive neuron loss	<b>Neuron number remains relatively stable, but neuronal function may decline</b>
Affects approximately 10 percent of older Americans	<b>Occurs in everyone, but the extent and nature of changes varies widely</b>
Declines are often severe and progressive	<b>Changes are variable and gradual</b>





## Know the facts about cognitive aging

MISCONCEPTION	FACT
Maintaining cognitive health means preserving your memory.	<b>Cognitive health is far more than having a good memory.</b> It also involves decision making, attention, and problem solving.
Cognitive function always declines with age.	<b>Aging can have both positive and negative effects on cognition.</b> Wisdom and expertise can increase with age. Older adults experience fewer negative emotions, such as anger and worry, than people in young adulthood and middle age, and they report feeling greater satisfaction with life in general.
There's nothing you can do to improve your cognitive health.	<b>There are actions individuals and families can take to help support their cognitive health and adapt to age-related cognitive changes.</b> See the next page for more information.
Brain neurons die as you age, so there is no way to prevent cognitive decline.	<b>In the absence of disease, neuron death is minimal.</b> There are a number of actions you can take to support your cognitive health.

## RESOURCES RELATED TO OLDER ADULT DRIVING

Safe driving relies on many elements of cognition, such as processing speed, decision making, multitasking, and memory. All of these functions can decline with age. Deciding whether to limit driving or stop altogether can be a difficult decision for older adults and their families because it can affect self-esteem and the ability to live independently.

However, there are many resources to help older adults drive safely or determine when it might be necessary to limit driving. For example, the American Automobile Association offers a defensive driving course called RoadWise Drive. The California Department of Motor Vehicles provides a 15-question online self-assessment to help older drivers and their families determine whether they are driving safely, and other states and organizations offer similar opportunities for assessment, as well as resources for decision making.

**Visit [www.nas.edu/cognitiveaging](http://www.nas.edu/cognitiveaging) to access a list of online resources about older adult driving.**



## The top 3 actions you can take to help protect your cognitive health as you age

- 1 Be physically active.** Staying physically active can promote cognitive health in middle-aged and older adults.
- 2 Reduce your cardiovascular risk factors (including hypertension, diabetes, and smoking).** Maintaining cardiovascular health supports cognitive health.
- 3 Manage your medications.** A number of medications can have a negative effect on cognitive function when used alone or in combination with other medications. The effects can be temporary or long-term. It's important to review all of your medications with a health care professional and learn about their effects on cognitive health.

### Other actions that may promote cognitive health

- Be socially and intellectually active, and continually seek opportunities to learn.
- Get adequate sleep and seek professional treatment for sleep disorders, if needed.
- Talk to your health care provider to learn more about preventing delirium (a decline in cognitive function that can be associated with some medications and hospitalization).





## RESOURCES RELATED TO COGNITIVE AGING AND FINANCIAL DECISION MAKING

Age-related declines in cognitive function may make older adults vulnerable to financial fraud or abuse at a time when significant financial decisions need to be made, such as planning for retirement. In 2010 alone, victims of elder financial abuse lost an estimated \$2.9 billion, which includes loss of money and goods to legitimate businesses, scams, family, and friends and indirectly through medical insurance fraud. According to the National Council on Aging, the top 10 financial scams targeting older adults include tele-marketing, Internet scams, and sales of anti-aging products.

Fortunately, there are many resources available to raise awareness and help older adults, their families, and financial advisers avoid abuse and make sound financial decisions, including AARP's "Scam Jams" and "Fraud Watch Network," the Consumer Financial Protection Bureau's Office of Financial Protection for Older Americans, and the Federal Trade Commission's "Pass It On" financial fraud awareness campaign.

**Visit [www.nas.edu/cognitiveaging](http://www.nas.edu/cognitiveaging) to access a list of resources related to cognitive aging and financial decision making.**

For more resources, visit  
[www.nas.edu/cognitiveaging](http://www.nas.edu/cognitiveaging)



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## Brain Health As You Age: You Can Make a Difference!



### Brain Health: You Can Make a Difference!

This webpage offers evidence-based resources that can help professionals, older adults, and people with disabilities promote brain health. You can use the resources to educate yourself and others.

- **Brain Health Basics.** Learn and teach others about the risks related to brain health and how to reduce them.
- **Medicine, Age, and Your Brain.** Learn and teach others about the impact that some medications can have on an older adult's brain.
- **Brain Injury.** Learn and teach others about how to prevent brain injury and how to get help if you do have one.
- **Dementia.** Learn how to create "dementia-capable" long-term services and supports at the state and local levels to help people who have Alzheimer's disease and other types of dementia.

Stay tuned for future additions to this site!

Thank you for using our Brain Health Resources. If you have any questions about the materials or how to use them, please contact [jane.tilly@acl.hhs.gov](mailto:jane.tilly@acl.hhs.gov).

### Brain Health Basics

ACL's Brain Health Resource has a power point presentation, educator guide, one page handout for consumers, and a supplementary handout with a detailed list of resources on many brain health topics. The Administration for Community Living, National Institutes for Health (NIH), and Centers for Disease Control and Prevention (CDC) developed these materials together.

- The **PowerPoint presentation (PPT, 1.81MB)** helps people learn how to reduce the risks related to brain health. A **Spanish version (PPTX, 1.76MB)** of this powerpoint presentation is available. This presentation covers:
  - Aging and health
  - Good health and the normal aging brain
  - Threats to brain health
  - Healthy aging for your body and brain
- The **Educator Guide (PDF, 1.58MB)** offers additional information for presenters to share with audiences
- A **one-page handout (PDF, 534KB)** for the audience covers the basics of brain health. A **Spanish version (PDF, 313KB)** of this handout is available.
- A **supplementary handout (PDF, 372KB)** includes more information and resources on the topics covered in the presentation materials were developed in 2014.
- The Spanish translations are available thanks, in part, to the Alzheimer's Association.

### Medicine, Age, and Your Brain

ACL's Medicine, Age, and Your Brain has a power point presentation, a brochure for educators, and a one page handout for consumers.





- The **PowerPoint presentation (PPT, 581KB)** helps people learn about the impact some medicines can have on an older person's brain and the importance of talking with a doctor about this topic.
- The **Educator Brochure (PDF, 838KB)** offers additional information for presenters to share with audiences.
- A **one-page handout (PDF, 574KB)** for the audience covers some medicines' potential impact on brain health.

## Brain Injury

Use this brochure, **Brain Injuries: Prevention, Rehabilitation, and Community Living**, to educate yourself and others about brain injuries, how to prevent them, and what happens after they occur. The pamphlet covers:

- Brain injury statistics
- Causes of brain injuries
- Prevention of brain injuries
- Health and rehabilitation after injury
- Sources of help after injury content was developed in 2015.


## Dementia

Learn about dementia-capable long-term services and supports for people with the disease and their family caregivers. Issue brief topics:




1. **Dementia-capability Basics.** This issue brief, **Dementia-capable States and Communities: the Basics (PDF)**, defines dementia-capability and explores:
  - Educating people about brain health
  - Identifying and referring people with possible dementia for a diagnosis
  - Ensuring that program eligibility and resource allocation take into account the impact of cognitive disabilities.
  - Ensuring effective staff communication with people with dementia and their caregivers
  - Ensuring services are person- and family-centered
  - Educating workers about dementia
  - Implementing quality assurance systems that measure dementia-capability
  - Encouraging development of dementia-friendly communities
2. **Wandering.** This issue brief, **Responding to the Wandering Behavior of People with Dementia (PDF)**, discusses one of the more difficult symptoms of dementia by:
  - Describing the service needs of people who are at risk of wandering
  - Discussing person-centered approaches to meeting their needs
  - Providing information about services options that can address wandering
3. **Promoting Community Living.** This policy brief, **Promoting Community Living for Older Adults Who Need Long-term Services and Supports (PDF, 299KB)**:
  - Argues that many states could be reducing older adults' use of nursing homes by providing more home and community-based services to them when they have disabilities.
  - Summarizes the evidence about the effects of providing more HCBS
  - Offers recommendations to states
  - Describes the special circumstances of older adults with dementia



## Brain Health As You Age: You Can Make a Difference!



A presentation by:



1

## Aging and Health

- Aging well depends on your:
  - Genes
  - Environment
  - Lifestyle
- Healthy lifestyle choices may help you maintain a healthy body and brain

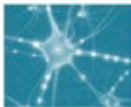


2

## Age-Related Changes in Memory and Learning

**You may find:**

- Increased difficulty finding words
- More problems in multi-tasking
- Mild decreases in ability to pay attention



**You can still:**

- Learn new things
- Create new memories
- Improve vocabulary and language skills

3

## Possible Risks or Threats to Brain Health

- Some medicines, or improper use of them
- Smoking
- Excessive use of alcohol
- Heart disease, diabetes, and other health problems
- Poor diet
- Insufficient sleep
- Lack of physical activity
- Little social activity and being alone most of the time

4



## Medicines and Brain Health

Some medicines – and combinations of them – can affect your thinking and the way your brain works.



*Talk with your health care provider about the drugs you take and possible side effects on memory, sleep and brain function.*

5

## Smoking and Brain Health

- Benefits of quitting smoking at any age:
  - Lower risk of heart attacks, stroke, and lung disease
  - Better blood circulation
  - Not exposing others to second-hand smoke

**There are free resources available to help you quit smoking.**



6

## Alcohol's Effect on Brain Health

- Slow or impaired communication among brain cells, even with moderate use
- Poor driving, slurred speech, fuzzy memory, drowsiness, dizziness
- Long-term changes to balance, memory and emotions, coordination, and body temperature



**Staying away from alcohol can reverse some changes.**

Some medicines can be dangerous when mixed with alcohol.

7

## Common Conditions that Affect Brain Health

- Heart disease, high blood pressure
- Diabetes
- Alzheimer's disease
- Stroke
- Traumatic brain injury
- Depression
- Sleep problems



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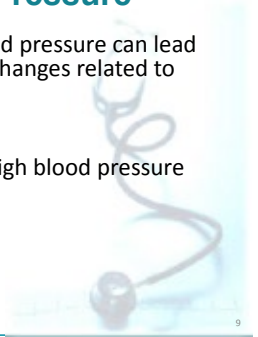


## Heart Disease and High Blood Pressure

Heart disease and high blood pressure can lead to stroke and blood vessel changes related to dementia.

### How to reduce risk:

- Control cholesterol and high blood pressure
- Exercise
- Eat healthy foods
- Quit smoking
- Limit use of alcohol



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## Diabetes

- Damages blood vessels throughout your body, including your brain
- Increases risk for stroke and heart attack
- May increase risk for memory problems and Alzheimer's disease
- Maintaining a healthy weight through physical activity and healthy eating can prevent or control diabetes

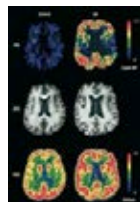
Talk with your health care provider about the combination of lifestyle and medicine that works for you.

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## Alzheimer's Disease

Alzheimer's is a buildup of harmful proteins in the brain, the death of brain cells, and loss of connections among them.

- Known risks:
  - Age
  - Genes, in some people
  - Head injury
- Suspected risks:
  - Heart disease
  - High blood pressure at mid-life
  - Lack of physical activity
  - Depression
  - Diabetes



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## Alzheimer's Disease (continued)

- Some therapies can treat Alzheimer's symptoms. They do not slow down the disease's changes in the brain.
- Some approaches show promise in reducing risk of cognitive decline or Alzheimer's, but need more testing:
  - Exercise
  - Healthy diet
  - Controlling high blood pressure, heart disease, diabetes
  - Cognitive "brain" training

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## Brain Injury

- Older adults are at higher risk of falling and other accidents that can cause brain injury

### How to reduce risk:



- Exercise to improve balance and coordination
- Take a fall prevention class
- Make your home safer
- Review medicines and vision with your health care provider
- Wear safety belts and helmets
- Get enough sleep

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## Depression

- Feelings of sadness or loss of interest in favored activities that last for weeks at a time
- Not a normal part of aging
- Some medicines can cause depression
- Confusion or attention problems caused by depression can sometimes look like dementia
- Treatment can involve therapy and medicine



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## Sleep Apnea

- Short pauses in breathing while sleeping
- Can lead to injury, high blood pressure, stroke, or memory loss, all of which can affect brain health
- Treatment begins with lifestyle changes, such as avoiding alcohol, losing weight, and quitting smoking
- Use of special devices, ordered by your doctor, may also help

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## So, What Can You Do to Protect Brain Health?

### Actions that may help:

- Take care of your health
- Eat healthy foods
- Be active
- Learn new things
- Connect with family, friends, and communities



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## Take Care of Your Health

- Get recommended health screenings
- Manage health problems like diabetes, high blood pressure, and high cholesterol
- Consult with your health care provider to make sure your medicines are right for you
- Reduce risk for brain injuries due to falls, and other types of accidents
- Quit smoking



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## Eat Healthily

- Fruits and vegetables
- Whole grains
- Lean meats, fish, poultry
- Low-fat or non-fat dairy products
- Less solid fat, sugar and salt
- Proper portion sizes
- Adequate fluids



Look into healthy meal programs, like those provided by your Area Agency on Aging.

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## Get Moving

- Physical activity may:
  - Reduce risks of diabetes, heart disease, depression, and stroke
  - Prevent falls
  - Improve connections among brain cells
- Get at least 150 minutes of exercise each week. Move about 30 minutes on most days. Walking is a good start.
- Join programs that can help you learn to move safely.
- Check with your health care provider if you haven't been active and want to start a vigorous exercise program.



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## Keep Your Mind Active

- Do mentally stimulating activities
- Read books and magazines
- Play games
- Learn new things
- Take or teach a class
- Be social through work or volunteering



Clinical trials have not proven that these types of activities will prevent Alzheimer's disease, but they can be fun.

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## Stay Connected

- People who have meaningful activities, like volunteering, say they feel happier and healthier
- Social activities are linked to reduced risk for some health problems, including dementia
- Join in social and other programs through your Area Agency on Aging, Senior Center, or other community organizations

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## What Can You Do Today?

- Pick one thing you can do that may help your brain
- Think of small, first steps such as:
  - Taking a 10-minute walk a few times a week
  - Adding one serving of vegetables each day
  - Making an appointment for health screenings or a physical exam
- Write down what you will do and when
- Get support from family, friends, or community groups!



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## For More Information

- Community Programs:
  - Contact a local Area Agency on Aging (AAA)
  - Contact a local Aging & Disability Resource Center (ADRC)
  - Or, go to <http://eldercare.gov/>
- National Institutes of Health: <http://nih.gov>
- National Institute on Aging at NIH: <http://nia.nih.gov>
- ClinicalTrials.gov, a service of NIH: <http://clinicaltrials.gov>
- Centers for Disease Control and Prevention:
  - <http://www.cdc.gov/aging>
  - <http://www.cdc.gov/physicalactivity>

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# Brain Health As You Age: You Can Make a Difference!



We all want to stay healthy and independent as we get older. Along with keeping our bodies in good shape, we want to keep our minds healthy, too.

Developing a brain disease or injury as you age depends on a mix of your family's genes, your environment, and your health choices.

Diseases and conditions that affect brain health include:

- Genetic makeup
- Certain medicines, smoking and excessive alcohol
- Health problems like diabetes and heart disease
- Diseases like depression and Alzheimer's
- Brain injury
- Poor diet, insufficient sleep, lack of physical and social activity

Some risks to brain health cannot be controlled or prevented, like your genes. Others, like health choices, are under your control. For example, you can:

- Take care of your health
- Eat a healthy diet
- Drink alcohol moderately, if at all
- Get active and stay active
- Sleep 7-8 hours each night
- Learn new things
- Connect with your family, friends, and communities



## Brain Health As You Age: You Can Make a Difference!



Your doctor or health care provider can provide information to you about taking care of your health, and there are a number of resources on the Internet and at libraries on healthy choices in diet, exercise, and social activities.

### Resources

For more information on local programs and resources about health and aging, you can contact your local Area Agency on Aging (AAA) by calling 1-800-677-1116 or visiting the Website <http://www.eldercare.gov>.

You can also check out the following user-friendly resources:

<http://www.nih.gov>

The Website of the National Institutes of Health has information on prevention and treatment for many conditions and disorders related to brain health. It's National Institute on Aging focuses on a variety of age-related health conditions and ways to lead a healthier life as you grow older, at <http://www.nia.nih.gov>. To find out about participating in research studies, visit <http://www.clinicaltrials.gov>.

<http://www.cdc.gov/aging/aginginfo/index.htm>

This Website from the Centers for Disease Control and Prevention has links to a wide variety of healthy aging topics of interest to older adults.



# Salud cerebral con el paso de los años: ¡Usted puede hacer la diferencia!



Todos queremos permanecer saludables e independientes aun con el avance de los años. Tanto como mantener nuestro cuerpo en buena forma, también queremos mantener una mente sana.

El desarrollo de una enfermedad o lesión cerebral a medida que envejece depende de una combinación de sus genes, el ambiente y las opciones de salud que usted escoge.

Las enfermedades y condiciones que afectan al cerebro incluyen:

- Composición genética
- Ciertos medicamentos, fumar y uso excesivo de alcohol
- Problemas de salud, tales como la diabetes y las enfermedades cardiovasculares
- Enfermedades tales como la depresión y el Alzheimer
- Lesiones cerebrales
- Dieta poco saludable, no dormir lo suficiente, falta de actividad física y social

Algunos factores que afectan a la salud cerebral no se pueden controlar ni prevenir. Otros, como las opciones de salud que usted escoge, están bajo su control. Por ejemplo, usted puede:

- Cuidar su salud
- Comer de forma saludable
- Si acaso toma bebidas alcohólicas, hacerlo moderadamente
- Ser activo y mantenerse así
- Dormir 7-8 horas cada noche
- Aprender cosas nuevas
- Mantenerse conectado con su familia, amigos y su comunidad





## Salud cerebral con el paso de los años: ¡Usted puede hacer la diferencia!

Su médico o proveedor de atención médica puede darle información sobre el cuidado de su salud, y hay muchos recursos en el internet y en las bibliotecas sobre opciones saludables referentes a la dieta, el ejercicio y las actividades sociales.

### Recursos

Para más información sobre programas locales y recursos sobre la salud y el envejecimiento, usted puede contactar a su Area Agency on Aging (AAA, por sus siglas en inglés) local llamando al 1-800-677-1116 o visite su sitio web

**<http://www.eldercare.gov>**

También puede consultar los siguientes recursos que son fáciles de usar:

**<http://salud.nih.gov/>**

El sitio web de los Institutos Nacionales de la Salud provee información sobre la prevención y el tratamiento de muchas condiciones y trastornos relacionados con la salud del cerebro. Su Instituto Nacional Sobre el Envejecimiento se centra en una variedad de condiciones de salud relacionadas con la edad y también ofrece información sobre cómo llevar una vida más saludable a medida que va envejeciendo, en <https://www.nia.nih.gov/espanol>. Para aprender más acerca de cómo participar en estudios de investigación, visite <http://www.clinicaltrials.gov>.

**<http://www.cdc.gov/aging/aginginfo/index.htm>**

Este sitio web de los Centros para el Control y la Prevención de Enfermedades tiene enlaces a una amplia variedad de temas referentes al envejecimiento saludable de interés para los adultos mayores.



**To: Our Medicare Patients:**

**Subject: Medicare Annual Wellness and Other Preventive Visits**

Beginning January 1, 2011, Medicare covers an “Annual Wellness Visit” in addition to the one-time “Welcome to Medicare” exam. The “Welcome to Medicare” exam occurs only once during your first twelve months as a Medicare patient. You may receive your Annual Wellness Visit after you have been with Medicare for more than one year, or it has been at least one year since your “Welcome to Medicare” exam.

Initial Preventive Physical Exam (IPPE)	“Welcome to Medicare” is only for <i>new</i> Medicare patients. This must be done in the 1 <sup>st</sup> year as a Medicare patient.
Annual Wellness Visit, Initial	At least 1 yr after the “Welcome to Medicare” exam.
Annual Wellness Visit, Subsequent	Once a year (more than 1 yr + 1 day after the last Wellness Visit).

The Annual Wellness Visit is not the same thing as what many people often refer to as their yearly physical exam. Medicare is very specific about what the “Annual Wellness Visit” includes and excludes.

At the Annual Wellness Visit, your doctor will talk to you about your medical history, review your risk factors, and make a personalized prevention plan to keep you healthy. The visit does *not* include a hands-on exam or any testing that your doctor may recommend, nor does it include any discussion about any new or current medical problems, conditions, or medications. You may schedule another visit to address those issues *or* your doctor may charge the usual Medicare fees for such services that are beyond the scope of the Annual Wellness Visit.

If you would like to schedule an annual physical, including any lab work or other diagnostic testing, medication management, vaccinations, and other services, please understand that these services will be charged and covered according to Medicare’s usual coverage guidelines. However, you may still develop a care plan based on the Annual Wellness Visit criteria.

We appreciate the trust you put in us to take care of your health care needs and hope that you will take advantage of this new benefit to work with your physician in creating your personalized prevention plan.

*See the attached list to bring with you to your appointment.*



What you should bring to your Annual Wellness Visit:

The names of all your doctors:

Name	Specialty

A list of all your medications

Name of medicine	Dose (if you remember)

Have any of your close relatives had any health changes?    \_\_\_ Yes    \_\_\_ No

Has your mood changed?    \_\_\_ Yes    \_\_\_ No

Do you worry about falling?    \_\_\_ Yes    \_\_\_ No

Are you worried about your memory?    \_\_\_ Yes    \_\_\_ No

Are there any preventive tests you have done recently?  
(such as lab tests, mammograms, x-rays)    \_\_\_ Yes    \_\_\_ No

Have you had any recent immunizations?    \_\_\_ Yes    \_\_\_ No

Do you have a living will or advance directive?  
(If you have one, *please bring a copy of it with you.*)    \_\_\_ Yes    \_\_\_ No



## Clinician Fact Sheet

## Detection of Cognitive Impairment

### ■ Why use Cognitive Impairment Warning Signs?

- Supports patient-centered care and Veteran-to-provider communication.
- Provides an opportunity for clinicians to initiate a conversation with the patient and/or the family.

### ■ How are Cognitive Impairment Warning Signs used in clinical care?

The appropriate use of Cognitive Impairment Warning Signs will prompt a structured assessment of cognition and diagnostic evaluation for cognitive impairment within primary care.

### ■ Next steps if warning signs are present

- Focused history from patient and caregiver and review of systems emphasizing:
  - Onset and course of cognitive signs and symptoms;
  - History of head trauma, psychiatric disorders, history of atherosclerotic vascular disease and vascular risk factors;
  - Family and social history including drug and alcohol use;
  - Medication review;
  - Safety and functional status, driving and firearm use, history of falls;
  - Symptoms of delirium.
- Focused physical exam emphasizing the cardiovascular system; neurologic exam including mental status exam; and objective cognitive testing.
- Standard laboratory testing including thyroid stimulating hormone, complete blood count; electrolytes and calcium, hepatic-panel, blood urea nitrogen, creatinine, glucose, vitamin B12, and Human Immunodeficiency Virus testing with documented verbal consent.
- Advanced diagnostic testing, neuropsychological evaluation or brain imaging may be warranted when indicated by history and physical exam or for complex cases.

### Keep in mind:

- Warning signs, by themselves, are not diagnostic of cognitive impairment but simply suggest that further evaluation is warranted.
- Brief, structured cognitive assessments alone are not sufficient to diagnose cognitive impairment but are an important part of the diagnostic evaluation.
- Delirium and depression may present with similar symptoms as cognitive impairment and need to be considered before a diagnosis of cognitive impairment is made.
- Sensory impairment, adverse drug events, or concurrent psychiatric or metabolic illnesses may also be mistaken for cognitive impairment.

### VHA does not recommend screening asymptomatic older individuals

VHA's recommendation differs from the U.S. Preventive Services Task Force,<sup>2</sup> which concludes that the current evidence is insufficient to assess the benefits and harms of screening for cognitive impairment. The main reasons for VHA's conclusion include:

- Lack of evidence to support a benefit to identification of early cognitive impairment.
- There is adequate evidence of harms from drug therapy for cognitive impairment, including bradycardia, nausea, bladder outlet obstruction, and others.<sup>6</sup>

### FOR MORE INFORMATION:

- VHA Screening for Cognitive Impairment Guidance Statement: [http://vaww.prevention.va.gov/CPS/Screening\\_for\\_Cognitive\\_Impairment.asp](http://vaww.prevention.va.gov/CPS/Screening_for_Cognitive_Impairment.asp)
- Clinician Fact Sheet Detection of Cognitive Impairment: [http://www.prevention.va.gov/docs/NCP\\_CPS\\_Factsheet\\_Cognitive\\_Impairment.pdf](http://www.prevention.va.gov/docs/NCP_CPS_Factsheet_Cognitive_Impairment.pdf)
- USPSTF Cognitive Impairment in Older Adults: Screening: <http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/cognitive-impairment-in-older-adults-screening?ds=1&s=dementia>
- The 2016 DSC Recommendations are available on the VHA Office of Geriatrics & Extended Care Internet web site: [http://www.va.gov/GERIATRICS/GEC\\_Data\\_Reports.asp](http://www.va.gov/GERIATRICS/GEC_Data_Reports.asp).

### REFERENCES:

<sup>1</sup>VHA Screening for Cognitive Impairment Guidance Statement: [http://vaww.prevention.va.gov/CPS/Screening\\_for\\_Cognitive\\_Impairment.asp](http://vaww.prevention.va.gov/CPS/Screening_for_Cognitive_Impairment.asp)

<sup>2</sup>U.S. Preventive Health Services Task Force, March 2014. Cognitive Impairment in Older Adults - Screening: <http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/cognitive-impairment-in-older-adults-screening?ds=1&s=dementia>

<sup>3</sup>Langa KM, Larson EB, Crimmins EM, et al. A comparison of the prevalence of dementia in the United States in 2000-2012. *JAMA Intern Med.* doi: 10.1001/jamainternmed.2016.6807 Published online November 21, 2016.

<sup>4</sup>National Chronic Care Consortium & Alzheimer's Association, 2003; Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia, p.7; [https://www.alz.org/national/documents/brochure\\_toolsfordassesstreat.pdf](https://www.alz.org/national/documents/brochure_toolsfordassesstreat.pdf)

<sup>5</sup>Adapted with permission from the National Institute on Aging: NIH Publication No. 10-5442, September 2010, <http://purl.fdlp.gov/GPO/gpo3714>

<sup>6</sup>Lin, JS et al. Screening for cognitive impairment in adults: A systematic review for the U.S. Preventive Services Task Force. *Ann. Int. Med.* Nov 5 2013;159(9):601-612.





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## OVERVIEW

In its 2015 report, the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis recommends that:

- PCPs should routinely use a brief cognitive test and other structured assessment instruments to detect cognitive impairment (GSA, 2015).
- If a brief cognitive test is used, results of the test should be documented in the older adult's medical record. The specific cognitive test used and the person's score should also be documented. If a brief cognitive test is not used, PCPs should note why; for example, the test was not offered, or the older adult refused to take it (GSA, 2015).

The objective of using a brief cognitive test and other structured assessment instruments is to determine whether older adult patients should have a diagnostic evaluation (KAER Step 3). As noted in the previous section on KAER Step 1, PCPs, health plans, and health care systems can use various tools and approaches to achieve this objective including the following:

- Use one or more of the approaches in KAER Step 1 to detect signs and symptoms of cognitive impairment and then recommend that older adults with such signs and symptoms receive a brief cognitive test and other structured assessments (KAER Step 2). Based on results of the brief cognitive test and other structured assessments, PCPs could then conduct or refer older adults with cognitive impairment for a diagnostic evaluation (KAER Step 3).
- Use one or more of the approaches in KAER Step 1 to detect signs and symptoms of cognitive impairment and then conduct or refer older adults with such signs and symptoms for a diagnostic evaluation, thus skipping KAER Step 2.
- Use a brief cognitive test and other structured assessment instruments (KAER Step 2) to determine which older adults should receive or be referred for a diagnostic evaluation, thus skipping KAER Step 1.



## STEP 2 : ASSESS

In addition to brief cognitive tests for the older adult, this section presents and discusses two other types of structured assessment instruments to detect cognitive impairment: brief informant questionnaires to obtain family members' perceptions about the older adult's cognition; and brief self-report questionnaires to obtain the older adult's perceptions about his or her own cognition. All three types of assessment instruments can be used in any PCP visit, including initial and subsequent Annual Wellness Visits.

It is important to emphasize that there is no "gold standard" single test for the detection of cognitive impairment, and no brief cognitive test is diagnostic. Use of these tests is instead intended to assist PCPs in identifying older adults with cognitive impairment who should receive a diagnostic evaluation.





## APPROACHES

### USE A BRIEF COGNITIVE TEST TO DETECT COGNITIVE IMPAIRMENT.

Brief cognitive tests administered to older adult patients can help PCPs detect cognitive impairment in order to determine which patients should receive a diagnostic evaluation. The GSA Workgroup selected three brief cognitive tests for inclusion in this toolkit: the [Mini-Cog](#), the [General Practitioner Assessment of Cognition \(GPCOG\)](#), and the [Memory Impairment Screen](#). Each of these tests is shown in this section of the toolkit along with instructions for scoring.

To select the brief cognitive tests for inclusion in the toolkit, the GSA Workgroup reviewed the recommendations of two other workgroups that were formed to identify brief cognitive tests for use in Annual Wellness Visits. The National Institute on Aging (NIA) formed one of the other workgroups at the request of the U.S Centers for Medicare & Medicaid Services (CMS). The NIA Workgroup solicited input from other federal agencies, assessment experts, clinicians, and others, and developed criteria for selecting instruments to detect cognitive impairment in the primary care setting. The criteria required that the selected instruments must meet all of the following conditions:

- Take 5 minutes or less to administer.
- Be free of charge with simple access.
- Apply to the Medicare population and be designed to assess age-related cognitive impairment.
- Assess memory and at least one other cognitive function.
- Have been validated in a U.S. community-based sample or primary care settings and used in the United States after validation, between 2001 and 2011.

The NIA Workgroup identified seven brief cognitive tests that met these criteria out of more than 130 assessment instruments studied.



Concurrent with the NIA Workgroup activities, the Alzheimer’s Association convened an expert workgroup to provide guidance for PCPs about cognitive assessment during Annual Wellness Visits (Cordell et al., 2013). The Alzheimer’s Association Workgroup reviewed the findings of six systematic reviews of brief cognitive tests and selected three brief cognitive tests as most suitable for routine use in primary care setting. The three tests have the following attributes: require 5 minutes or less to administer; have been validated in a community or primary care setting; have good to excellent psychometric properties; can be used in a clinical setting without payment for copyrights; are easy to administer by medical staff members who are not physicians; and are relatively free from education, language, and cultural bias.

Both the NIA and Alzheimer’s Association Workgroups identified the [Mini-Cog](#) as meeting their criteria. For that reason, the GSA Workgroup decided to include the [Mini-Cog \(Appendix A-1\)](#) in this toolkit. The GSA Workgroup also decided to include the two other brief cognitive tests recommended by the Alzheimer’s Association Workgroup: the [GPCOG \(Appendix A-2\)](#) and the [Memory Impairment Screen \(Appendix A-3\)](#).

PCPs, health plans, and health care systems could select any one of the three brief cognitive tests for routine use in their primary care practices:

- [The Mini-Cog](#) asks the older adult to learn and later recall three words and to draw a clock with the hands set at 11:10.
- [The GPCOG](#) asks the older adult to learn and later recall a name and address, to give the current date, to name something that happened in the news recently, and to draw a clock with the hands set at 11:10.
- [The Memory Impairment Screen](#) asks the older adult to learn four words and a category related to each word, for example, the word “checkers” and the category “game.” The older adult is then distracted with other activities for a few minutes and subsequently asked to recall four words. If he or she cannot recall a word, the category is given as a clue, and the older adult is again asked to recall the word.



As discussed earlier, there is considerable disagreement about the best approach to detect cognitive impairment in older adults, with some clinician experts favoring routine use of a brief cognitive test and other clinician experts favoring use of signs and symptoms of cognitive impairment to identify older adults who should receive further cognitive assessment and a diagnostic evaluation, if indicated. Among clinician experts who favor the use of a brief cognitive test, there is also disagreement about the patient age at which use of a brief cognitive test should begin. Starting ages that are often proposed include 60, 65, 70, 75, and 80 years of age.

Disagreement about the patient age at which use of a brief cognitive test should begin reflects, on the one hand, a belief that cognition should be considered one of the important vital signs that should be measured routinely in all older adults, starting at age 60 or 65 years. Clinician experts who favor a later starting age point out, however, that asking PCPs to use a brief cognitive test in their patients aged 60 to 74 years, when cognitive impairment and dementia are much less common than in older age groups, will result in apparently unnecessary time spent by busy PCPs and perhaps increased resistance to the routine use of these tests for older adults of any age. PCPs, health plans, and health care systems that choose to use a brief cognitive test to detect cognitive impairment in their older adult patients will have to weigh these different perspectives to select the age at which the test will be routinely used.

In addition to the [Mini-Cog](#), the NIA Workgroup identified six other brief cognitive tests that take 5 minutes or less to administer and meet all criteria established by the workgroup: the Brief Alzheimer's Screen, the Mental Status Questionnaire, the Short Blessed Test, the Short Portable Mental Status Questionnaire, the Six-Item Screener, and the Short Test of Mental Status. Information about these six brief cognitive tests is available in a searchable, [online database](#) created by NIA (2012). More than 100 other assessment instruments identified by the NIA Workgroup are also shown in the searchable database. These additional assessment instruments include cognitive tests that take longer than 5 minutes to administer, structured questionnaires to obtain family members' perceptions about the older adult's cognition, and structured questionnaires to obtain the older adult's perceptions about his or her own cognition.





The NIA has published two documents about detecting cognitive impairment in older adults that may be useful for PCPs, health plans, and health care systems. A 2014 NIA document, [\*Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians\*](#), discusses why it is important to assess cognitive impairment in older adults, when use of a brief cognitive test is indicated, and how cognitive impairment is evaluated (NIA Alzheimer’s Disease Education and Referral Center, 2014) (**Appendix A-4**). The NIA has also added a new section to its clinician handbook, *Talking with Your Older Patient*. The new section, “Talking with Patients about Cognitive Problems,” discusses cognitive impairment in older adults, deciding when to use a brief cognitive test, and how to conduct the test (NIA, 2016b).

PCPs, health plans, and health care systems that do not currently use a brief cognitive test with their older adult patients could consider the three brief cognitive tests shown in this toolkit and decide whether one of the tests would fit well with their existing primary care structure, organization, and procedures. Alternatively, they could consider the other brief cognitive tests that are included in the NIA searchable database (NIA, 2012).





### Non-PCP Primary Care Office Staff Can Help With Detection of Cognitive Impairment in Older Adult Patients

Trained, non-PCP primary care office staff can use many of the approaches and tools discussed thus far in this toolkit to assist PCPs in detecting cognitive impairment in their older adult patients. For example, trained non-PCP staff can ask older adult patients whether they have noticed changes in their memory; they can be alert for the signs and symptoms discussed in the previous section on KAER Step 1; and they can administer and score brief cognitive tests. Findings from these activities can then be given to the PCP who will decide whether patients should receive further cognitive assessment or a diagnostic evaluation.

The Rural Older Adult Memory (ROAM) study tested the feasibility of using non-PCP medical assistants to help in the detection of cognitive impairment in adults aged 75 years and older in rural, primary care health clinics in Oregon (Boise et al., 2010). As shown in **Figure A-1**, the assessment used in the ROAM study included two of the approaches listed in KAER Step 1 (a question for the older adult patient about whether he or she has noticed a change in memory that concerns him or her and a similar question for a family member or other person who accompanied the person to the primary care visit). The assessment also included a brief cognitive test, asking the older adult to learn and later recall three words. Non-PCP medical assistants were trained to ask the questions, conduct the test, enter the results on a brief form, and place the form on the charts of patients whose scores indicated cognitive impairment. Before placing the form on the patient's chart, the medical assistants also checked a box on the form to indicate whether they personally had concerns about the patient's memory.



### Figure A-1. ROAM Assessment Process Using Non-PCP Medical Assistants

*Question 1:* The medical assistant asks the patient: “Our clinicians are asking us to do a memory assessment on all of our patients aged 75 and older. Is there a family member or companion here with you who can participate in the beginning of the visit when we do this assessment so that I can ask him/her some questions about your memory?”

*Question 2:* The medical assistant asks the patient: “Have you noticed a change in your memory that concerns you?” If the patient asks for clarification, the medical assistant uses these examples: “For example, have you had problems remembering things that you used to be able to remember, like appointments and family occasions, or problems taking medications according to instructions? Have you had problems with tasks, such as writing checks or paying bills?”

*Question 3:* If someone is with the patient, the medical assistant asks that person, “Have you noticed a change in [patient’s name] memory that concerns you?” If the person asks for clarification, the medical assistant uses these examples: “For example, has he/she had problems repeating him/herself, or remembering things that he/she used to be able to remember, like appointments and family occasions, or problems taking medications according to instructions? Has he/she had problems with tasks such as writing checks or paying bills?”

*Memory Test:* Before doing vital signs and asking the patient about the reason for the PCP visit, the medical assistant asks: “As part of the memory assessment, I’m going to ask you to remember three words. Then after a few minutes, I’m going to ask you to tell me those words. The words are PONY, QUARTER, ORANGE. Please repeat these for me now.”

*Question 4:* After doing vital signs and asking the patient about the reason for the PCP visit, the medical assistant asks: “Can you tell me what those three words were that I asked you to remember?”

*Question 5:* The medical assistant notes his or her own concerns related to the patient’s memory or confusion based on either the clinic visit, communication with the patient or family members, or other interactions.

*Scoring questions 2, 3, and 4 and attaching the form to the patient’s chart:*

If the patient remembered none or one item on question 4, OR if answers to questions 2 and/or 3 are “yes,” OR if the patient refused to answer, the medical assistant attaches the results to the patient’s chart for review by the PCP.

Source: Boise et al., 2010.



## STEP 2 : ASSESS

Of 427 older adult patients who were given the assessment, 46% had scores that indicated cognitive impairment (Boise et al., 2010). Surveys of patients who participated in the study show that a very high proportion said they had no concerns about or were pleased to have their memory evaluated. Medical assistants reported that the process was easy to incorporate in their work routine, and PCPs rated the project as moderately or highly successful in increasing the identification of cognitive impairment.

Interestingly, medical assistants' expressed concerns about patients' memory or confusion were much more strongly associated with PCPs' decisions about whether a patient should receive further cognitive evaluation than either the concerns of the patient or family member about change in the patient's memory or the patient's performance on the three-word recall test. Specifically, PCPs scheduled further cognitive evaluation for 77% of the patients about whom medical assistants expressed concerns, compared with only 37% of the patients who expressed concerns about their own memory, 43% of the patients whose family members expressed concerns about the patient's memory, and 39% of patients whose score on the three-word recall test indicated cognitive impairment.







## USE A BRIEF FAMILY QUESTIONNAIRE TO OBTAIN FAMILY MEMBERS' PERCEPTIONS OF THE OLDER ADULT'S COGNITION.

Use of a brief, structured family questionnaire can help PCPs obtain the perceptions of a family member or other informant about changes in the older adult's memory, other cognitive functions, and cognition-related behaviors.

Three validated family questionnaires along with instructions for scoring are shown in this toolkit:

- [AD8 Informant Interview](#) (**Appendix A-5**)
- [GPCOG Informant Interview](#) (**Appendix A-6**)
- [Short Form Informant Questionnaire on Cognitive Decline in the Elderly \(Short IQCODE\)](#) (**Appendix A-7**)

Each of these questionnaires can be completed in a few minutes by most family members.

All three questionnaires focus on change. As noted earlier, the focus on change reflects the core requirement for a decline in memory and other cognitive functions to justify a diagnosis of dementia. Research findings and clinician experience indicate that family members are often able to report changes and decline in an older adult's cognition accurately and may be more likely to notice the changes than PCPs or other primary care office staff who have not known the older adult for as long.

The three questionnaires ask the family member or informant to think about changes that have occurred over a considerable time period, ranging from "several years" for the AD8, to 5 to 10 years for the GPCOG Informant Interview, and 10 years for the IQCODE. The three questionnaires also differ somewhat in the number and specific questions asked and the response options given:

- [The AD8](#) includes 8 questions and 3 response categories: yes, a change; no, no change; and not applicable or don't know.
- [The GPCOG Informant Interview](#) includes 6 questions and 4 response categories: yes; no; don't know; and not applicable.
- [The Short IQCODE](#) includes 16 questions and 5 response categories: much improved; a bit improved; not much change; a bit worse; and much worse.





PCPs, health plans, and health care systems that do not currently use a brief family questionnaire to help detect cognitive impairment in their older adult patients could decide to use any one of the three questionnaires. Additional family questionnaires that are intended to obtain family members' perceptions of older adults' cognition can be found in the NIA searchable database previously described (NIA, 2012).

[The Alzheimer's Association Medicare Detection of Cognitive Impairment Workgroup created an algorithm](#) that illustrates the recommended process for detecting cognitive impairment in older adults (Cordell et al. 2013) (**Appendix A-8**). The algorithm starts with recognition of signs and symptoms of cognitive impairment using approaches and tools that were discussed in the previous section on KAER Step 1. It then shows use of one of the three brief cognitive tests and one of the three family questionnaires discussed thus far in this section on KAER Step 2. The algorithm ends with the provision or referral for a diagnostic evaluation for dementia (KAER Step 3).

It is important to note that the brief family questionnaires discussed in this section differ from another kind of family questionnaire that is used after the older adult's cognitive impairment has been detected and more often, after dementia has been diagnosed. That kind of family questionnaire is intended to identify the needs and resources of family caregivers in order to provide information and services that will help them with caregiving tasks and reduce negative impacts that are often associated with caregiving.





## USE A BRIEF SELF-REPORT QUESTIONNAIRE TO OBTAIN OLDER ADULTS' PERCEPTIONS OF THEIR OWN COGNITION.

Brief self-report questionnaires that ask older adults about changes in their own cognition are seldom used in primary care. This is at least in part because of a widespread perception that older adults with cognitive impairment often do not or cannot report accurately about their cognition because of denial and/or reduced awareness and insight that is often associated with cognitive impairment and dementia. Low current use of brief, self-report questionnaires about cognition in primary care may also reflect greater PCP confidence in the results of brief cognitive tests that measure cognition directly. In addition, some PCPs may not be familiar with brief self-report questionnaires intended to obtain older adults' perceptions of their own cognition.

Three brief self-report questionnaires are included in this toolkit. Two of the self-report questionnaires, [the AD8 \(Appendix A-5\)](#) and [the Short IQCODE \(Appendix A-7\)](#), use the same questions as the two family questionnaires with the same names that were discussed earlier in this section, but the questions are asked of the older adult, not the family member. Both of these self-report questionnaires have been tested in primary care contexts and found to be useful, particularly in people with mild cognitive impairment. The third self-report questionnaire [Know the 10 Signs](#) was developed by the Alzheimer's Association (2009) (**Appendix A-9**).

Any of these self-report questionnaires could be used in any primary care visit, including initial and subsequent Annual Wellness Visits. The questionnaires can be given to older adult patients to complete in the primary care waiting room or given or mailed to older adult patients to complete at home and bring with them to their next primary care visit.

As previously noted, there is a widespread perception that older adults with cognitive impairment often do not or cannot report accurately about their cognition because of denial and/or reduced awareness and insight that is often associated with cognitive impairment and dementia. A recent IOM report (2015c) discusses the validity of older adults' self-reports of cognitive impairment, based on studies that compare older adults' reports of memory problems, often referred to as "subjective memory complaints," and the older adults' cognitive status as measured with objective cognitive tests. Some of these studies have found that older adults' reports of memory problems are often associated with depression, other psychological distress, and personality characteristics such as conscientiousness and neuroticism, rather than with objectively measured cognitive impairment. Other, more recent, longitudinal studies have found that older adults' reports of memory problems are often associated with real cognitive impairment and may predict future cognitive decline (IOM, 2015c). One expert in mild cognitive



impairment and dementia told the IOM committee that subjective memory complaints may represent very early awareness of changes in cognition that are too subtle to detect with objective cognitive tests (Petersen, 2014).

The IOM report notes that most studies that include older adults with various levels of cognitive impairment have found a stronger association between self-reported memory complaints and objectively measured cognitive status in older adults with no or very mild cognitive impairment than in older adults with moderate or severe cognitive impairment (IOM, 2015c). Likewise, studies that include older adults with depressive symptoms have generally found a stronger association between subjective memory complaints and objectively measured cognitive status in older adults with fewer depressive symptoms than in older adults with more depressive symptoms. In addition, one study of more than 17,000 women ages 70 to 81 years old found that women who had many subjective memory complaints were more likely than women with fewer subjective memory complaints to have objectively measured cognitive impairment (Amariglio et al., 2011).

Clearly, awareness of memory and other cognitive problems varies greatly among older adults who have cognitive impairment. The studies cited in the IOM report suggest that self-report questionnaires for older adults are likely to be most accurate and therefore most useful for PCPs when the questionnaires are used with older adults who express concerns about their memory or have other signs and symptoms that indicate mild cognitive impairment.



### AD8 Self-Rating Questionnaire

[The AD8 Self-Rating Questionnaire \(Appendix A-5\)](#) uses the same 8 questions as the AD8 Informant Questionnaire discussed earlier in this section and the same 3 response categories: yes, a change; no, no change; and not applicable or don't know. Instructions for use of the self-rating questionnaire say that the older adult should be asked to rate changes in his or her ability for each of the items, *without* attributing causality. The AD8 developers point out that the Self-Rating Questionnaire may be better than other self-report questionnaires at capturing self-reported symptoms of cognitive decline for three reasons (Galvin et al., 2007):

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

A study of the AD8 conducted in 325 dyads of older adults and informants (mainly spouses and adult children) found that the older adults' self-ratings were correlated with their scores on objective cognitive tests, but these correlations were weaker than correlations between informant ratings and the older adults' scores on objective cognitive tests (Galvin et al., 2007). The researchers conclude that informant ratings are generally more accurate in detecting subtle signs of cognitive decline in older adults, but AD8 self-ratings by older adults provide useful information about older adults' cognitive ability and are especially valuable for increasing understanding about an older adult's perceptions about change in his or her own cognition. They emphasize that the AD8 Self-Rating Questionnaire is most useful for older adults with mild cognitive impairment and older adults for whom there is no available informant (Galvin et al., 2007).



### Short IQCODE Self-Report Questionnaire

[The Short IQCODE Self-Report Questionnaire \(IQCODE-SR\) \(Appendix A-7\)](#) uses the same 16 questions as the Short IQCODE Informant Questionnaire discussed earlier in this section and the same 5 response categories: much improved, a bit improved, not much change, a bit worse, and much worse. Jansen and coworkers (2008) used the 16-item IQCODE-SR to improve detection of cognitive impairment in older adult patients of a large primary care practice in the Netherlands. The questionnaire was mailed to 4,823 community-dwelling adults aged 75 years and older. The older adults were asked to complete the questionnaire with or without assistance and to return it by mail, indicating whether they had received assistance. Those who returned the questionnaire and scored above a preset score were considered at high risk for cognitive impairment.

Of the 4,823 older adults who were mailed an IQCODE-SR questionnaire, 59% (2,841 individuals) returned it, and approximately one-third of those (915 individuals) reported having received help to complete it. Of the 2,841 individuals who returned the questionnaire, 16% (451 individuals) scored above the preset score indicating high risk for cognitive impairment. The individuals were, on average, older, had more impairments in activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and were more likely to have had assistance in completing the questionnaire than individuals who scored below the preset score indicating high risk for cognitive impairment (Jansen et al., 2008).

Based on these findings, the researchers conclude that the mailed IQCODE-SR was successful in identifying older adult patients at high risk for cognitive impairment who should receive further cognitive assessment (Jansen et al., 2008). At the same time, they acknowledge that the questionnaire was not completed by 41% of the sample, many of whom undoubtedly also had high risk for cognitive impairment. Moreover, some older adults who completed the questionnaire but lacked insight about their cognitive impairment were probably counted wrongly as not having high risk for cognitive impairment. It is likely that use of the IQCODE-SR in the primary care office would have resulted in a much higher proportion of completed questionnaires and perhaps fewer instances in which older adults who lacked insight about their cognitive impairment were not identified as high risk. Using the IQCODE-SR in the primary care office would have delayed identification of cognitive impairment, however, since older adults would be offered the questionnaire only if they came in for a primary care visit. Using the questionnaire in the office probably would also have required more staff time than using the mailed questionnaire.





### Know the 10 Signs

The Alzheimer’s Association’s [Know the 10 Signs](#) (**Appendix A-9**) questionnaire is a checklist based on the Association’s widely publicized “Ten Warning Signs of Alzheimer’s.” For each warning sign, the checklist provides a two- or three-sentence description and an example of “What’s typical,” that is, what would *not* count as a warning sign. Individuals are encouraged to check off each warning sign about which they have concerns and to take the checklist to their next doctor visit.

The [Know the 10 Signs](#) questionnaire is available online to older adults and their families. The GSA Workgroup is not aware of PCPs who are currently using the questionnaire to learn about their older patients’ perceptions of their own cognition. Such use would be possible, however. The concepts and words used in the questionnaire are not simple; thus, this questionnaire would probably be most appropriate for older adult patients who express concerns about their memory or other cognitive abilities but are likely to have very mild, if any, cognitive impairment. Some PCPs, health plans, and health care systems may decide to offer the questionnaire to such patients in response to the patients’ expressed concerns.





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**Mini-Cog™**

**Instructions for Administration & Scoring**

ID: \_\_\_\_\_ Date: \_\_\_\_\_

**Step 1: Three Word Registration**

Look directly at person and say, “Please listen carefully. I am going to say three words that I want you to repeat back to me now and try to remember. The words are [select a list of words from the versions below]. Please say them for me now.” If the person is unable to repeat the words after three attempts, move on to Step 2 (clock drawing).

The following and other word lists have been used in one or more clinical studies.<sup>1-3</sup> For repeated administrations, use of an alternative word list is recommended.

Version 1	Version 2	Version 3	Version 4	Version 5	Version 6
Banana	Leader	Village	River	Captain	Daughter
Sunrise	Season	Kitchen	Nation	Garden	Heaven
Chair	Table	Baby	Finger	Picture	Mountain

**Step 2: Clock Drawing**

Say: “Next, I want you to draw a clock for me. First, put in all of the numbers where they go.” When that is completed, say: “Now, set the hands to 10 past 11.”

Use preprinted circle (see next page) for this exercise. Repeat instructions as needed as this is not a memory test. Move to Step 3 if the clock is not complete within three minutes.

**Step 3: Three Word Recall**

Ask the person to recall the three words you stated in Step 1. Say: “What were the three words I asked you to remember?” Record the word list version number and the person’s answers below.

Word List Version: \_\_\_\_\_ Person’s Answers: \_\_\_\_\_

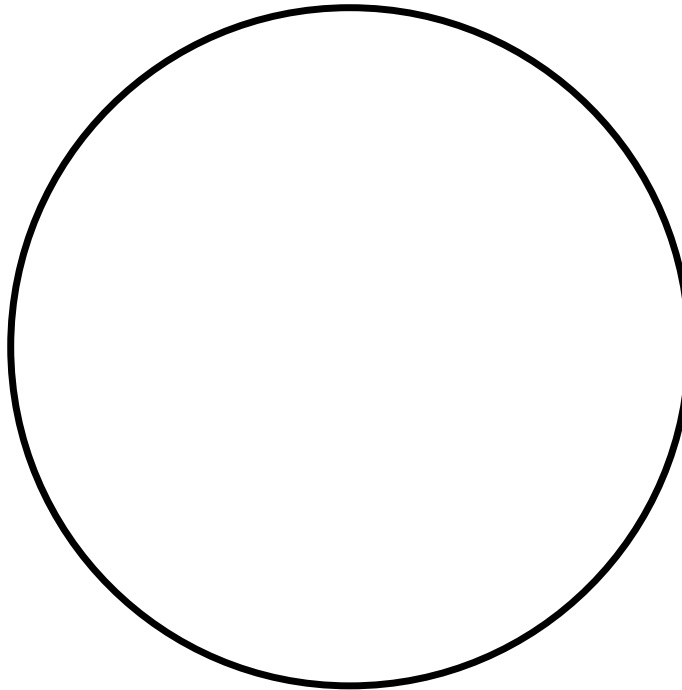
**Scoring**

Word Recall: _____ (0-3 points)	1 point for each word spontaneously recalled without cueing.
Clock Draw: _____ (0 or 2 points)	Normal clock = 2 points. A normal clock has all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
Total Score: _____ (0-5 points)	Total score = Word Recall score + Clock Draw score.  A cut point of <3 on the Mini-Cog™ has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.



## Clock Drawing

ID: \_\_\_\_\_ Date: \_\_\_\_\_



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Patient name: \_\_\_\_\_

Date: \_\_\_\_\_

## **GPCOG Screening Test**

### **Step 1: Patient Examination**

*Unless specified, each question should only be asked once*

#### **Name and Address for subsequent recall test**

1. *“I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington.” (Allow a maximum of 4 attempts).*

#### **Time Orientation**

2. *What is the date? (exact only)*

**Correct**      **Incorrect**



#### **Clock Drawing** – use blank page

3. *Please mark in all the numbers to indicate the hours of a clock (correct spacing required)*
4. *Please mark in hands to show 10 minutes past eleven o'clock (11.10)*





#### **Information**

5. *Can you tell me something that happened in the news recently? (Recently = in the last week. If a general answer is given, eg “war”, “lot of rain”, ask for details. Only specific answer scores).*



#### **Recall**

6. *What was the name and address I asked you to remember*

John

Brown

42

West (St)

Kensington



*(To get a total score, add the number of items answered correctly)*  
**Total correct** (score out of 9)

/9
----

**If patient scores 9, no significant cognitive impairment and further testing not necessary.**

**If patient scores 5-8, more information required. Proceed with Step 2, informant section.**

**If patient scores 0-4, cognitive impairment is indicated. Conduct standard investigations.**





## MEMORY IMPAIRMENT SCREEN (MIS)

### Instructions for Administration

1. Show patient a sheet of paper with the 4 items to be recalled in 24-point or greater uppercase letters (on other side), and ask patient to read the items aloud.
2. Tell patient that each item belongs to a different category. Give a category cue and ask patient to indicate which of the words belongs in the stated category (eg, "Which one is the game?"). Allow up to 5 attempts. Failure to complete this task indicates possible cognitive impairment.
3. When patient identifies all 4 words, remove the sheet of paper. Tell patient that he or she will be asked to remember the words in a few minutes.
4. Engage patient in distractor activity for 2 to 3 minutes, such as counting to 20 and back, counting back from 100 by 7, spelling WORLD backwards.
5. FREE RECALL — 2 points per word: Ask patient to state as many of the 4 words he or she can recall. Allow at least 5 seconds per item for free recall. Continue to step 6 if no more words have been recalled for 10 seconds.
6. CUED RECALL — 1 point per word: Read the appropriate category cue for each word not recalled during free recall (eg, "What was the game?").

Word	Cue	Free recall (2 pts.)	Cued Recall (1 pts)
Checkers	Game		
Saucer	Dish		
Telegram	Message		
Red Cross	Organization		

### Scoring

**The maximum score for the MIS is 8.**

- 5-8 No cognitive impairment
- ≤ 4 Possible cognitive impairment

**Contact Albert Einstein College of Medicine to use this test.**

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## WORD LIST

CHECKERS

SAUCER

TELEGRAM

RED CROSS

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## Assessing Cognitive Impairment in Older Patients

### *A Quick Guide for Primary Care Physicians*

As a primary care practice, you and your staff are often the first to address a patient's complaints—or a family's concerns—about memory loss or possible dementia.<sup>1,2</sup> This quick guide provides information about assessing cognitive impairment in older adults.

With this information, you can identify emerging cognitive deficits and possible causes, following up with treatment for what may be a reversible health condition. Or, if Alzheimer's disease or another dementia is found, you can help patients and their caregivers prepare for the future. Brief, nonproprietary risk assessment and screening tools are available.<sup>2</sup>

#### **This quick guide addresses:**

- ✓ Why is it important to assess cognitive impairment in older adults?
- ✓ When is screening indicated?
- ✓ How can physicians and staff find time for screening?
- ✓ How is cognitive impairment evaluated?

#### **Why is it important to assess cognitive impairment in older adults?**

Cognitive impairment in older adults has a variety of possible causes, including medication side effects, metabolic and/or endocrine derangements, delirium due to intercurrent illness, depression, and dementia, with Alzheimer's dementia being most common. Some causes, like medication side effects and depression, can be reversed with treatment. Others, such as Alzheimer's disease, cannot be reversed, but symptoms can be treated for a period of time and families can be prepared for predictable changes.

Many people who are developing or have dementia do not receive a diagnosis. One study showed that physicians were unaware of cognitive impairment in more than 40 percent of their cognitively impaired patients.<sup>3</sup> Another study found that more than half of patients with dementia had not received a clinical cognitive evaluation by a physician.<sup>17</sup> The failure to evaluate memory or cognitive complaints is likely to hinder treatment of underlying disease and comorbid conditions, and may present safety issues for the patient and others.<sup>4,5</sup> In many cases, the cognitive problem will worsen over time.<sup>2,4,6</sup>



## Benefits of Early Screening

- ✓ **If screening is negative:** Concerns may be alleviated, at least at that point in time.
- ✓ **If screening is positive and further evaluation is warranted:** The patient and physician can take the next step of identifying the cause of impairment (for example, medication side effects, metabolic and/or endocrine imbalance, delirium, depression, Alzheimer's disease). This may result in:
  - Treating the underlying disease or health condition
  - Managing comorbid conditions more effectively
  - Averting or addressing potential safety issues
  - Allowing the patient to create or update advance directives and plan long-term care
  - Ensuring the patient has a caregiver or someone to help with medical, legal, and financial concerns
  - Ensuring the caregiver receives appropriate information and referrals
  - Encouraging participation in clinical research

Most patients with memory, other cognitive, or behavior complaints want a diagnosis to understand the nature of their problem and what to expect.<sup>6-10</sup> Some patients (or families) are reluctant to mention such complaints because they fear a diagnosis of dementia and the future it portends. In these cases, a primary care provider can explain the benefits of finding out what may be causing the patient's health concerns.

Pharmacological treatment options for Alzheimer's-related memory loss and other cognitive symptoms are limited, and none can stop or reverse the course of the disease. However, assessing cognitive impairment and identifying its cause, particularly at an early stage, offers several benefits.

### When is screening indicated?

The U.S. Preventive Services Task Force, in its recent review and recommendation regarding routine screening for cognitive impairment, noted that "although the overall evidence on routine screening is insufficient, clinicians should remain alert to early signs or symptoms of cognitive impairment (for example, problems with memory or language) and evaluate as appropriate."<sup>11</sup> The Dementia Screening Indicator (<http://bit.ly/1pxk5rl>) can help guide clinician decisions about when it may be appropriate to screen for cognitive impairment in the primary care setting.<sup>12</sup>

### How can physicians and their staff find time for screening?

Trained staff using readily available screening tools need only **10 minutes or less** to initially assess a patient for cognitive impairment. While screening results alone are insufficient to diagnose dementia, they are an important first step. The AD8 and Mini-Cog are among many possible tools. For a searchable database that describes instruments to detect cognitive impairment in older adults, see [www.nia.nih.gov/research/cognitive-instrument](http://www.nia.nih.gov/research/cognitive-instrument).



Assessment for cognitive impairment can be performed at any visit but is now a required component of the Medicare Annual Wellness Visit (<http://go.cms.gov/1E9Mlub>).<sup>4,13</sup> Coverage for wellness and, importantly, for follow-up visits is available to any patient who has had Medicare Part B coverage for at least 12 months.

## How is cognitive impairment evaluated?

Positive screening results warrant further evaluation. A combination of cognitive testing and information from a person who has frequent contact with the patient, such as a spouse or other care provider, is the best way to more fully assess cognitive impairment.<sup>14</sup>

A primary care provider may conduct an evaluation or refer to a specialist such as a geriatrician, neurologist, geriatric psychiatrist, or neuropsychologist. If available, a local memory disorders clinic or Alzheimer's Disease Center ([www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers](http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers)) may also accept referrals.

Genetic testing, neuroimaging, and biomarker testing are not generally recommended for clinical use at this time.<sup>2,15</sup> These tests are primarily conducted in research settings.

Interviews to assess memory, behavior, mood, and functional status (especially complex actions such as driving and managing money<sup>16</sup>) are best conducted with the patient alone, so that family members or companions cannot prompt the patient. Information can also be gleaned from the patient's behavior on arrival in the doctor's office and interactions with staff.

Note that patients who are only mildly impaired may be adept at covering up their cognitive deficits and reluctant to address the problem.

Family members or close companions can also be good sources of information. Inviting them to speak privately may allow for a more candid discussion. Per HIPAA regulations, the patient should give permission in advance. An alternative would be to invite the family member or close companion to be in the examining room during the patient's interview and contribute additional information after the patient has spoken. Brief, easy-to-administer informant screening tools, such as the short IQCODE or the AD8, are available.

## Points to Remember

- ✓ Patients should be screened for cognitive impairment if:
  - the person, family members, or others express concerns about changes in his or her memory or thinking, or
  - you observe problems/changes in the patient's memory or thinking, or
  - the patient is age 80 or older.
- ✓ Other risk factors that could indicate the need for cognitive-impairment screening include: low education, history of type 2 diabetes, stroke, depression, and trouble managing money or medications.
- ✓ Instruments for brief screening are available and can be used in an office visit.
- ✓ Patients, particularly those who express a concern, likely want to know what the underlying problem is.
- ✓ Refer to a specialist if needed.





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### More Information

For links to additional resources (tools, guidelines, recommendations), see the online version of this tip sheet at:

[www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-adults](http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-adults).

For more information about Alzheimer's disease and other dementias, contact:

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

1-800-438-4380 (toll-free)

[adear@nia.nih.gov](mailto:adear@nia.nih.gov)

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

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and other dementias, find clinical trials, and sign up for email updates.



## AD8 Dementia Screening Interview

Patient ID#: \_\_\_\_\_

CS ID#: \_\_\_\_\_

Date: \_\_\_\_\_

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	<b>YES, A change</b>	<b>NO, No change</b>	<b>N/A, Don't know</b>
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. <b>Daily</b> problems with thinking and/or memory			
<b>TOTAL AD8 SCORE</b>			



## The AD8 Administration and Scoring Guidelines

*A spontaneous self-correction is allowed for all responses without counting as an error.*

The questions are given to the respondent on a clipboard for self-administration or can be read aloud to the respondent either in person or over the phone. It is preferable to administer the AD8 to an informant, if available. If an informant is not available, the AD8 may be administered to the patient.

When administered to an informant, specifically ask the respondent to rate change in the patient.

When administered to the patient, specifically ask the patient to rate changes in his/her ability for each of the items, **without** attributing causality.

If read aloud to the respondent, it is important for the clinician to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems). There should be a one second delay between individual items.

No timeframe for change is required.

The final score is a sum of the number items marked “Yes, A change”.

**Interpretation of the AD8** (Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, *Neurology* 2005;65:559-564)

A screening test in itself is insufficient to diagnose a dementing disorder. The AD8 is, however, quite sensitive to detecting early cognitive changes associated many common dementing illness including Alzheimer disease, vascular dementia, Lewy body dementia and frontotemporal dementia.

Scores in the impaired range (see below) indicate a need for further assessment. Scores in the “normal” range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

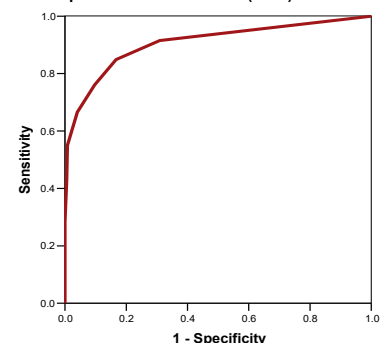
Based on clinical research findings from 995 individuals included in the development and validation samples, the following cut points are provided:

- 0 – 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

Administered to either the informant (preferable) or the patient, the AD8 has the following properties:

- Sensitivity >84%
- Specificity >80%
- Positive Predictive Value > 85%
- Negative Predictive Value > 70%
- Area under the Curve: 0.908; 95%CI: 0.888-0.925

Receiver Operator Characteristics (ROC) curve for AD8





Patient name: \_\_\_\_\_

## GPCOG Screening Test Informant Interview

Date: \_\_\_\_\_

Informant's name: \_\_\_\_\_

Informant's relationship to patient, i.e. informant is the patient's: \_\_\_\_\_

**These six questions ask how the patient is compared to when  
s/he was well, say 5 – 10 years ago**

*Compared to a few years ago:*

	Yes	No	Don't Know	N/A
▪ Does the patient have more trouble remembering things that have happened recently than s/he used to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
▪ Does he or she have more trouble recalling conversations a few days later?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
▪ When speaking, does the patient have more difficulty in finding the right word or tend to use the wrong words more often?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
▪ Is the patient less able to manage money and financial affairs (e.g. paying bills, budgeting)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
▪ Is the patient less able to manage his or her medication independently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
▪ Does the patient need more assistance with transport (either private or public)? <small>(If the patient has difficulties due only to physical problems, e.g. bad leg, tick 'no')</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**(To get a total score, add the number of items answered 'no', 'don't know' or 'N/A')**

Total score (out of 6)

**If patient scores 0-3, cognitive impairment is indicated. Conduct standard investigations.**





## **Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE)**

**by A. F. Jorm**

**Centre for Mental Health Research  
The Australian National University  
Canberra, Australia**

There is no copyright on the Short IQCODE. However, the author appreciates being kept informed of research projects which make use of it.

Note: As used in published studies, the IQCODE was preceded by questions to the informant on the subject's sociodemographic characteristics and physical health.



Now we want you to remember what your friend or relative was like 10 years ago and to compare it with what he/she is like now. 10 years ago was in 19\_\_ . Below are situations where this person has to use his/her memory or intelligence and we want you to indicate whether this has improved, stayed the same or got worse in that situation over the past 10 years. Note the importance of comparing his/her present performance with 10 years ago. So if 10 years ago this person always forgot where he/she had left things, and he/she still does, then this would be considered "Hasn't changed much". Please indicate the changes you have observed by circling the appropriate answer.

Compared with 10 years ago how is this person at:

	1	2	3	4	5
1. Remembering things about family and friends e.g. occupations, birthdays, addresses	Much improved	A bit improved	Not much change	A bit worse	Much worse
2. Remembering things that have happened recently	Much improved	A bit improved	Not much change	A bit worse	Much worse
3. Recalling conversations a few days later	Much improved	A bit improved	Not much change	A bit worse	Much worse
4. Remembering his/her address and telephone number	Much improved	A bit improved	Not much change	A bit worse	Much worse
5. Remembering what day and month it is	Much improved	A bit improved	Not much change	A bit worse	Much worse
6. Remembering where things are usually kept	Much improved	A bit improved	Not much change	A bit worse	Much worse
7. Remembering where to find things which have been put in a different place from usual	Much improved	A bit improved	Not much change	A bit worse	Much worse
8. Knowing how to work familiar machines around the house	Much improved	A bit improved	Not much change	A bit worse	Much worse

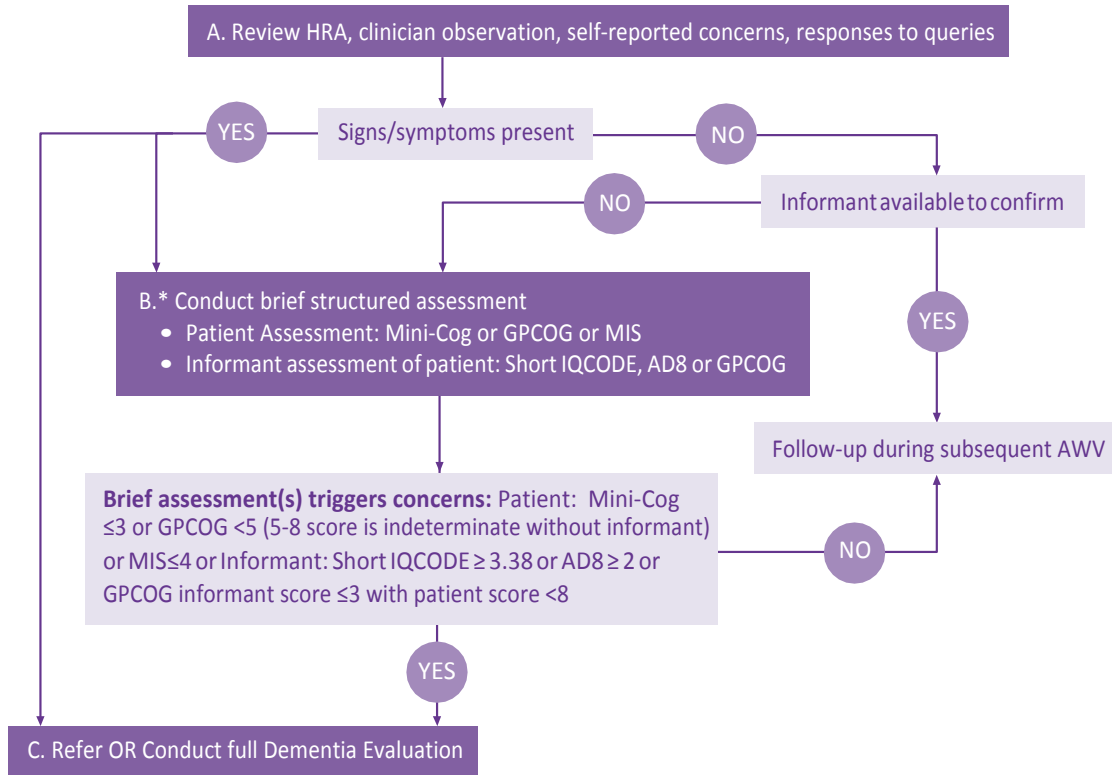


9. Learning to use a new gadget or machine around the house	Much improved	A bit improved	Not much change	A bit worse	Much worse
10. Learning new things in general	Much improved	A bit improved	Not much change	A bit worse	Much worse
11. Following a story in a book or on TV	Much improved	A bit improved	Not much change	A bit worse	Much worse
12. Making decisions on everyday matters	Much improved	A bit improved	Not much change	A bit worse	Much worse
13. Handling money for shopping	Much improved	A bit improved	Not much change	A bit worse	Much worse
14. Handling financial matters e.g. the pension, dealing with the bank	Much improved	A bit improved	Not much change	A bit worse	Much worse
15. Handling other everyday arithmetic problems e.g. knowing how much food to buy, knowing how long between visits from family or friends	Much improved	A bit improved	Not much change	A bit worse	Much worse
16. Using his/her intelligence to understand what's going on and to reason things through	Much improved	A bit improved	Not much change	A bit worse	Much worse



# ALZHEIMER'S ASSOCIATION®

## Medicare Annual Wellness Visit Algorithm for Assessment of Cognition



\*No one tool is recognized as the best brief assessment to determine if a full dementia evaluation is needed. Some providers repeat patient assessment with an alternate tool (e.g., SLUMS, or MoCA) to confirm initial findings before referral or initiation of full dementia evaluation.

**AD8**= Eight-item Informant Interview to Differentiate Aging and Dementia; **AWV**= Annual Wellness Visit; **GPCOG** = General Practitioner Assessment of Cognition; **HRA** = Health Risk Assessment; **MIS** = Memory Impairment Screen; **MMSE** = Mini Mental Status Exam; **MoCA** = Montreal Cognitive Assessment; **SLUMS** = St. Louis University Mental Status Exam; **Short IQCODE** = Short Informant Questionnaire on Cognitive Decline in the Elderly

Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimers Dement.* 2013;9(2):141-150. Available at <http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012025010.pdf>.





# KNOW the 10 SIGNS

EARLY DETECTION MATTERS

If you notice any of the 10 Warning Signs of Alzheimer's in yourself or someone you know, don't ignore them. Please consult your physician.

## #1 Memory changes that disrupt daily life

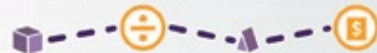
One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. For example:



**Typical age-related changes:** Sometimes forgetting names or appointments, but remembering them later.

## #2 Challenges in planning or solving problems

Some people may have difficulty concentrating and take much longer to do things than they did before.



**Typical age-related changes:** Making occasional errors when balancing a checkbook.

## #3 Difficulty completing familiar tasks

People with Alzheimer's often find it hard to complete daily tasks such as:



**Typical age-related changes:** Occasionally needing help to use the settings on a microwave or record a television show.

## #4 Confusion with time or place

People with Alzheimer's can lose track of dates, seasons and the passage of time.

They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.



**Typical age-related changes:** Getting confused about the day of the week but figuring it out later.

## #5 Trouble understanding visual images and spatial relationships



Some people may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

**Typical age-related changes:** Vision changes related to cataracts.

## #6 New problems with words in speaking or writing

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name.

**Typical age-related changes:** Sometimes having trouble finding the right word.



## #7 Misplacing things and losing the ability to retrace steps

A person with Alzheimer's disease may put things in unusual places.

They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.



**Typical age-related changes:** Misplacing things from time to time.

## #8 Decreased or poor judgment

People with Alzheimer's may demonstrate unusual changes in judgment or decision making.

For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers.

They may pay less attention to grooming or keeping themselves clean.



**Typical age-related changes:** Making a bad decision once in a while.

## #9 Withdrawal from work or social activities

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may also avoid being social because of the changes they have experienced.



**Typical age-related changes:** Sometimes feeling weary of work, family and social obligations.

## #10 Changes in mood and personality

The mood and personalities of people with Alzheimer's can change.

They may be easily upset in places where they are out of their comfort zone.

They can become confused, suspicious, depressed, fearful or anxious.



**Typical age-related changes:** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.





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## OVERVIEW

In its 2015 report, the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis recommends that:

- If, as a result of using one or more approaches to detect cognitive impairment, PCPs find that the older adult has cognitive impairment, PCPs should, at a minimum, rule out reversible, physiological causes of cognitive impairment per published clinical practice guidelines and recommendations (e.g., thyroid or vitamin deficiency) by ordering appropriate laboratory tests (GSA, 2015).
- Consistent with relevant health care system protocols, if any, and PCP training and experience, PCPs should conduct a diagnostic evaluation for dementia per published clinical guidelines and recommendations (GSA, 2015).
- PCPs who are unable for any reason to conduct a diagnostic evaluation for dementia should refer patients with cognitive impairment to a clinical specialist or team (e.g., geriatrician, neurologist, geriatric psychiatrist, neuropsychologist, nurse practitioner with geropsychiatric expertise, or memory disorders clinic) for a diagnostic evaluation per published clinical practice guidelines and recommendations (GSA, 2015).

Many older adults who have cognitive impairment do not receive a diagnostic evaluation to determine whether they have dementia. Findings from a study of a nationally representative sample of Americans aged 70 years and older indicate that less than half (45%) of those who were diagnosed with dementia in an extensive, in-person diagnostic evaluation conducted for the study had previously received a diagnostic evaluation (Kotagal et al., 2014). Other studies have similar findings (Bradford et al., 2009).





There are many reasons that older adults who have cognitive impairment may not receive a diagnostic evaluation, including the following:

- The older adult's cognitive impairment has not been detected; if cognitive impairment is not detected, a diagnostic evaluation is unlikely to be conducted to determine its cause.
- The older adult's cognitive impairment has been detected, but the PCP decides not to recommend a diagnostic evaluation; sometimes this occurs because the PCP thinks no additional or useful information will be gained from a diagnostic evaluation. In addition, anecdotal evidence suggests that older adults and family members sometimes ask the PCP not to recommend a diagnostic evaluation because of fear or shame about the possibility of a confirmed dementia diagnosis.
- The PCP, the older adult, and/or family members mistakenly assume that the older adult's score on a brief cognitive test or apparent signs and symptoms of cognitive impairment are sufficient evidence for a dementia diagnosis and that no additional evaluation is needed.
- The older adult's cognitive impairment has been detected and the PCP has recommended a diagnostic evaluation, but the older adult does not follow through on the recommendation. This may occur because the older adult does not want to know the diagnosis, does not want others to know, or is afraid of consequences, such as loss of his or her driver's license, rejection for health or long-term care insurance, or refused admission to an assisted living facility.

It is unclear how often each of the above-listed reasons accounts for instances in which older adults with cognitive impairment do not receive a diagnostic evaluation. Research suggests, however, that the last reason, failure of the older adult to follow through on the PCP's referral for a diagnostic evaluation, may account for a substantial proportion of such instances. Two studies conducted in a large health care system in Indiana (Boustani et al., 2005; Fowler et al., 2015) and one study conducted in eight VA medical centers in the Midwest (McCarten et al., 2012) found that large proportions of the older adults with cognitive impairment whose PCP recommended a diagnostic evaluation did not follow through to get the evaluation (48%, 67%, and 72%, respectively).

These data and the above-listed reasons clearly demonstrate that perceptions, assumptions, and actions of three groups—PCPs, older adults, and family members—contribute to the problem that many older adults with cognitive impairment do not receive a diagnostic evaluation. Although this toolkit focuses on PCPs, the GSA Workgroup believes it is critical to acknowledge the involvement of all three groups in the development of the problem and, therefore, the importance of involving all three groups in finding ways to solve it.



As noted at the beginning of this toolkit, without a diagnostic evaluation, older adults who have treatable conditions that are either causing their cognitive impairment or exacerbating the cognitive impairment caused by their dementia are unlikely to receive treatments for these conditions. Likewise, older adults who have dementia but do not receive a diagnostic evaluation are unlikely to get a dementia diagnosis. Without a diagnosis, they and their families are unlikely to benefit from educational, supportive, and skill-building services that can improve health-related outcomes and well-being for the person with dementia and reduce stress, depression, and feelings of isolation and burden for family members. Without a diagnosis, older adults with dementia are also unlikely to benefit from post-diagnostic medical care that can help to mitigate their dementia-related symptoms and accommodate any negative effects of their dementia on their co-existing medical conditions and treatment for those conditions, and vice versa.

A systematic review of English-language studies published from 1980 to 2008 identified a wide array of factors that can limit the proportion of patients with dementia that receives a dementia diagnosis (Bradford et al., 2009). The factors were categorized as physician-related, patient-related, family-related, and system-related. The 2015 GSA Workgroup report includes a table, *Barriers to PCP Diagnosis of Dementia (Figure E-1)*, which summarizes the physician-related factors identified by six sources including the systematic review.







### Figure E-1. Barriers to PCP Diagnosis of Dementia

- Brief time for office visits.
- Need to focus office time on diagnosis and treatment of the person's other physical health problems.
- Inadequate diagnostic skills.
- Concerns about the risk of misdiagnosis.
- Limited availability of specialists to help with diagnosis.
- Reluctance to refer the person or family to a specialist for diagnosis.
- Worry that diagnosis will result in increased demand for limited resources, including physician time for communicating with and supporting family members.
- Ambivalence about the value of diagnosis.
- Belief that the symptoms are just normal aging.
- Belief that the person or family doesn't want to know.
- Concerns about the negative effect of a dementia diagnosis on the person or family.
- Uncertainty about whether and how to disclose the diagnosis to the person or family.
- Difficulty explaining or discussing dementia with the person or family.
- Perceived lack of effective drug treatments.
- Lack of awareness about nondrug treatments and community services and supports that have been shown to benefit people with dementia and their families.
- Reluctance to acknowledge dementia in patients who are friends, neighbors, or members of the same religious or social group.
- Low reimbursement for diagnosis.

Sources: Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Boise et al., 2010; Bradford, Kunik, Schulz, Williams, & Singh, 2009; Fortinsky, Leighton, & Wasson, 1995; Fortinsky & Wasson, 1997; Hinton et al., 2007.





Patient-related and family-related factors identified by the systematic review as limiting the proportion of patients with dementia that receives a diagnostic evaluation are: an assumption that cognitive changes are part of normal aging, a perception of limited treatment options, concern about the cost of treatment, lack of health insurance, and communication problems (Bradford et al., 2009). For patients, these communication problems include forgetting to mention cognitive symptoms and relying on the PCP to bring up that topic. For families, the identified communication problems include difficulty talking with the older adult and the PCP about cognitive impairment and dementia and interpretation of PCP silence as a sign that nothing is wrong.

Additional patient-related factors identified by the systematic review are: concern about the effects of treatment, patient denial of need or refusal to accept assessment or treatment, fear of the possibility of dementia, and fear that a dementia diagnosis might threaten immigration status and lead to deportation. Additional family-related factors are: lack of knowledge of dementia and its symptoms, misattribution of symptoms to another condition or medication, uncertainty about the appropriate choice of medical provider, denial or preference not to know the diagnosis, doubts about the value of diagnosis and treatment, fear of stigmatization or other negative consequences for the patient, fear of confirming the family member's own risk for dementia, fear that the patient might be denied admission to a nursing home or other care facility, and concerns about emotional, financial or other negative effects of diagnosis on the family. Caregiver-related factors also include the perception that there is a lack of physicians capable of making a diagnosis and concern that the diagnostic process will be too time consuming.

System-related factors identified in the systematic review are insufficient PCP time with patients, insufficient availability of community services and specialists for consultation, low financial reimbursement for dementia care, and limitations on diagnostic tests that are imposed by managed care or state health systems.

The wide array of physician-related, patient-related, family-related, and system-related factors identified as limiting the proportion of older adults with dementia that receives a dementia diagnosis suggests both challenges and opportunities for increasing that proportion. Many of the same factors influence other aspects of the diagnostic process, resulting, for example, in dementia diagnoses that have been made but are not documented in the patient's medical record or disclosed to the patient and/or family.



## STEP 3 : EVALUATE

This section presents approaches and tools that may be helpful to PCPs in conducting a diagnostic evaluation, documenting the diagnosis, and disclosing it to the older adult and family. The section also presents several available tools that PCPs may be able to use to increase older adults' and family members' understanding about the importance of diagnostic evaluation for older adults with cognitive impairment.





## APPROACHES

Due to differences in the structure, organization, and usual primary care procedures among and between single PCP offices, physician group practices, health plans, and health care systems, approaches and tools for diagnostic evaluation that fit and are useful for one PCP practice setting will not fit or be useful for other PCP practice settings. Moreover, some single PCP offices, group practices, health plans, and health care systems already have procedures in place for diagnostic evaluation for dementia, whereas others have no such procedures in place; thus approaches and tools that are timely for some PCP practice settings are not timely for others. The approaches and tools presented below are intended to provide information and options that will help single PCP offices, group practices, health plans, and health care systems formulate new procedures or evaluate and perhaps improve their existing procedures for conducting diagnostic evaluations for dementia and documenting and disclosing dementia diagnoses.

### CONDUCT A DIAGNOSTIC EVALUATION.

A diagnostic evaluation for dementia is intended to determine first whether a person with cognitive impairment has dementia or a non-dementia condition that is causing the cognitive impairment. If the diagnostic evaluation shows that the person has dementia, the next step is to identify the cause(s) of the dementia, such as Alzheimer's disease, vascular conditions, Lewy body disease, frontotemporal degeneration, or a combination of these and other possible, although less common, causes.

Dementia is a syndrome characterized by cognitive and functional impairments. Specific criteria for a diagnosis of dementia come from various sources. The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000), which is still used by some and perhaps many PCPs and other health care professionals, requires deficits in two or more cognitive domains, including memory impairment and at least one of the following: aphasia, apraxia, agnosia, or disturbance in executive functioning. The deficits must cause significant impairment in social or occupational functioning. They must constitute a decline from the person's previous level of functioning, and they may not occur solely in the course of delirium.



The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*, published in 2013, does not use the term “dementia.” Instead, *DSM-5* uses the term “neurocognitive disorder.” 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. Unlike the *DSM-IV-TR* criteria, memory impairment is no longer a required criterion. Like the *DSM-IV-TR* criteria, the *DSM-5* criteria require that the cognitive impairment(s) must constitute a decline from a previous level of functioning; that they are sufficient to interfere with independent functioning; and that they do not occur solely in the course of delirium (American Psychiatric Association, 2013).

Figure E-2 shows the recommended components of a diagnostic evaluation for dementia based on the GSA Workgroup’s review of six published guideline and recommendation documents that are intended mainly, although not exclusively, 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). The six guideline and recommendation documents use slightly different terms and categorize the components slightly differently, but they all include the eight components shown in the figure: medical history, cognitive and mental status testing, functional assessment, physical and neurological examination, neuropsychological testing, laboratory tests, neuroimaging, and specialist referral. **Figure E-2** lists several assessment tools for cognitive testing, depression, and functional impairment because many PCPs, physician group practices, health plans, and health care systems may already be using an assessment tool for one or more of these domains and will probably want to incorporate that assessment tool in diagnostic evaluations for dementia. With the exception of the Mini-Mental State Examination (MMSE) (Folstein et al., 1975), the assessment tools listed in the figure are included as appendices to this section:

- Appendix E-1: Montreal Cognitive Assessment (MoCA)
- Appendix E-2: Saint Louis University Mental Status (SLUMS) Examination
- Appendix E-3: Confusion Assessment Method (CAM)
- Appendix E-4: Patient Health Questionnaire-9 (PHQ-9)
- Appendix E-5: Geriatric Depression Scale (GDS)
- Appendix E-6: Center for Epidemiologic Studies Depression Scale (CES-D)
- Appendix E-7: Katz Index of Independence in Activities of Daily Living (ADL)
- Appendix E-8: Instrumental Activities of Daily Living (IADL)
- Appendix E-9: Functional Activities Questionnaire (FAQ)





## Figure E-2. Components of a Diagnostic Evaluation for Dementia

### Medical History

Obtain a medical history through a clinical interview with the older adult and at least one additional informant. 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. 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

Conduct cognitive testing using validated assessment instruments that measure multiple cognitive domains. Recommended instruments include the [Montreal Cognitive Assessment \(MoCA\)](#) (**Appendices E-1a and E1b**) and the [Saint Louis University Mental Status \(SLUMS\) Examination](#) (**Appendix E-2**).

Many PCPs and others continue to use the Mini-Mental State Examination (MMSE) (Folstein et al., 1975). A private company now holds the copyright for the MMSE, charges a fee for each use, and increasingly enforces the charge. Thus the MMSE is not shown in this toolkit.

Use validated instruments to test for delirium and depression, for example, the [Confusion Assessment Method \(CAM\)](#) (**Appendix E-3**), the [Patient Health Questionnaire-9 \(PHQ-9\)](#) (**Appendix E-4**), the [Geriatric Depression Scale \(GDS\)](#) (**Appendix E-5**), or the [Center for Epidemiologic Studies-Depression \(CES-D\) Scale](#) (**Appendix E-6**).

### Functional Assessment

Functional impairment is usually assessed by asking the older adult and a family member or other informant about the older adult's 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) (**Appendix E-7**). 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) (**Appendix E-8**); 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) (**Appendix E-9**).

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

### Physical and Neurological Examination

Conduct a physical and neurological examination to assess walking, gait disturbances, balance, coordination, speech and language impairment, 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 re-evaluations.

### Laboratory Tests

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

- Completed blood cell count
- Serum B<sub>12</sub>
- Serum calcium
- Folate
- Glucose
- Serum Electrolytes
- Thyroid function tests
- Liver function tests
- Renal function tests

### Neuroimaging

Recommendations for use of neuroimaging in 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 in clinical diagnostic evaluations for dementia. Other sources say that neuroimaging, including CT and MRI scans 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 Medicare for patients who meet specified criteria: 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 (CMS, 2004). 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

PCPs should consider referral to a specialist, such as a neurologist, geriatric psychiatrist, neuropsychologist, geriatrician, nurse practitioner with geropsychiatric experience, or 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.

Sources: American Academy of Neurology, 2013; American Geriatrics Society, 2011; American Psychological Association, 2012; Galvin & Sadowsky, 2012; Geldmacher & Kerwin, 2013; Group Health Cooperative, 2012.





Clearly, the focus and amount of time spent on each of the components in Figure E-2 will vary for different patients and situations. Some parts of each component may have already been conducted by the PCP or other primary care office staff in the process of determining whether the older adult has cognitive impairment (KAER steps 1 and 2). For example, parts or all of the medical history may have been obtained, and some cognitive and functional tests may have been conducted and do not need to be repeated.

All six documents reviewed by the GSA Workgroup to identify recommended components of a diagnostic evaluation for dementia endorse a central role for PCPs in diagnosing dementia in older adults. They acknowledge that some older adults with cognitive impairment present first to a physician specialist, such as a neurologist, geriatric psychiatrist, or geriatrician, or a specialty memory clinic. The documents also acknowledge the need for specialist referrals in specified situations (see “Specialist Referral” in Figure E-2). The guideline and recommendation documents point out, however, that older adults with cognitive impairment usually present first to a PCP and that PCPs can successfully conduct diagnostic evaluations for most of these individuals. They also note that because of the increasing number of older adults with cognitive impairment, PCPs are likely to be conducting a growing number of such diagnostic evaluations.

The six guideline and recommendation documents generally encourage early diagnosis and emphasize the importance of obtaining input, whenever possible, from a family member or other informant who knows the older adult well. The guideline and recommendation documents also stress the importance of identifying treatable causes of cognitive impairment, focusing in particular on depression, medications, hypothyroidism, vitamin B<sub>12</sub> deficiency, and comorbid health conditions, all of which can cause cognitive impairment and are often treatable and sometimes reversible.

It is not clear how many PCPs conduct diagnostic evaluations for dementia using the eight components shown in Figure E-2. A 2008 mail survey of a random sample of U.S. members of the American Academy of Family Physicians asked about usual practices in detection, diagnosis, and ongoing primary care for patients aged 65 years and older with dementia (Stewart et al., 2014). The survey had a 60% response rate. The great majority of the physician respondents (90%) said they conduct diagnostic evaluations for dementia based on signs or symptoms or concerns expressed by a patient and/or caregiver. Almost all the physician respondents (95%) said they routinely collect patient history as part of the diagnostic process; 93% said they routinely order



lab work as part of the process; 73% said they routinely conduct additional cognitive testing; 66% said they routinely order brain imaging; and 40% said they refer some patients with dementia to specialists, usually to verify the diagnosis. Identified barriers to diagnostic evaluation cited by physician respondents included inadequate clinician time and lack of diagnostic tools.

To the extent that these and other PCPs are already conducting diagnostic evaluations for some or all of their older patients with cognitive impairment, the diagnostic tests noted in Figure E-2 may be helpful. For single PCP offices, group practices, health plans, and health care systems that are not currently conducting comprehensive diagnostic evaluations, the components and tools discussed in this section could be helpful in the development of routine procedures for diagnosing dementia in primary care. As noted earlier, procedures will probably vary considerably because of differences in the structure, organization, and existing primary care procedures in single PCP offices, group practices, health plans, and health care systems. In particular, variation is likely in the components of the diagnostic evaluation that are defined as the sole responsibility of the PCP versus other health care providers, including physician specialists, who work in the same group practice or health care system or are available through outside referrals.





### IDENTIFY THE CAUSE(S) OF DIAGNOSED DEMENTIA.

Once dementia has been diagnosed, the next step is identification of the cause(s) of the dementia. Common causes of dementia in older adults include Alzheimer's disease, vascular conditions, Lewy body disease, frontotemporal degeneration, and combinations of these and other diseases and conditions.

A two-page publication from the Alzheimer's Association (n.d.-c), [In Brief for Healthcare Professionals: Differentiating Dementias](#) (**Appendix E-10**), provides an overview of diseases and conditions that cause dementia and a useful table that compares dementia caused by Alzheimer's disease, vascular conditions, Lewy body disease, frontotemporal degeneration, and Parkinson's disease in terms of usual course, presentation, risk factors, and imaging results.

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, however, 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 growing recognition for identifying the causes of dementia in primary care and other clinical contexts are still unclear, and diagnostic criteria and procedures for clinical use are not available.

Some PCPs, group practices, health plans, and health care systems already have criteria and procedures in place for diagnosis of the cause(s) of dementia. Other PCPs, group practices, health plans, and health care systems that do not have criteria and procedures for diagnosing these conditions may be able to use the information presented below as a starting point for developing such criteria and procedures. It should be noted that diagnosing the cause(s) of dementia can be difficult and may require more than one PCP visit and specialist referrals.

The *DSM-5* includes diagnostic criteria and codes for neurocognitive disorders (dementia) caused by Alzheimer's disease, vascular disease, frontotemporal lobar degeneration, Lewy bodies, traumatic brain injury, HIV infection, substance-medication use, prion disease, Parkinson's disease, and Huntington's disease, as well as neurocognitive disorders (dementia) due to another medical condition, multiple etiologies, or unspecified (American Psychiatric Association, 2013).

The *International Classification of Diseases, Tenth Revision (ICD-10)* also includes diagnostic codes for dementia caused by various diseases and conditions (CDC, 2016). A table of commonly used *ICD-10* diagnostic codes for Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, and mild cognitive impairment is shown in **Appendix E-11**.



In addition to *DSM-5* and *ICD-10* criteria and codes, the GSA Workgroup identified a few additional sources that may be useful to PCPs, health plans, and health care systems in developing or revising their diagnostic procedures for some of the most common causes of dementia. These additional sources are organized by the cause of dementia.

### **Dementia Caused by Alzheimer’s Disease**

[Current clinical criteria and procedures for the diagnosis of dementia caused by Alzheimer’s disease were developed by an NIA and Alzheimer’s Association Workgroup](#) (McKhann et al., 2011). The Alzheimer’s Association has also developed free [Alzheimer’s Disease Pocketcard app](#) for health care professionals that includes clinical information on the diagnosis of Alzheimer’s disease and other assessment and care related issues. The app can be downloaded free at [www.alz.org/health-care-professionals/physicians-app.asp](http://www.alz.org/health-care-professionals/physicians-app.asp).

### **Dementia Caused by Vascular Conditions**

Various vascular conditions can cause dementia, including stroke, multiple small strokes, white matter brain lesions, atherosclerosis, and microbleeds. A review by Korczyn, Vakhapova, and Grinberg (2012) cites several sources of clinical criteria for diagnosis of dementia caused by vascular conditions, including Chui et al. (1992) and Roman et al. (1993), but notes that there is no gold standard for this diagnosis. The review by Korczyn and coworkers 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, one useful resource for PCPs, health plans, and health care systems is the [1993 NINDS–AIREN Criteria for the Diagnosis of Vascular Dementia](#) (Roman et al., 1993). In addition, the website of the [University of California San Francisco Memory and Aging Center](#) has a 2010 article about vascular dementia that includes diagnostic guidelines.



### Dementia Caused by Lewy Body Disease

The Lewy Body Dementia Association (LBDA) has several publications that may be useful to PCPs, health plans, and health care systems that are developing or revising their diagnostic criteria and procedures for Lewy body dementia. A two-page document, [Lewy Body Dementia Diagnosis](#) (LBDA, 2015a), provides information about the criteria and procedures for diagnosing this condition, based on McKeith and coworkers (2005). It also includes diagnostic criteria for a related condition, Parkinson's disease dementia.

Another one-page LBDA (2009) document [Lewy Body Dementias: Symptoms and Diagnostic Criteria](#), shows symptoms and areas of deficit for Lewy body dementia and Parkinson's disease dementia.

### 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 2011 documents provide 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) provides four easily accessible documents that may be useful to PCPs, health plans, and health care systems in developing or revising their diagnostic criteria and procedures for frontotemporal degeneration:

- [Evaluation and Diagnosis](#)
- [Behavioral Variant Frontotemporal Degeneration](#)
- [Semantic Variant Primary Progressive Aphasia](#)
- [Nonfluent/Agrammatic Variant Primary Progressive Aphasia](#)





### DOCUMENT THE DEMENTIA DIAGNOSIS AND IDENTIFIED CAUSE(S).

Dementia diagnoses are not always documented in the patient's medical record. It is unclear how often this occurs, but some research suggests that it may be common enough to raise concern. One study found, for example, that 17% of primary care physicians who reported that they had diagnosed dementia in some of their older adult patients had not documented the diagnosis in the older adults' medical records (Chodesh et al., 2004).

PCPs may decide not to document a dementia diagnosis for various reasons, including expressed or assumed preferences of the older adult or a family member. Even if a dementia diagnosis is not documented, the PCP who made the diagnosis is likely to be aware of the older adult's dementia and able to take it into consideration in providing medical care and referrals for community services for the older adult. The problem occurs when that PCP is not available and/or another PCP or other health care professional has to make decisions about or provide medical care for the older adult. These other PCPs and health care professionals probably will not be aware of the older adult's dementia.

On average, older adults with dementia have very high numbers of transitions between care settings (Callahan et al., 2012; Callahan et al., 2015). If an older adult's dementia diagnosis is not documented in his or her medical record, the diagnosis is unlikely to be included in transfer information provided when the older adult transitions from one care setting to another. As a result, PCPs and other health care professionals and providers in that care setting may not be aware of the dementia, especially when the older adult first arrives. In these situations, lack of documentation of an older adult's dementia diagnosis could jeopardize his or her safety and the appropriateness of care he or she receives. To avoid this problem, PCPs, group practices, health plans, and health care systems could institute routine documentation of dementia diagnoses and include relevant check boxes in electronic medical records.



### DISCLOSE THE DIAGNOSIS AND CAUSE(S) TO THE OLDER ADULT AND FAMILY UNLESS OTHERWISE INDICATED.

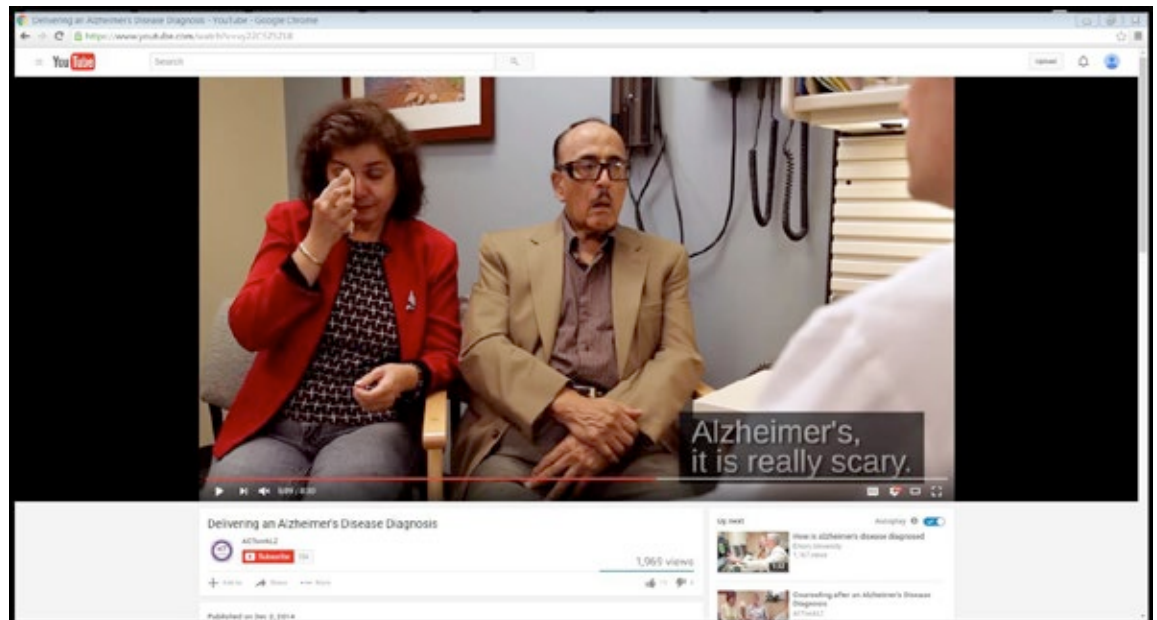
Many older adults with diagnosed dementia and their family members are not aware of the diagnosis. Data from a nationally representative sample of older adults and Medicare records show that in the period from 2007 to 2009, only 34.8% of older adults with a dementia diagnosis in their Medicare records or a Medicare claim for treatment of Alzheimer's disease or dementia said (or their proxy respondent said) that a doctor had ever told the older adult or proxy respondent that the older adult had Alzheimer's disease or any other type of dementia (U.S. Office of Disease Prevention and Health Promotion, 2016). Likewise, in a sample of 193 older veterans with diagnosed dementia, only 24% of the veterans and 67% of their family caregivers reported that they were aware of the diagnosis (Bradford et al., 2011).

Older adults with dementia certainly may not remember that they were told about their dementia diagnosis. Likewise, family members may not remember or may chose not to report having been told about the diagnosis. It is concerning, nevertheless, that large proportions of older adults who have a dementia diagnosis are not aware, and their families are not aware, of the diagnosis.

There has been considerable disagreement about whether a dementia diagnosis should be disclosed to the patient (Carpenter & Dave, 2004; Bamford et al., 2004). Results from studies conducted with family caregivers have found that most of caregivers prefer to be told the diagnosis although they often complain about the way it was disclosed (Connell et al., 2004).



One study of the effects of diagnostic disclosure on 62 older adults with dementia found they generally did not experience the post-disclosure anxiety and depression that some commentators have predicted (Carpenter et al., 2008). In fact, anxiety levels were reduced for some of older adults, perhaps because they had finally received the diagnostic information. The disclosure procedures used by the health care system involved in the study included many of the suggestions families and others have made about how to improve the process. An 8-minute video created by ACT on Alzheimer's illustrates some of these suggested changes (ACT on Alzheimer's, 2014).



[\*Delivering an Alzheimer's Disease Diagnosis\*](#)



A 2012 Alzheimer’s Association publication, [\*In Brief for Healthcare Professionals: Increasing Disclosure of Dementia Diagnosis\*](#) (Appendix E-12) and a set of talking points in the Group Health Cooperative (2012) Dementia and Cognitive Impairment Diagnosis and Treatment Guideline (Figure E-3) provide additional ideas that PCPs may want to use or adapt for disclosing dementia diagnoses.

### Figure E-3. Delivering a Diagnosis of Dementia

#### Talking Points From the Group Health Cooperative Dementia and Cognitive Impairment Diagnosis and Treatment Guideline

- “Memory changes are due to abnormal accumulation of proteins in the brain, which interfere with the essential functions of thinking and processing. Basically these proteins clog things up.”
- “Most people who have dementia don’t end up in nursing homes—they can live at home with family, be reasonably content, and have nice lives.”
- “Eventually, dementia will cause a worsening in your ability to handle regular tasks, such as shopping, finances, and medications. But we’ll talk regularly, and we’ll manage that.”
- “Dementia is not hereditary in most cases.”
- “Dementia is a progressive condition with no cure, but we have treatments for symptoms. And proper care and planning can greatly alleviate the burden of dementia.”
- “It is important for you and your family to plan for the future, and it is especially important for you to make legal plans. The sooner legal planning starts, the more you may be able to participate. Legal planning includes advance directives.”

Source: Group Health Cooperative, 2012. (Conversation 1a.)



## INCREASE OLDER ADULT AND FAMILY UNDERSTANDING ABOUT THE IMPORTANCE OF DIAGNOSTIC EVALUATION.

As noted at the beginning of this section, older adults and families often contribute to the problem that the older adult with cognitive impairment does not receive a diagnostic evaluation. They may mistakenly assume that the older adult's score on a brief cognitive test or apparent signs and symptoms of cognitive impairment are sufficient evidence for a dementia diagnosis and that no additional evaluation is needed. Even when the PCP recommends a diagnostic evaluation, the older adult and/or the family may not follow through on the recommendation. Failure to follow through on the PCP recommendation 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 older adult's driver's license, rejection for health or long-term care insurance, or refused admission to an assisted living facility or other senior residence.

The [GSA Workgroup report](#) provides a table that discusses many potential benefits of an early diagnosis of dementia, worded primarily from the perspective of the older adult and family members (GSA, 2015) (**Appendix E-13**). While PCPs may be able to draw important messages from the text, it is not clear that the table itself is a useful tool for older adults and families.

A 2016 Alzheimer's Association publication, [In Brief for Healthcare Professionals: Special Issues in Memory Loss, Alzheimer's Disease, and Dementia](#), suggests messages PCPs can use to convince patients to come in for a diagnostic evaluation (**Appendix E-14**).

The best tool the GSA Workgroup has found thus far for older adults and families comes from the Alzheimer's and Dementia Alliance of Wisconsin (2009) (**Figure E-4**).





## Figure E-4. Importance of an Early Diagnosis of Dementia

### Early Diagnosis Is Key.

There are at least a dozen advantages to obtaining an early and accurate diagnosis when cognitive symptoms are first noticed.

#### 1. Your symptoms might be reversible.

The symptoms you are concerned about might be caused by a condition that is reversible. And even if there is also an underlying dementia such as Alzheimer's disease, diagnosis and treatment of reversible conditions can improve brain function and reduce symptoms.

#### 2. It may be treatable.

Some causes of cognitive decline are not reversible, but might be treatable. Appropriate treatment can stop or slow the rate of further decline.

#### 3. With treatments, the sooner the better.

Treatment of Alzheimer's and other dementia-causing diseases is typically most effective when started early in the disease process. Once more effective treatments become available, obtaining an early and accurate diagnosis will be even more crucial.

#### 4. Diagnoses are more accurate early in the disease process.

A more accurate diagnosis is possible when a complete history can be taken early in the disease process, while the person is still able to answer questions and report concerns and when observers can still recall the order in which symptoms first appeared. Obtaining an accurate diagnosis can be difficult once most of the brain has become affected.

#### 5. It's empowering.

An earlier diagnosis enables the person to participate in his or her own legal, financial, and long-term care planning and to make his or her wishes known to family members.

#### 6. You can focus on what's important to you.

It allows people the opportunity to reprioritize how they spend their time—focusing on what matters most to them—perhaps completing life goals such as travel, recording family history, completing projects, or making memories with grandchildren while they still can.

#### 7. You can make your best choices.

Early diagnosis can prevent unwise choices that might otherwise be made in ignorance—such as moving far away from family and friends, or making legal or financial commitments that will be hard to keep as the disease progresses.

#### 8. You can use the resources available to you.

Individuals diagnosed early in the disease process can take advantage of early-stage support groups and learn tips and strategies to better manage and cope with the symptoms of the disease.

#### 9. Participate or advocate for research.

Those diagnosed early can also take advantage of clinical trials—or advocate for more research and improved care and opportunities.

#### 10. You can further people's understanding of the disease.

Earlier diagnosis helps to reduce the stigma associated with the disease when we learn to associate the disease with people in the early stages, when they are still cogent and active in the community.

#### 11. It will help your family.

An earlier diagnosis gives families more opportunity to learn about the disease, develop realistic expectations, and plan for their future together—which can result in reduced stress and feelings of burden and regret later in the disease process.

#### 12. It will help you, too.

Early diagnosis allows the person and family to attribute cognitive changes to the disease rather than to personal failings—preserving the person's ego throughout the disease process.

Taken all together, these advantages result in a higher quality of life for the person afflicted, less stress for family care partners, and more time to treasure the present and prepare for the future.

Source: Alzheimer's and Dementia Alliance of Wisconsin, 2009.



## STEP 3 : EVALUATE

The GSA Workgroup believes that additional tools are needed to increase older adults' and family members' understanding about the importance of diagnostic evaluation for older adults with cognitive impairment. Such tools should be designed in various formats for delivery through print, online, and other media. They could be created jointly by organizations that represent PCPs and organizations that represent older adults, persons with cognitive impairment and dementia, and families. Once created, the tools could be disseminated widely by these and other organizations to their members and the older adults and families they represent.

As noted at the beginning of this section, it is clear that PCPs, older adults, and family members contribute in different ways to the problem that many older adults with cognitive impairment do not receive a diagnostic evaluation. Involving organizations that represent all these groups in the creation and dissemination of tools to address the problem is likely to be more effective than expecting that PCPs or the physician practices, health plans, or health care systems they work for to address it on their own.





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## Montreal Cognitive Assessment (MoCA)

### Administration and Scoring Instructions

The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal.

#### 1. Alternating Trail Making:

Administration: The examiner instructs the subject: *"Please draw a line, going from a number to a letter in ascending order. Begin here [point to (1)] and draw a line from 1 then to A then to 2 and so on. End here [point to (E)]."*

Scoring: Allocate one point if the subject successfully draws the following pattern: 1 –A- 2- B- 3- C- 4- D- 5- E, without drawing any lines that cross. Any error that is not immediately self-corrected earns a score of 0.

#### 2. Visuoconstructional Skills (Cube):

Administration: The examiner gives the following instructions, pointing to the **cube**: *"Copy this drawing as accurately as you can, in the space below"*.

Scoring: One point is allocated for a correctly executed drawing.

- Drawing must be three-dimensional
- All lines are drawn
- No line is added
- Lines are relatively parallel and their length is similar (rectangular prisms are accepted)

A point is not assigned if any of the above-criteria are not met.

#### 3. Visuoconstructional Skills (Clock):

Administration: Indicate the right third of the space and give the following instructions: *"Draw a clock. Put in all the numbers and set the time to 10 past 11"*.

Scoring: One point is allocated for each of the following three criteria:

- Contour (1 pt.): the clock face must be a circle with only minor distortion acceptable (e.g., slight imperfection on closing the circle);
- Numbers (1 pt.): all clock numbers must be present with no additional numbers; numbers must be in the correct order and placed in the approximate quadrants on the clock face; Roman numerals are acceptable; numbers can be placed outside the circle contour;
- Hands (1 pt.): there must be two hands jointly indicating the correct time; the hour hand must be clearly shorter than the minute hand; hands must be centred within the clock face with their junction close to the clock centre.

A point is not assigned for a given element if any of the above-criteria are not met.



#### 4. **Naming:**

**Administration:** Beginning on the left, point to each figure and say: *“Tell me the name of this animal”*.

**Scoring:** One point each is given for the following responses: (1) lion (2) rhinoceros or rhino (3) camel or dromedary.

#### 5. **Memory:**

**Administration:** The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: *“This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn’t matter in what order you say them”*. Mark a check in the allocated space for each word the subject produces on this first trial. When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a second time with the following instructions: *“I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time.”* Put a check in the allocated space for each word the subject recalls after the second trial.

At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, *“I will ask you to recall those words again at the end of the test.”*

**Scoring:** No points are given for Trials One and Two.

#### 6. **Attention:**

**Forward Digit Span: Administration:** Give the following instruction: *“I am going to say some numbers and when I am through, repeat them to me exactly as I said them”*. Read the five number sequence at a rate of one digit per second.

**Backward Digit Span: Administration:** Give the following instruction: *“Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order.”* Read the three number sequence at a rate of one digit per second.

**Scoring:** Allocate one point for each sequence correctly repeated, (*N.B.:* the correct response for the backwards trial is 2-4-7).

**Vigilance: Administration:** The examiner reads the list of letters at a rate of one per second, after giving the following instruction: *“I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If I say a different letter, do not tap your hand”*.

**Scoring:** Give one point if there is zero to one errors (an error is a tap on a wrong letter or a failure to tap on letter A).





**Serial 7s: Administration:** The examiner gives the following instruction: “Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop.” Give this instruction twice if necessary.

**Scoring:** This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correction subtraction, 2 points for two-to-three correct subtractions, and 3 points if the participant successfully makes four or five correct subtractions. Count each correct subtraction of 7 beginning at 100. Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction. For example, a participant may respond “92 – 85 – 78 – 71 – 64” where the “92” is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the item would be given a score of 3.

### 7. **Sentence repetition:**

**Administration:** The examiner gives the following instructions: “I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]: **I only know that John is the one to help today.**” Following the response, say: “Now I am going to read you another sentence. Repeat it after me, exactly as I say it [pause]: **The cat always hid under the couch when dogs were in the room.**”

**Scoring:** Allocate 1 point for each sentence correctly repeated. Repetition must be exact. Be alert for errors that are omissions (e.g., omitting “only”, “always”) and substitutions/additions (e.g., “John is the one who helped today;” substituting “hides” for “hid”, altering plurals, etc.).

### 8. **Verbal fluency:**

**Administration:** The examiner gives the following instruction: “Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready? [Pause] Now, tell me as many words as you can think of that begin with the letter F. [time for 60 sec]. Stop.”

**Scoring:** Allocate one point if the subject generates 11 words or more in 60 sec. Record the subject’s response in the bottom or side margins.

### 9. **Abstraction:**

**Administration:** The examiner asks the subject to explain what each pair of words has in common, starting with the example: “Tell me how an orange and a banana are alike”. If the subject answers in a concrete manner, then say only one additional time: “Tell me another way in which those items are alike”. If the subject does not give the appropriate response (fruit), say, “Yes, and they are also both fruit.” Do not give any additional instructions or clarification. After the practice trial, say: “Now, tell me how a train and a bicycle are alike”. Following the response, administer the second trial, saying: “Now tell me how a ruler and a watch are alike”. Do not give any additional instructions or prompts.



**Scoring:** Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable:

Train-bicycle = means of transportation, means of travelling, you take trips in both;

Ruler-watch = measuring instruments, used to measure.

The following responses are **not** acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.

### 10. **Delayed recall:**

**Administration:** The examiner gives the following instruction: “I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember.” Make a check mark ( ✓ ) for each of the words correctly recalled spontaneously without any cues, in the allocated space.

**Scoring:** Allocate 1 point for each word recalled freely **without any cues**.

#### **Optional:**

Following the delayed free recall trial, prompt the subject with the semantic category cue provided below for any word not recalled. Make a check mark ( ✓ ) in the allocated space if the subject remembered the word with the help of a category or multiple-choice cue. Prompt all non-recalled words in this manner. If the subject does not recall the word after the category cue, give him/her a multiple choice trial, using the following example instruction, “Which of the following words do you think it was, NOSE, FACE, or HAND?”

Use the following category and/or multiple-choice cues for each word, when appropriate:

FACE: **category cue:** part of the body

**multiple choice:** nose, face, hand

VELVET: **category cue:** type of fabric

**multiple choice:** denim, cotton, velvet

CHURCH: **category cue:** type of building

**multiple choice:** church, school, hospital

DAISY: **category cue:** type of flower

**multiple choice:** rose, daisy, tulip

RED: **category cue:** a colour

**multiple choice:** red, blue, green

**Scoring:** No points are allocated for words recalled with a cue. A cue is used for clinical information purposes only and can give the test interpreter additional information about the type of memory disorder. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.

### 11. **Orientation:**

**Administration:** The examiner gives the following instructions: “Tell me the date today”. If the subject does not give a complete answer, then prompt accordingly by saying: “Tell me the [year, month, exact date, and day of the week].” Then say: “Now, tell me the name of this place, and which city it is in.”

**Scoring:** Give one point for each item correctly answered. The subject must tell the exact date and the exact place (name of hospital, clinic, office). No points are allocated if subject makes an error of one day for the day and date.

**TOTAL SCORE:** Sum all subscores listed on the right-hand side. Add one point for an individual who has 12 years or fewer of formal education, for a possible maximum of 30 points. A final total score of 26 and above is considered normal.



**MONTREAL COGNITIVE ASSESSMENT (MOCA)**  
Version 7.1 Original Version

NAME:  
Education:  
Sex:

Date of birth :  
DATE:

VISUOSPATIAL / EXECUTIVE							POINTS		
	Copy cube  	Draw CLOCK (Ten past eleven) (3 points)     [ ] [ ] [ ] Contour      Numbers      Hands					___/5		
NAMING									
 [ ]	 [ ]	 [ ]					___/3		
MEMORY		Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.	FACE	VELVET	CHURCH	DAISY	RED	No points	
		1st trial							
		2nd trial							
ATTENTION		Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 Subject has to repeat them in the backward order [ ] 7 4 2						___/2	
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [ ] FBACMNAAJKLBAFAKDEAAAJAMOF AAB						___/1	
		Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 4 or 5 correct subtractions: <b>3 pts</b> , 2 or 3 correct: <b>2 pts</b> , 1 correct: <b>1 pt</b> , 0 correct: <b>0 pt</b>						___/3	
LANGUAGE		Repeat : I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]					___/2		
		Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)					___/1		
ABSTRACTION		Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler					___/2		
DELAYED RECALL		Has to recall words WITH NO CUE	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only	___/5
Optional		Category cue							
		Multiple choice cue							
ORIENTATION		[ ] Date	[ ] Month	[ ] Year	[ ] Day	[ ] Place	[ ] City	___/6	
© Z.Nasreddine MD <a href="http://www.mocatest.org">www.mocatest.org</a> Normal ≥ 26 / 30		TOTAL      ___/30 Add 1 point if ≤ 12 yr edu							



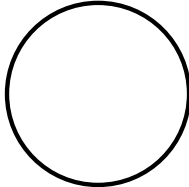

# VAMC SLUMS EXAMINATION

Questions about this assessment tool? E-mail [aging@slu.edu](mailto:aging@slu.edu)

Name \_\_\_\_\_ Age \_\_\_\_\_

Is the patient alert? \_\_\_\_\_ Level of education \_\_\_\_\_

\_\_\_/1  
\_\_\_/1  
\_\_\_/1  
\_\_\_/3  
\_\_\_/3  
\_\_\_/5  
\_\_\_/2  
\_\_\_/4  
\_\_\_/2  
\_\_\_/8

1. What day of the week is it?
2. What is the year?
3. What state are we in?
4. Please remember these five objects. I will ask you what they are later.  
Apple      Pen      Tie      House      Car
5. You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20.
  - 1 How much did you spend?
  - 2 How much do you have left?
6. Please name as many animals as you can in one minute.
  - 0 0-4 animals
  - 1 5-9 animals
  - 2 10-14 animals
  - 3 15+ animals
7. What were the five objects I asked you to remember? 1 point for each one correct.
8. I am going to give you a series of numbers and I would like you to give them to me backwards. For example, if I say 42, you would say 24.
  - 0 87
  - 1 648
  - 1 8537
9. This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.
  - 2 Hour markers okay
  - 2 Time correct
10. Please place an X in the triangle.
 
11. Which of the above figures is largest?
11. I am going to tell you a story. Please listen carefully because afterwards, I'm going to ask you some questions about it.  
 Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.
  - 2 What was the female's name?
  - 2 When did she go back to work?
  - 2 What work did she do?
  - 2 What state did she live in?

TOTAL SCORE \_\_\_\_\_

SCORING		
HIGH SCHOOL EDUCATION		LESS THAN HIGH SCHOOL EDUCATION
27-30	NORMAL	25-30
21-26	MILD NEUROCOGNITIVE DISORDER	20-24
1-20	DEMENTIA	1-19

CLINICIAN'S SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_ TIME \_\_\_\_\_

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Issue Number 13, Revised 2012

Editor-in-Chief: Sherry A. Greenberg, PhD(c) MSN, GNP-BC  
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## The Confusion Assessment Method (CAM)

By: Christine M. Waszynski, MSN, APRN, BC, Hartford Hospital

**WHY:** Delirium is present in 10%-31% of older medical inpatients upon hospital admission and 11%-42% of older adults develop delirium during hospitalization (Siddiqi, House, & Holmes, 2006; Tullmann, Fletcher, & Foreman, 2012). Delirium is associated with negative consequences including prolonged hospitalization, functional decline, increased use of chemical and physical restraints, prolonged delirium post hospitalization, and increased mortality. Delirium may also have lasting negative effects including the development of dementia within two years (Ehlenbach et al., 2010) and the need for long term nursing home care (Inouye, 2006). Predisposing risk factors for delirium include older age, dementia, severe illness, multiple comorbidities, alcoholism, vision impairment, hearing impairment, and a history of delirium. Precipitating risk factors include acute illness, surgery, pain, dehydration, sepsis, electrolyte disturbance, urinary retention, fecal impaction, and exposure to high risk medications. Delirium is often unrecognized and undocumented by clinicians. Early recognition and treatment can improve outcomes. Therefore, patients should be assessed frequently using a standardized tool to facilitate prompt identification and management of delirium and underlying etiology.

**BEST TOOL:** The Confusion Assessment Method (CAM) is a standardized evidence-based tool that enables non-psychiatrically trained clinicians to identify and recognize delirium quickly and accurately in both clinical and research settings. The CAM includes four features found to have the greatest ability to distinguish delirium from other types of cognitive impairment. There is also a CAM-ICU version for use with non-verbal mechanically ventilated patients (See *Try This:*<sup>®</sup> CAM-ICU).

**VALIDITY AND RELIABILITY:** Both the CAM and the CAM-ICU have demonstrated sensitivity of 94-100%, specificity of 89-95% and high inter-rater reliability (Wei, Fearing, Eliezer, Sternberg, & Inouye, 2008). Several studies have been done to validate clinical usefulness.

**STRENGTHS AND LIMITATIONS:** The CAM can be incorporated into routine assessment and has been translated into several languages. The CAM was designed and validated to be scored based on observations made during brief but formal cognitive testing, such as brief mental status evaluations. Training to administer and score the tool is necessary to obtain valid results. The tool identifies the presence or absence of delirium but does not assess the severity of the condition, making it less useful to detect clinical improvement or deterioration.

**FOLLOW-UP:** The presence of delirium warrants prompt intervention to identify and treat underlying causes and provide supportive care. Vigilant efforts need to continue across the healthcare continuum to preserve and restore baseline mental status.

### MORE ON THE TOPIC:

Best practice information on care of older adults: [www.ConsultGerIRN.org](http://www.ConsultGerIRN.org).

The Hospital Elder Life Program (HELP), Yale University School of Medicine. Home Page: [www.hospitalelderlifeprogram.org/](http://www.hospitalelderlifeprogram.org/)

CAM Disclaimer: [www.hospitalelderlifeprogram.org/private/cam-disclaimer](http://www.hospitalelderlifeprogram.org/private/cam-disclaimer).

Useful websites for clinicians including the CAM Training Manual:

[www.hospitalelderlifeprogram.org/pdf/TheConfusionAssessmentMethodTrainingManual.pdf](http://www.hospitalelderlifeprogram.org/pdf/TheConfusionAssessmentMethodTrainingManual.pdf)

Cole, M.G., Ciampi, A., Belzile, E., & Zhong, L. (2009). Persistent delirium in older hospital patients: A systematic review of frequency and prognosis. *Age and Ageing*, 38(1), 19-26.

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### The Confusion Assessment Method Instrument:

1. **[Acute Onset]** Is there evidence of an acute change in mental status from the patient's baseline?
- 2A. **[Inattention]** Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?
- 2B. **(If present or abnormal)** Did this behavior fluctuate during the interview, that is, tend to come and go or increase and decrease in severity?
3. **[Disorganized thinking]** Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?
4. **[Altered level of consciousness]** Overall, how would you rate this patient's level of consciousness? (Alert [normal]; Vigilant [hyperalert, overly sensitive to environmental stimuli, startled very easily], Lethargic [drowsy, easily aroused]; Stupor [difficult to arouse]; Coma; [unarousable]; Uncertain)
5. **[Disorientation]** Was the patient disoriented at any time during the interview, such as thinking that he or she was somewhere other than the hospital, using the wrong bed, or misjudging the time of day?
6. **[Memory impairment]** Did the patient demonstrate any memory problems during the interview, such as inability to remember events in the hospital or difficulty remembering instructions?
7. **[Perceptual disturbances]** Did the patient have any evidence of perceptual disturbances, for example, hallucinations, illusions or misinterpretations (such as thinking something was moving when it was not)?
- 8A. **[Psychomotor agitation]** At any time during the interview did the patient have an unusually increased level of motor activity such as restlessness, picking at bedclothes, tapping fingers or making frequent sudden changes of position?
- 8B. **[Psychomotor retardation]** At any time during the interview did the patient have an unusually decreased level of motor activity such as sluggishness, staring into space, staying in one position for a long time or moving very slowly?
9. **[Altered sleep-wake cycle]** Did the patient have evidence of disturbance of the sleep-wake cycle, such as excessive daytime sleepiness with insomnia at night?

### The Confusion Assessment Method (CAM) Diagnostic Algorithm

#### Feature 1: Acute Onset or Fluctuating Course

This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Did the (abnormal) behavior fluctuate during the day, that is, tend to come and go, or increase and decrease in severity?

#### Feature 2: Inattention

This feature is shown by a positive response to the following question: Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?

#### Feature 3: Disorganized thinking

This feature is shown by a positive response to the following question: Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

#### Feature 4: Altered Level of consciousness

This feature is shown by any answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert [normal]), vigilant [hyperalert], lethargic [drowsy, easily aroused], stupor [difficult to arouse], or coma [unarousable]

**The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.**

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Inouye, S., van Dyck, C., Alessi, C., Balkin, S., Siegel, A. & Horwitz, R. (1990). Clarifying confusion: The confusion assessment method. *Annals of Internal Medicine*, 113(12), 941-948.



Best Practices in Nursing  
Care to Older Adults

general assessment series

A series provided by The Hartford Institute for Geriatric Nursing,  
New York University, College of Nursing

EMAIL [hartford.ign@nyu.edu](mailto:hartford.ign@nyu.edu) HARTFORD INSTITUTE WEBSITE [www.hartfordign.org](http://www.hartfordign.org)  
CLINICAL NURSING WEBSITE [www.ConsultGerIRN.org](http://www.ConsultGerIRN.org)



The official website for the  
Confusion Assessment Method tools is

<https://www.hospitalelderlifeprogram.org/delirium-instruments>

At this site,  
anyone can register to access information about  
and copies of the instrument.



## PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(Use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING   0   +      +      +       
=Total Score:     

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## Geriatric Depression Scale (short form)

**Instructions:** Circle the answer that best describes how you felt over the past week.

- |   |     |    |
|---|-----|----|
| 1. Are you basically satisfied with your life?                            | yes | no |
| 2. Have you dropped many of your activities and interests?                | yes | no |
| 3. Do you feel that your life is empty?                                   | yes | no |
| 4. Do you often get bored?  | yes | no |
| 5. Are you in good spirits most of the time?                              | yes | no |
| 6. Are you afraid that something bad is going to happen to you?           | yes | no |
| 7. Do you feel happy most of the time?                                    | yes | no |
| 8. Do you often feel helpless?  | yes | no |
| 9. Do you prefer to stay at home, rather than going out and doing things? | yes | no |
| 10. Do you feel that you have more problems with memory than most?        | yes | no |
| 11. Do you think it is wonderful to be alive now?                         | yes | no |
| 12. Do you feel worthless the way you are now?                            | yes | no |
| 13. Do you feel full of energy?   | yes | no |
| 14. Do you feel that your situation is hopeless?                          | yes | no |
| 15. Do you think that most people are better off than you are?            | yes | no |

**Total Score** \_\_\_\_\_



# Geriatric Depression Scale (GDS) Scoring Instructions

**Instructions:** Score 1 point for each bolded answer. A score of 5 or more suggests depression.

- |     |  |            |           |
|-----|--|------------|-----------|
| 1.  | Are you basically satisfied with your life?                            | yes        | <b>no</b> |
| 2.  | Have you dropped many of your activities and interests?                | <b>yes</b> | no        |
| 3.  | Do you feel that your life is empty?                                   | <b>yes</b> | no        |
| 4.  | Do you often get bored?  | <b>yes</b> | no        |
| 5.  | Are you in good spirits most of the time?                              | yes        | <b>no</b> |
| 6.  | Are you afraid that something bad is going to happen to you?           | <b>yes</b> | no        |
| 7.  | Do you feel happy most of the time?                                    | yes        | <b>no</b> |
| 8.  | Do you often feel helpless?  | <b>yes</b> | no        |
| 9.  | Do you prefer to stay at home, rather than going out and doing things? | <b>yes</b> | no        |
| 10. | Do you feel that you have more problems with memory than most?         | <b>yes</b> | no        |
| 11. | Do you think it is wonderful to be alive now?                          | yes        | <b>no</b> |
| 12. | Do you feel worthless the way you are now?                             | <b>yes</b> | no        |
| 13. | Do you feel full of energy?  | yes        | <b>no</b> |
| 14. | Do you feel that your situation is hopeless?                           | <b>yes</b> | no        |
| 15. | Do you think that most people are better off than you are?             | <b>yes</b> | no        |

*A score of  $\geq 5$  suggests depression*      **Total Score** \_\_\_\_\_

Ref. Yes average: The use of Rating Depression Series in the Elderly, in Poon (ed.): Clinical Memory Assessment of Older Adults, American Psychological Association, 1986





## Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

Week	During the Past			
	Rarely or none of the time (less than 1 day )	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**SCORING:** zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.



### Katz Index of Independence in Activities of Daily Living (ADL)

<b>Activities</b> Points (1 or 0)	<b>Independence</b> (1 Point) NO supervision, direction or personal assistance	<b>Dependence</b> (0 Points) WITH supervision, direction, personal assistance or total care
BATHING  Points: _____	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity	(0 POINTS) Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing
DRESSING  Points: _____	(1 POINT) Get clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING  Points: _____	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING  Points: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE  Points: _____	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder
FEEDING  Points: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.

Total Points: \_\_\_\_\_

Score of 6 = High, Patient is independent.

Score of 0 = Low, patient is very dependent.

\*\*Slightly adapted. Katz S., Down, TD, Cash, HR, et al. (1970) progress in the development of the index of ADL. *Gerontologist* 10:20-30. Copyright The Gerontological Society of America. Reproduced by permission of the publisher.



Madlyn and Leonard  
**Abramson Center  
for Jewish Life**



**INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)**

M.P. Lawton & E.M. Brody

A. Ability to use telephone

- |   |   |
|---|---|
| 1. Operates telephone on own initiative; looks up and dials numbers, etc. | 1 |
| 2. Dials a few well-known numbers   | 1 |
| 3. Answers telephone but does not dial                                    | 1 |
| 4. Does not use telephone at all.   | 0 |

B. Shopping

- |   |   |
|---|---|
| 1. Takes care of all shopping needs independently | 1 |
| 2. Shops independently for small purchases        | 0 |
| 3. Needs to be accompanied on any shopping trip.  | 0 |
| 4. Completely unable to shop.                     | 0 |

C. Food Preparation

- |  |   |
|--|---|
| 1. Plans, prepares and serves adequate meals independently                                 | 1 |
| 2. Prepares adequate meals if supplied with ingredients                                    | 0 |
| 3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet. | 0 |
| 4. Needs to have meals prepared and served.  | 0 |

D. Housekeeping

- |  |   |
|--|---|
| 1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") | 1 |
| 2. Performs light daily tasks such as dish-washing, bed making                           | 1 |
| 3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.       | 1 |
| 4. Needs help with all home maintenance tasks.   | 1 |
| 5. Does not participate in any housekeeping tasks.                                       | 0 |

E. Laundry

- |   |   |
|---|---|
| 1. Does personal laundry completely             | 1 |
| 2. Launders small items; rinses stockings, etc. | 1 |
| 3. All laundry must be done by others.          | 0 |

F. Mode of Transportation

- |  |   |
|--|---|
| 1. Travels independently on public transportation or drives own car.               | 1 |
| 2. Arranges own travel via taxi, but does not otherwise use public transportation. | 1 |
| 3. Travels on public transportation when accompanied by another.                   | 1 |
| 4. Travel limited to taxi or automobile with assistance of another.                | 0 |
| 5. Does not travel at all.   | 0 |

G. Responsibility for own medications

- |  |   |
|--|---|
| 1. Is responsible for taking medication in correct dosages at correct time.      | 1 |
| 2. Takes responsibility if medication is prepared in advance in separate dosage. | 0 |
| 3. Is not capable of dispensing own medication.                                  | 0 |

H. Ability to Handle Finances

- |   |   |
|---|---|
| 1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income. | 1 |
| 2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.   | 1 |
| 3. Incapable if handling money.   | 0 |

**Source:** Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." Gerontologist 9:179-186, (1969).

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# Functional Activities Questionnaire

## Administration

Ask informant to rate patient’s ability using the following scoring system:

- Dependent = 3
- Requires assistance = 2
- Has difficulty but does by self = 1
- Normal = 0
- Never did [the activity] but could do now = 0
- Never did and would have difficulty now = 1

Writing checks, paying bills, balancing checkbook	
Assembling tax records, business affairs, or papers	
Shopping alone for clothes, household necessities, or groceries	
Playing a game of skill, working on a hobby	
Heating water, making a cup of coffee, turning off stove after use	
Preparing a balanced meal	
Keeping track of current events	
Paying attention to, understanding, discussing TV, book, magazine	
Remembering appointments, family occasions, holidays, medications	
Traveling out of neighborhood, driving, arranging to take buses	
<b>TOTAL SCORE:</b>	

## Evaluation

Sum scores (range 0-30). Cutpoint of 9 (dependent in 3 or more activities) is recommended to indicate impaired function and possible cognitive impairment.

Pfeffer RI et al. Measurement of functional activities in older adults in the community. J Gerontol 1982; 37(3):323-329. Reprinted with permission of The Gerontological Society of America, 1030 15<sup>th</sup> Street NW, Suite 250, Washington, DC 20005 via Copyright Clearance Center, Inc.

These guidelines/tools are informational only. They are not intended or designed as a substitute for the reasonable exercise of independent clinical judgment by practitioners considering each patient’s needs on an individual basis. Guideline recommendations apply to populations of patients. Clinical judgment is necessary to design treatment plans for individual patients. For more information, visit our Web site at [www.aviviahealth.com](http://www.aviviahealth.com). To contact our Chief Medical Officer, please call 1-888-4AVIVIA (1-888-428-4842).



# in brief

## for healthcare professionals

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Issue 7

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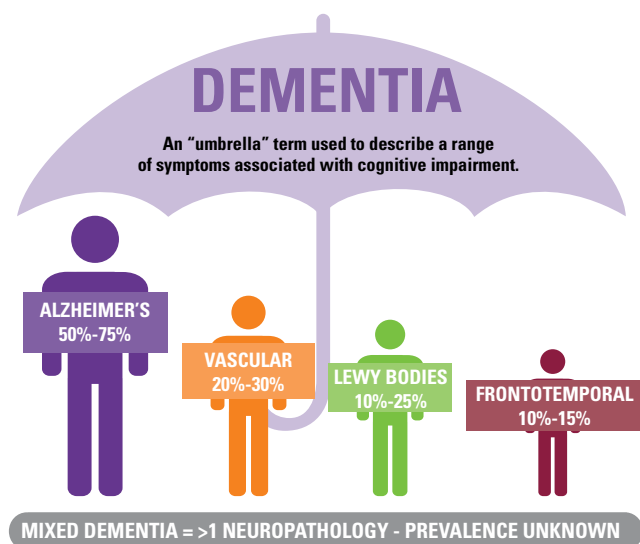
### Differentiating Dementias

“My mom has dementia, not Alzheimer’s.” This statement reflects the lack of understanding among patients and caregivers that dementia is not a specific disease but a range of symptoms associated with cognitive impairment severe enough to affect a person’s ability to perform everyday activities. Alzheimer’s disease (AD) is the most prevalent cause of dementia, but there are many other causes as well. Other common types of dementia include vascular dementia (VaD), dementia with Lewy bodies (DLB), Parkinson dementia (PD), frontotemporal dementia (FTD), and mixed dementia (2 or more etiologies, most commonly AD and VaD)(Figure 1). Creutzfeldt-Jakob disease, Huntington’s, Wernicke-Korsakoff syndrome, and normal pressure hydrocephalus are just a few of the dementias that appear less frequently.

Physicians often define dementia based on the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. The latest version, the fifth edition (DSM-5), includes a new, broader diagnostic category called major neurocognitive disorders (NCD), which incorporates the former diagnosis of dementia.<sup>1</sup> To meet the *DSM-5* criteria for major neurocognitive disorder, an individual must have evidence of significant cognitive decline in memory or another cognitive ability, such as language or learning, that *interferes* with independence in everyday activities. For example, an individual may need assistance with complex activities such as paying bills or managing medications. Mild cognitive impairment, or MCI, is now subsumed under the *DSM-5* criteria for mild neurocognitive disorder—an individual has evidence of modest cognitive decline, but the impairment *does not interfere* with performing complex activities. It might take more effort, but a person can still pay bills and manage their medications.

Although there are commonalities among the dementias (or NCDs), examining the course and clinical features of a patient’s cognitive impairment can help differentiate between the various common subtypes (Table 1). This helps determine the treatment and support services appropriate for the dementia.

Figure 1. Common Forms of Dementia



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*Table 1. Differentiating between common forms of dementia*

	AD	VaD	DLB	PaD	FTD
<b>Course</b>	<ul style="list-style-type: none"> <li>Insidious onset and gradual progression<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Presentation based on extent and location of cerebrovascular event (CVE)<sup>1</sup></li> <li>Often stepwise decline<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Insidious onset and gradual progression<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Insidious onset and gradual progression<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Insidious onset and gradual progression<sup>1</sup></li> </ul>
<b>Presentation</b>	<ul style="list-style-type: none"> <li>Memory loss and impaired learning early in the disease<sup>1</sup></li> <li>Visuospatial and language deficits present in moderate to severe stage<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Temporal relationship between CVE and onset of cognitive impairment<sup>1</sup></li> <li>Memory loss usually secondary to impairment in frontal/executive function<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Fluctuating cognition with early changes in attention and executive function<sup>1</sup></li> <li>Detailed, recurrent visual hallucinations present early in the disease<sup>1</sup></li> <li>Cognitive symptoms start shortly before or concurrently with motor symptoms<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Established Parkinson's disease of at least a year duration before onset of cognitive decline<sup>1,2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Behavioral variant: Impaired social cognition and/or executive abilities with behavioral symptoms such as disinhibition, apathy, lack of empathy, compulsive behavior and hyperorality<sup>1</sup></li> <li>Language variant: Loss of word memory, including speech production, word finding and comprehension, and grammar<sup>1</sup></li> <li>Many present with both types<sup>1</sup></li> </ul>
<b>Associated features</b>	<ul style="list-style-type: none"> <li>Behavioral and psychological symptoms are common                             <ul style="list-style-type: none"> <li>Early: Depression, apathy<sup>1</sup></li> <li>Moderate to severe: psychotic features, agitation, wandering<sup>1</sup></li> <li>Late: Gait disturbance, dysphagia, incontinence, myoclonus, seizures<sup>1</sup></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>History of stroke and/or transient ischemic attacks<sup>1</sup></li> <li>Personality and mood changes<sup>1</sup></li> <li>May exhibit parkinsonian features such as psychomotor slowing, but not sufficient for Parkinson's diagnosis<sup>1</sup></li> <li>Slow, gradual progression often due to small vessel disease<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Rapid eye movement sleep behavior disorder may be early sign<sup>1</sup></li> <li>Nearly 50% have severe neuroleptic sensitivity<sup>1</sup></li> <li>Falls, syncope and transient loss of consciousness are common<sup>1</sup></li> <li>Autonomic dysfunction<sup>1</sup></li> <li>Often a history of delirium during illness or surgery<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Apathy, anxious or depressed mood, hallucinations, delusions, personality changes, rapid eye movement sleep disorder and excessive daytime sleepiness<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Extrapyramidal symptoms may be present<sup>1</sup></li> <li>Overlaps with other neurological conditions such as progressive supranuclear palsy, corticobasal degeneration and motor neuron disease<sup>1</sup></li> <li>Visual hallucinations may be present<sup>1</sup></li> <li>Majority (3/4) present between the ages of 56 to 65<sup>2</sup></li> </ul>
<b>Risk factors</b>	<ul style="list-style-type: none"> <li>Age, genes, Down's, traumatic brain injury<sup>1</sup></li> <li>Family history of Alzheimer's disease in a first-degree relative doubles the risk<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Hypertension, diabetes, smoking obesity, hypercholesterolemia, high homocysteine levels and other risk factors for atrial fibrillation and athero- and arteriosclerosis<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Genetic risk identified but no family history in most cases<sup>1,2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Exposure to herb- and pesticides, duration of disease<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Up to 40% are familial<sup>2</sup></li> <li>Present in up to 10% of patients with motor neuron disease<sup>2</sup></li> <li>Brief cognitive assessments often normal<sup>2</sup></li> </ul>
<b>Imaging</b>	<ul style="list-style-type: none"> <li>Hippocampal and temporoparietal cortical atrophy<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Infarcts and white hyperintensities<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Lewy bodies found primarily in the cortex<sup>1</sup></li> <li>Medial temporal structures preserved<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Lewy bodies found primarily in the basal ganglia<sup>1</sup></li> <li>Medial temporal structures preserved<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Pattern of brain atrophy dependent on subtype<sup>1</sup></li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>Often occurs with VaD<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Only 5-10% have pure VaD<sup>2</sup></li> <li>Often occurs with AD and/or DLB<sup>1,2</sup></li> <li>Depression is often present<sup>2</sup></li> </ul>	<ul style="list-style-type: none"> <li>Frequently coexists with AD and/or VaD<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>Distinguish from neuroleptic-induced parkinsonism, which may occur when dopamine-blocking drugs are prescribed for behavioral symptoms<sup>1</sup></li> <li>Often coexists with AD and VaD<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li>May be mistaken for depression, bipolar disorder or schizophrenia<sup>1</sup></li> </ul>

This table can help inform a full dementia evaluation, but it is not a diagnostic tool. Primary care practitioners should consider seeking the opinion of a dementia expert in cases in which it is warranted. For more information on these and other types of dementia, visit [alz.org/hcps](http://alz.org/hcps).



**Commonly Used ICD-10 Codes for  
Alzheimer’s Disease, Vascular Dementia, Frontotemporal Dementia,  
Dementia With Lewy Bodies, and Mild Cognitive Impairment**

G30.0	Alzheimer's disease with early onset
G30.1	Alzheimer's disease with late onset
G30.8	Other Alzheimer’s disease
G30.9	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
G31.0	Frontotemporal dementia
G31.83	Dementia with Lewy bodies
G31.84	Mild cognitive impairment, so stated

Source: ICD-10-CM Tabular List of Diseases and Injuries, pps. 193, 194, 242, 243.

Retrieved from <https://www.cms.gov/Medicare/Coding/ICD10/2016-ICD-10-CM-and-GEMs.html>, click on 2016 Code Tables and Index, select Tabular pdf.



# in brief for healthcare professionals

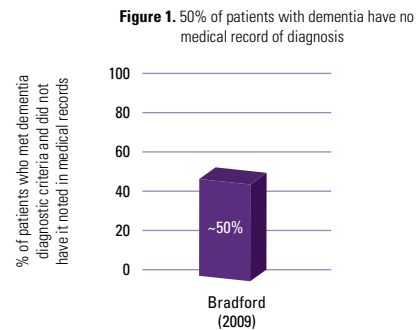
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## Increasing Disclosure of Dementia Diagnosis

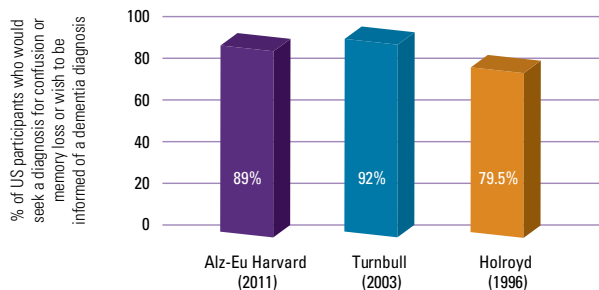
The issue of disclosure of a dementia diagnosis and what is best for patients and families has been debated around the world over the past 2 decades.<sup>1-6</sup> Literature reviews continue to show that clinicians who suspect dementia often do not disclose or document a formal diagnosis.<sup>3,4</sup> As a result, approximately 50% of patients with dementia have no documentation of diagnosis in their medical record (Figure 1).<sup>7</sup> A recent study of caregivers' experience with the diagnostic process reported that it took >2 years after the initial physician visit for some patients to receive a dementia diagnosis.<sup>8</sup> Caregivers also reported a sense of reluctance among doctors to disclose the diagnosis.<sup>8</sup>



## Divergence Between Common Perceptions About Dementia Diagnosis and Published Data

Physicians have cited many barriers to diagnosing dementia, including doubts about the value of diagnosis given limited treatment options, concern over risk of misdiagnosis, and lack of knowledge of local dementia support services.<sup>7</sup> However, based on published data, perceptions that disclosure of dementia diagnosis is not preferred or causes psychological distress among individuals and family members should be challenged.

**Figure 2.** Surveys of US adults  
Majority want to know dementia diagnosis



### A majority of patients want to know if they have Alzheimer's disease

A recent 5-country survey<sup>9</sup> (France, Germany, Poland, Spain, and the US) examining public attitudes about Alzheimer's disease found the following:

- More than 80% of all adults (N=2,678) and 89% of US adults (N=639) responded that if they had memory or confusion symptoms, they would go to a doctor to determine if the cause was Alzheimer's disease. This US finding is consistent with previously published reports over the last 2 decades (Figure 2).<sup>10,11</sup>
- Of the US respondents, 65% said that even if they were asymptomatic they would likely or somewhat likely be interested in getting a medical test that would determine if they would get Alzheimer's disease in the future (if one becomes available).



### Most family members appreciate the benefits of diagnosis

Connell and colleagues surveyed 178 black and white adults who had a family with Alzheimer's disease. The purpose of the study was to examine racial differences in the perceived benefits and barriers to a dementia diagnosis.<sup>6</sup>

- More than 75% of family members rated the following benefits of diagnosis as being very or extremely important: 1) let family know what was wrong with relative; 2) allowed family to get information about Alzheimer's disease; and 3) allowed family to plan for the future.
- Black respondents endorsed the above benefits more often than whites and indicated that involving their family members in important decisions, such as making a will and using community services, also were very important to extremely important benefits of diagnosis.
- Only 6% of all respondents strongly agreed that "it is easier to not know what the diagnosis is."

### Diagnosis does not cause psychological stress in most patients and their families

Physician conjecture that a dementia diagnosis may lead to depression or even suicide has been reported.<sup>12</sup> Empirical findings on the issue are primarily limited to retrospective or review studies in populations with comorbid depression, a well-known risk factor for suicide.<sup>13,14</sup> To examine psychological stress, Carpenter and colleagues evaluated 90 individuals and their companions before a dementia evaluation and after dementia disclosure using the 15-item Geriatric Depression Scale (GDS) and the State-Trait Anxiety Inventory (STAI).<sup>15</sup>

- Sixty-nine percent of individuals were diagnosed with very mild or mild dementia.
- No clinically significant changes were noted in depressive symptoms in either the persons diagnosed with dementia or their companion (Figure 3).
- Anxiety decreased or remained unchanged after diagnostic feedback for most groups (Figure 4).

Authors noted, "Gaining knowledge and developing a treatment plan, individuals may realize that they can take an active role in managing the illness, enhancing a sense of self-efficacy where before they might have felt helpless."

**Changes in depression and anxiety, pre-evaluation vs post-disclosure, in individuals and companions seeking a dementia evaluation.**



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## Table 2. Potential Benefits of Early Diagnosis of Dementia

Early diagnosis of dementia allows the person with the condition and his or her family and significant others to understand what is causing any observed decline in the person's cognitive and other abilities. It names the problem, eliminates the need for further searching to obtain a diagnosis, and validates concerns that have usually been present before a diagnosis is made.

If an early diagnostic evaluation shows that the person does not have dementia, the person and family are able to seek other causes for the person's cognitive decline, some of which may be partially or completely reversible with treatment.

Early diagnosis of dementia allows the person with the condition and his or her family and significant others to have important conversations about the person's wishes for his or her future care. The person with dementia has an opportunity to address legal and financial matters, designate a surrogate decision maker, and express preferences about future medical treatment and living arrangements while he or she still has decision-making capacity. This early planning can help to avoid crisis situations later on, when the person is no longer capable of expressing preferences or making decisions for himself or herself.

Early diagnosis of dementia allows the person with the condition and his or her family to think about and plan ways to avoid significant risks that are associated with cognitive decline for some people with dementia. These risks include financial losses due to reduced financial decision-making capacity and susceptibility to scams; accidents and injuries to the person with dementia or others due to unsafe use of tools, appliances, or guns; continuing to drive when the person is no longer capable of driving safely; and wandering and getting lost.

Early diagnosis allows the person with dementia and his or her family and significant others to benefit from dementia-specific support groups and other counseling, peer mentoring, disease education, socialization, exercise, and recreation programs that may be available in their community.

The currently available medications for Alzheimer's disease cannot prevent, cure, or delay the onset or progression of the disease, but they do help to reduce cognitive and other symptoms in some people with Alzheimer's for some time. Early diagnosis allows the person with dementia caused by Alzheimer's disease and his or her family to consider whether to try one or more of these medications.

Early diagnosis allows the person with dementia to decide whether to participate in research on new medications to prevent, cure, or delay the onset or progression of Alzheimer's and other diseases and conditions that cause dementia.

Early diagnosis of dementia allows family members to benefit from training about how to manage difficult caregiving issues, including dementia-related behavioral symptoms, and counseling and support to maintain their own health and reduce stress.

Early diagnosis can lead to more appropriate medical care and better health outcomes for the person with dementia. Without a diagnosis, people with dementia are more likely to receive medications for their other acute or chronic medical conditions that can worsen their cognitive functioning. In addition, people with dementia may be unable to report physical health symptoms accurately, comply with medical treatment recommendations, or take medications as prescribed. In the absence of a dementia diagnosis, PCPs, physician specialists, and other health care providers may not question a patient's reports about symptoms of coexisting medical conditions and compliance with recommended treatments, especially in the early stages of the patient's dementia. As a result, they may not be able to manage the patient's coexisting conditions effectively, resulting in potentially preventable worsening of the person's health and avoidable hospitalizations and emergency department visits.





# In Brief

## for Healthcare Professionals

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### Special Issues in Memory Loss, Alzheimer's Disease and Dementia

#### Quick Start

##### Some Patients Do Not Want to Have Their Memory Evaluated

- Help patients understand that the goal is to improve their memory and allow them to continue doing the activities that they enjoy.
- Explain that there are a number of medications available that could help them.

##### Some Patients Do Not Want You to Talk to Their Family

- A few patients are able to manage the disease on their own, at least for a while.
- For the majority of patients, involvement of family or friends is a critical part of the patient's care, helping him or her to deal with and manage memory loss due to Alzheimer's disease or another dementia.

#### The Patient Who Does Not Want to Come to the Appointment

Difficulty in convincing patients to come to appointments to evaluate their memory can sometimes be one of the biggest obstacles faced by families. Patients do not want to come to the appointment for a variety of reasons. Some patients may not want to come to the appointment because they are fearful of the diagnosis of Alzheimer's disease, particularly if they watched their parent, spouse, or friend suffer with this disorder. Others may not want to come to the appointment because they are afraid they will be sent to a nursing home. And some may simply not want to come to the appointment because they do not recognize a problem and cannot be bothered with coming.

We admit that we have not been able to convince every patient to come to an appointment. We have, however, been successful with a couple of strategies. The most reliable of these is to explain to the patient (typically on the phone) that our goal is to improve their memory to allow them to continue doing the activities that they enjoy, and that there are a number of medications available to help their memory, and even to delay the onset of Alzheimer's disease. Sometimes it is not even what you say, but just spending a minute and making a connection with the patient helps to make the appointment less frightening.

A number of families will grab us in the hallway prior to the appointment and say something like, "Please measure her blood pressure... the only way I was able to get her to you was to pretend that this was for her routine blood pressure check." Although we do not condone deception as a way to bring a patient to an appointment (in part because it may lead to mistrust, in part because of the ethical implications), patients brought in this way typically do just fine. These patients discover that a memory evaluation is quite similar to other medical evaluations, not as frightening or threatening as they had feared.

#### The Patient Who Does Not Want You to Talk to Their Family

Sometimes it happens that patients come to the clinic and they do not want you to tell their family about their memory difficulties. Should we agree with respecting their desire for confidentiality, despite the difficulties and potential danger in which they may be placing themselves and others? Or should we insist that their family be involved? Our answer is that it depends upon the circumstances (see patient examples below). For the vast majority of patients, the involvement of family or friends is a critical part of the patient's care, helping him or her to deal with and manage memory loss whether due to Alzheimer's disease or due to another dementia. There are a few patients, however, who are able to manage the disease on their own, at least for a while.



## Case Study

### The First Patient

A patient came to our office about 10 years ago, driving himself the three hours to get to our clinic, with concerns about his memory. He had noticed mild changes in his memory, and was worried that he might be at the earliest stage of Alzheimer's disease. He had watched his father go through the disease, and so he knew the signs well. After evaluating him we made a diagnosis of mild cognitive impairment, and prescribed a course of medication. He did not want us to mention anything to his children or his wife, which we thought was acceptable at the time given how mild his memory difficulties were, how responsibly he was acting, and that he was taking a medication which had the potential to improve his memory to the level which it was at the previous year.

Several years passed in this manner. His memory became worse, and he was diagnosed with very mild Alzheimer's disease dementia. At each visit we discussed the importance of letting his family know about his difficulties, but he continued to decline our suggestion. He was able to persuade us, however, that he was taking all of his medications correctly, was driving safely, not getting lost, and not running into any serious difficulties. Finally a minor crisis occurred at home when he forgot to come home to take the dog out for a walk—a small thing, but very uncharacteristic for him—and he ended up explaining to his family about his disease and about not wanting to burden them with it. Our next visit with the patient included his wife and two anxious sons. We had a very productive meeting and learned many things we wished we had known about earlier, such as that he used many woodworking tools in the basement and was beginning to have minor injuries associated with not using the tools correctly. Overall, however, we were pleased that we were able to provide good treatment to the patient while at the same time respecting his wishes not to tell his family about his memory problems.

### The Second Patient

Another patient came to our clinic several years ago. We knew that there were going to be some issues before she came in, because she had scheduled and then canceled the appointment four times before finally coming in to see us. It had also been clear to us ahead of time that she did not want her family involved, because when our secretary scheduled the visit and mentioned to the patient that she should bring someone close to her to the appointment, such as a family member or close friend, she adamantly refused to do so.

During the appointment she was incredibly anxious. We were sympathetic to her. It was perfectly clear that she was absolutely terrified that she might have Alzheimer's disease. Her mother had recently died of the disease, and we gathered that the experience of her mother's illness and death had been quite traumatizing to her. Her mother, however, first showed symptoms in her mid-80s and died at age 91. The patient herself was only 68 years old. Even before we finished interviewing her we could tell that her memory problems were significant, and we wondered whether she was really able to cover her difficulties as well as she stated.

We took an extra 10 minutes, and spoke with her about some of what we typically save for the first follow-up visit. We discussed that, if it turned out that she did have Alzheimer's disease, there are many treatments that could help her—more than were available when her mother was diagnosed. Additionally, we discussed a number of experimental treatments that were currently in clinical trials, treatments that had the possibility to significantly slow the progression of Alzheimer's disease.

We then asked about her family and, when we learned that they were supportive, we explained the importance of having her family with her. She hesitated, and we gently but firmly insisted that she involve her family and bring at least one family member with her to the follow-up appointment. We insisted because we were concerned that she needed the emotional support of family to effectively come to terms with her memory problems. Additionally, her memory was already poor enough such that she would be unable to hide it for long—assuming that it was not already apparent to those around her. Both her daughter and husband came with her to the next appointment, at which time we told her that she had mild Alzheimer's disease dementia. Although tears were shed, with their help she was able to accept the diagnosis, and she worked to have a positive attitude.

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## OVERVIEW

In its 2015 report, the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis recommends that:

- All older adults who are found to have a diagnosis of dementia be referred to all appropriate and available community services and online resources to learn more about the disease process and how to prepare for the future with a dementia diagnosis (GSA, 2015).
- Specific community resources should include the closest Area Agency on Aging (AAA), the closest Aging and Disability Resource Center (ADRC), and, as appropriate, the local or regional chapter of the Alzheimer's Association or other Alzheimer's support organization and local or regional organizations representing different causes of dementia, such as Lewy body disease and frontotemporal degeneration (GSA, 2015).

Older adults with dementia and their families differ in many ways that affect the kinds of community services and other resources that will benefit them. The kinds of services that are available in particular communities also differ greatly. Few PCPs have the time or the detailed knowledge of community services and other resources that would be required to connect their older adult patients with dementia and the patients' families with the services and other resources they need. PCPs can, however, refer older adult patients with dementia and their families to agencies, organizations, and individuals that can assist them in determining exactly what kinds of help they need and finding and accessing that help. PCPs can also encourage their older adult patients with dementia and the patients' families to work with the identified agency, organization, or individual to find the needed help. Over time, PCPs can ask the patients and families whether they are receiving the help they need and, if appropriate, continue to encourage them to work with the identified agency, organization, or individual to find that help. As dementia progresses, the needs of the older adult with dementia and his or her family and other caregivers are likely to change. PCPs can acknowledge these changes and encourage the patient and family to work with the identified agency, organization, or individual to find help that meets the patient's changing needs.

This section provides approaches and tools to help PCPs refer and connect their patients with dementia and the patients' families to agencies, organizations, and individuals that can assist them in identifying their needs and accessing help to meet those needs. The section assumes that PCPs generally will not go beyond this level of referrals because of time constraints and lack





of the detailed knowledge of community resources that is required to match the specific needs of older adults with dementia and their families to appropriate community services and other resources.

An important consideration in PCP referrals to agencies, organizations, and individuals that can provide assistance in identifying patient and family needs and accessing help to meet the needs is the extent to which the agencies, organizations, and individuals are knowledgeable about dementia and the care needs of people with dementia and their families. Efforts are currently underway in various communities and health care systems to increase knowledge about dementia and dementia-related care needs among organizations and individuals that provide assistance to older adults and families. PCPs cannot assume, however, that all agencies, organizations, and individuals that provide such assistance for older adults and families in general are knowledgeable about dementia and qualified to assist older adults with dementia and their families.







## APPROACHES

Approaches for referring and connecting older adults with dementia and their families to agencies, organizations, and individuals that can assist them in identifying their needs and accessing help to meet those needs vary for PCPs working in different settings. Some PCPs work in physician group practices, health plans, and health care systems that have case managers, care managers, patient navigators, or other staff who assist primary care patients and their families in determining what kind of help they need and accessing the needed help. Other PCPs work in single PCP offices and other practice settings that do not have such staff.

### CONNECT OLDER PATIENTS WITH DEMENTIA TO ASSISTANCE IN THE PCP'S ORGANIZATION TO IDENTIFY NEEDS AND ACCESS HELP.

Some physician group practices, health plans, and health care systems that have case managers, care managers, patient navigators, or other staff who assist primary care patients and their families in identifying their needs and accessing help to meet those needs limit this assistance to particular types of patients, often referred to as “high risk” patients, a term defined by the group practice, health plan, or health care system. PCPs who work in these practice settings should first find out whether patients with dementia are generally included among the types of patients who are eligible to receive assistance in identifying their needs and accessing help to meet those needs in the PCPs’ practice setting. If so, the PCPs should learn the procedures for referring their patients with dementia and the patients’ families for the assistance and use those procedures routinely for their patients with dementia.

### CONNECT OLDER PATIENTS WITH DEMENTIA TO COMMUNITY AGENCIES AND PROVIDERS TO IDENTIFY NEEDS AND ACCESS HELP.

PCPs who work in single practitioner offices and other practice settings that do not have case managers or other staff to assist patients with dementia and their families in identifying their needs and accessing help should connect those patients and families to community and other organizations and individuals (often referred to as “geriatric care managers”) that can provide this kind of assistance. Public agencies that provide such assistance for older adults with dementia and their families include AAA and ADRC. Private agencies, organizations, and individuals that provide this assistance



differ in various communities and regions. Some of these agencies, organizations, and individuals serve older adults in general, including persons with dementia, and other agencies and individuals serve only persons with dementia. In many communities and regions, the closest AAA or ADRC may have a list of private agencies and individuals that provide assistance to older adults with dementia and their families in determining what kind of help they need and accessing that help.

PCPs should have contact information for the nearest AAA, ADRC, and local or regional Alzheimer's Association chapter or other Alzheimer's support organization. Some Alzheimer's Association chapters and other Alzheimer's support organizations also provide assistance in determining needs and accessing services for older adults with other diseases and conditions that cause dementia, such as Lewy body disease, frontotemporal degeneration, and vascular conditions. Local and regional organizations that provide assistance targeted specifically for older adults with these other diseases and conditions also exist in some communities and regions, although they are less common than Alzheimer's organizations. The GSA Workgroup has developed a template (**Appendix R-1**) that PCPs, physician group practices, health plans, and health care systems can complete to provide the contact information needed to support PCP referrals to community and regional agencies organizations and individuals. The template also includes a list of the types of community services and other resources people with dementia and family caregivers may need. PCPs may want to use examples of services and resources from this list to explain to patients with dementia and their families why the PCP is referring them to an agency, organization, or individual that can help them identify their specific needs and find services and other resources to meet those needs.

Some national organizations provide assistance for people with dementia and their families in determining what kind of kind of help they need and finding that help. The Alzheimer's Association's national 24/7 Helpline is probably the best known of these sources (1-800-272-3900). The Alzheimer's Association also has an online [Community Resource Finder](#) that can help people with dementia and their families identify their specific needs and find help. Other national organizations also provide telephone and online assistance to help people with dementia and their families find needed services. Often these national organizations are able to refer or connect people with dementia and families to community or regional agencies, organizations, and individuals that can provide assistance in identifying needs and finding help. This can be useful for PCPs who do not already have contact information for the relevant agencies, organizations, and individuals in their own community or region.



Some local and regional Alzheimer’s Association chapters and other Alzheimer’s support organizations have telephone, email, or fax referral procedures that PCPs can use to connect older adult patients with dementia and patients’ families to an organization that can help them identify their needs and access help. Alzheimer’s Greater Los Angeles, an Alzheimer’s support organization, has a referral program, ALZ Direct Connect, that PCPs and others 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 [ALZ Direct Connect](#) referral form (**Appendix R-2**) includes a place for the person, family, or personal representative to sign, thereby giving the PCP permission to forward that individual’s contact information to Alzheimer’s Greater Los Angeles. With this signature, the organization can contact the person, family member, or organization to begin working with that individual to identify needs and find needed services and other resources. Many other Alzheimer’s support organizations, including many Alzheimer’s Association chapters have similar programs.

As noted earlier, PCPs cannot assume that all agencies, organizations, and individuals that provide general assistance to older adults and families in identifying needs and finding help are knowledgeable about dementia and qualified to assist older adults with dementia and their families. Efforts are currently underway in many communities to provide training about dementia and care, services, and supports for people with dementia for such agencies, organizations, and individuals. In Minnesota, for example, the state Board on Aging supported the development of a three-part, web-based training program for staff of the state’s Senior LinkAge Line (the state’s ADRC) to help them connect people with dementia and family caregivers to needed services and other resources; **Appendix R-3** describes the content of the training. Likewise, Alzheimer’s Greater Los Angeles is providing training for case managers in local health plans that serve individuals eligible for both Medicare and MediCal (California’s Medicaid program). A [Dementia Care Management Toolkit](http://www.alzgia.org/professionals/dementia-care-management-toolkit/) has been developed for this purpose, accessible at <http://www.alzgia.org/professionals/dementia-care-management-toolkit/>, which includes a care needs assessment tool (**Appendix R-4**) and more than 20 standardized care plans that case managers can use to identify problem areas and link families to community and other resources ([Standardized Care Plans for Older Adults and Families](#), **Appendix R-5**).



## MAINTAIN A LIST OF ONLINE RESOURCES AND REFER OLDER ADULTS AND FAMILIES TO RELEVANT RESOURCES.

PCPs who work in any setting should have a list of online sources of information about dementia that will be useful for people with cognitive impairment and dementia and their families. The NIA's Alzheimer's Disease Education and Referral Center (ADEAR), the national Alzheimer's Association, the Alzheimer's Foundation of America, the Lewy Body Dementia Association, the Association for Frontotemporal Dementia, and many other national, regional, and local organizations maintain websites that contain valuable, usually downloadable, information about dementia and diseases and conditions that cause dementia. For people with dementia and families who are comfortable using the Internet, these websites offer an extensive array of valuable fact sheets and other information and materials they can access without leaving their homes.

The large number of such websites, each with numerous potentially valuable fact sheets, information, and other materials, can be overwhelming, however, for many people with dementia, family members, and others. **Appendix R-6** provides examples of the available materials, with a primary focus on materials that could help older adults and family members understand and engage in the detection of cognitive impairment, diagnostic evaluation, and use of community services and other resources to meet their needs. PCPs may suggest that patients and/or families access one or more of the materials or PCPs may choose to have some of the materials printed so they can be given to patients and/or caregivers.



## PROVIDE GENERAL INFORMATION ABOUT AND ENCOURAGE PARTICIPATION IN AVAILABLE CLINICAL TRIALS.

PCPs who work in any setting should provide general information about clinical trials and encourage interested older adult patients with dementia and their families to use available online sources of specific information about such trials. Several sources provide information about clinical trials that are recruiting persons with dementia for studies of medications and other interventions for dementia and particular diseases and conditions that cause dementia. Some older adults with dementia and some family caregivers experience great emotional satisfaction from participating in such trials.

Two of the sources of information about clinical trials are:

- The NIA's ADEAR Center website, [Find Alzheimer's Disease and Related Clinical Trials](#), is a free online resource that allows users to search for relevant clinical trials being conducted in their geographic area.
- [The Alzheimer's Association's Trial Match](#), is a free, online resource that matches persons with dementia, caregivers, and healthy volunteers to clinical trials in their geographic area.

PCPs could recommend a 2014 NIA document on clinical trials, [Participating in Alzheimer's Research: For Yourself and Future Generations](#), which is targeted to persons with dementia and families.







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<b>Appendix R-1</b>	<a href="#"><u>Template for PCP Referrals to community and regional agencies</u></a>
<b>Appendix R-2</b>	<a href="#"><u>ALZ Direct Connect</u></a>
<b>Appendix R-3</b>	<a href="#"><u>Minnesota Senior LinkAge Line Training, provided by the Minnesota Board on Aging</u></a>
<b>Appendix R-4</b>	<a href="#"><u>Care Needs Assessment Tool</u></a>
<b>Appendix R-5</b>	<a href="#"><u>Standardized Care Plans for Older Adults and Families</u></a>
<b>Appendix R-6</b>	<a href="#"><u>Online Resources to help older adults, families, and others understand and engage in detection of cognitive impairment, diagnostic evaluation, and post-diagnostic referrals</u></a>



## Contact Information for Agencies, Organizations, and Individuals That Can Assist Persons With Dementia and Their Families in Identifying Their Needs and Accessing Help

### A Template for Primary Care Providers, Physician Group Practices, Health Plans, and Health Care Systems

The GSA Workgroup has developed a template for the contact information PCPs and others need to refer their patients with dementia and patients' families to agencies, organizations, and individuals that can help them identify their specific needs and access community services and other resources to meet the identified needs. The last part of the template is a list of the types of community services and other resources people with dementia and family caregivers may need. PCPs may want to use examples of services and resources from this list to explain to patients with dementia and their families why the PCP is referring them to an agency, organization, or individual that can help them identify their needs and access needed services and other resources.

The first section of the template could be completed by the PCP or someone else in the PCP's practice setting.

#### Closest Area Agency on Aging (AAA)

AAA name, phone number, email, and website

To find the closest AAA, go to [www.eldercare.gov](http://www.eldercare.gov); type in the primary care office zip code or city and state, and click on "search." On the page that comes up, scroll down in the box on the left, labelled "show all," to select "Area Agencies on Aging."

Area Agencies on Aging are public or private non-profit agencies designated by the state to respond to needs of older people in the AAA's geographic area, which may be a city, several towns, a single county, or several counties. Some PCPs, physician group practices, health plans, and health care systems provide care for people in large geographic areas that may be served by more than one AAA. "Area Agency on Aging" is a generic term, and the name of a particular AAA may differ.

#### Closest Aging and Disability Resource Center (ADRC)

ADRC name, phone number, email, and website

To find the closest ADRC, go to [www.eldercare.gov](http://www.eldercare.gov); type in the primary care office zip code or city and state, and click on "search." On the page that comes up, click on the box on the left, labelled "show all,"



to select “Aging and Disability Resource Centers.” In some areas, the AAA and ADRC are in the same agency.

ADRCs are one-stop centers intended to provide a single point of entry to the long-term care system. They provide information and assistance for older adults and individuals with disabilities who need either public or private long-term care services, professionals seeking assistance on behalf of their clients, and individuals planning for their future long-term care needs. ADRCs also serve as the entry point for publicly administered long-term services, including services funded by Medicaid, Older Americans Act, and state programs.

### Closest Alzheimer’s Association Chapter

Chapter name, phone number, email, and website

To find the closest Alzheimer’s Association chapter, go to [www.alz.org](http://www.alz.org), and click on “We Can Help.” On the page that comes up, click on “Local Chapters” on the left, and then on “chapter search.” On the page that comes up next, titled “In My Community,” enter the primary care office zip code or state, or click on your state in the map.

Alzheimer’s Association chapters provide information, emotional support, and assistance, including referrals and help to connect with community services and other resources, for persons with Alzheimer’s disease and other dementias, their families, other caregivers, and the general public.

### Other Alzheimer’s Support Organization

Organization name, phone number, email, and website

Some states and localities have Alzheimer’s support organizations that provide services similar to the services provided by Alzheimer’s Association chapters, that is, information, emotional support, and assistance, including referrals and help to connect with community services and other resources for persons with Alzheimer’s disease and other dementias, their families, other caregivers, and the general public. Some Alzheimer’s support organizations were previously Alzheimer’s Association chapters. As of mid-2016, there is no national website that lists the organizations. A google search for “Alzheimer’s support organization” in a particular locality identifies these organizations in addition to the local or regional Alzheimer’s Association chapter, local Alzheimer’s support groups, and other organizations. It is likely that the local AAA or ADRC (see above) can also provide the name and contact information for Alzheimer’s support organizations in its jurisdiction, if any.



## Professional Geriatric Care Managers

Names, phone numbers, email addresses, and websites, if any

The Aging Life Care Association (ALCA), formerly the National Association of Professional Geriatric Care Managers, has a website that allows anyone to search by zip code or city and state for geriatric care managers who are members of the ALCA. The website provides contact information for geriatric care managers and shows their professional level and practice areas. It does not include information about the geriatric care managers' experience or expertise in working with people with dementia or dementia family caregivers. The website is:

[http://www.aginglifecare.org/ALCA/About\\_Aging\\_Life\\_Care/Find\\_an\\_Aging\\_Life\\_Care\\_Expert/ALCA/About\\_Aging\\_Life\\_Care/Search/Find\\_an\\_Expert.aspx](http://www.aginglifecare.org/ALCA/About_Aging_Life_Care/Find_an_Aging_Life_Care_Expert/ALCA/About_Aging_Life_Care/Search/Find_an_Expert.aspx).

It is likely that the local AAA and ADRC (see above) and some Alzheimer's Association chapters and Alzheimer's support organizations will also be able to provide names and contact information for geriatric care managers in their geographic area.

## National Alzheimer's Association

Organization name, phone number, email, and website

The national Alzheimer's Association has a 24/7 telephone "Helpline" that people with dementia, family caregivers, and others can call with questions about community services and other resources (1-800-272-3900). The "Helpline" can also link callers to local and regional Alzheimer's Association chapters for further assistance.

The Alzheimer's Association also has an online "Community Resource Finder" that can help people with dementia and their families identify their specific needs and find needed community services and other resources (<http://communityresourcefinder.org>).

## Lewy Body Dementia Association

Organization name, phone number, email, and website

The national Lewy Body Dementia Association (LBDA) has support groups in some localities across the country. Names and contact information for these support groups are available at <https://www.lbda.org/lbd-local-support-groups>. The GSA Workgroup is not aware, however, of other local or regional agencies, organizations, or individuals that provide assistance specifically for people with Lewy body dementia and their families in identifying their needs and accessing needed community services and other resources. Many Alzheimer's Association chapters and other Alzheimer's support organizations provide this kind of assistance for people with Lewy body dementia and their families. AAAs and ADRCs in some localities may be able to provide contact information for other agencies, organizations, and individuals that provide assistance specifically for people with Lewy body dementia and their families in identifying needs and accessing needed community services and other resources.



## Association for Frontotemporal Degeneration

Organization name, phone number, email, and website

The national Association for Frontotemporal Degeneration (AFTD) has a telephone “Helpline” (1-866-507-7222) and responds to email questions ([info@theaftd.org](mailto:info@theaftd.org)) The GSA Workgroup is not aware of local or regional agencies, organizations or individuals that provide assistance specifically for people with frontotemporal dementia and their families in identifying their needs and accessing needed community services and other resources. Many Alzheimer’s Association chapters and other Alzheimer’s support organizations provide this kind of assistance for people with frontotemporal dementia and their families. AAAs and ADRCs in some localities may be able to provide contact information for other agencies, organizations, and individuals that provide assistance specifically for people with frontotemporal dementia and their families in identifying needs and accessing needed community services and other resources.

## Vascular Dementia

Organization name, phone number, email, and website

The GSA Workgroup is not aware of local, regional, or national organizations that provide assistance specifically for people with vascular dementia and their families in identifying their needs and accessing community services and other resources to meet the needs. Many Alzheimer’s Association chapters and other Alzheimer’s support organizations provide this kind of assistance for people with vascular dementia and their families. In addition, some acute care and rehabilitation hospitals and health care systems have care managers who assist stroke patients and their families to identify and access the services and other resources they need, and these case managers assist people with dementia caused by stroke. AAAs and ADRCs may be able to provide contact information for local and regional stroke clubs and other sources of assistance in identifying needs and community services and other resources for people with vascular dementia and their families.





As noted in the KAER toolkit, people with dementia and their families differ in many ways that affect the types of community services and other resources they need and will benefit them. The following list is intended to provide a broad overview of types of community services and other resources that may be needed by particular people with dementia and their families. The list is not comprehensive and may not include community services and resources that are important for some people with dementia and families. The list also does not include primary and acute medical care services.

The large number of types of community services and other resources in the list below and the important differences among people with dementia and their families explain why it is so important for PCPs to connect patients with dementia and their families to agencies, organizations, or individuals that can help them identify their specific needs and find community services and other resources to meet those needs.

- **Adult Day Programs**
- **Adult Protective Services**
- **Assistance With Money Management**
- **Assistance With Shopping, Cooking, Cleaning, Laundry, and Other Household Activities**
- **Assistance With Taking Medications**
- **Assisted Living Residences**
- **Behavioral Symptom Management**
- **Chore Services**
- **Financial Support, Benefits Counseling, and Assistance With Applications for Benefits**
- **Grief Counseling**
- **Home Modifications**
- **Hospice**
- **Housing**
- **Information and Education About Dementia**
- **In-Home Skilled Nursing**
- **Legal Services**
- **Meals on Wheels**
- **Mental Health Services**
- **Nursing Homes**
- **Occupational Therapy**
- **Peer Support, Mentoring, and In-Person, Telephone, and Online Discussion Groups for the Person With Dementia**
- **Personal Care Assistance, Including Help With Bathing, Dressing, Eating, and Toileting**
- **Personal Emergency Response Systems**
- **Physical Exercise**
- **Physical Therapy**
- **Professional Counseling for the Person With Dementia and/or the Family Caregiver**
- **Recreation for the Person With Dementia, the Family Caregiver, or Both**
- **Respite Services**
- **Skill-Building Training About Dementia Care for Family and Other Caregivers**
- **Socialization, Including Formal Social Activities and Opportunities for Informal Socialization**
- **Speech and Language Therapy**
- **Support Groups for the Person With Dementia and the Family Caregiver**
- **Telephone Helplines**



# ALZ DIRECT CONNECT

## REFERRAL PROGRAM

...partnering with Healthcare and Aging Service Providers to *improve care and support* for people with Alzheimer's or dementias & their families

**ALZ DIRECT CONNECT** allows healthcare and aging services providers to directly link patients/clients and families to **Alzheimer's Greater Los Angeles** for:

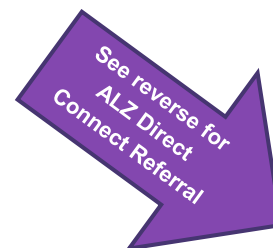
- access to **care coordination** and **psychosocial support**
- referrals to **supportive services** (often at no cost)
- help with **understanding the disease & navigating its progression**
- a 360 approach to care through **feedback to the referring provider**



### ADDITIONAL QUESTIONS?

Contact (323) 930-6277

**ALZ DIRECT CONNECT** does not fulfill mandatory legal reporting requirements for healthcare professionals. Alzheimer's Greater Los Angeles maintains high professional & ethical standards for care & safety and therefore reports any and all allegations or suspicions of elder abuse and/or child abuse.





## ALZ DIRECT CONNECT REFERRAL FORM

Fax or email this form to Alzheimer's Greater Los Angeles

Fax # 323.686.5106

Email [alzdirectconnect@alzla.org](mailto:alzdirectconnect@alzla.org)

Date \_\_\_\_\_

Check if primary contact

PATIENT/CLIENT NAME

Address \_\_\_\_\_

City \_\_\_\_\_ Zip \_\_\_\_\_

Phone# \_\_\_\_\_

Email \_\_\_\_\_

Primary Language:  English  Spanish  Other (specify)

Is the patient/client on Medi-Cal AND Medicare?

Yes  No

Check if primary contact

FAMILY CAREGIVER NAME (if available)

Address \_\_\_\_\_

City \_\_\_\_\_ Zip \_\_\_\_\_

Phone# \_\_\_\_\_

Email \_\_\_\_\_

Relationship to Patient/Client:  Spouse/Partner

Child  Professional Caregiver  Other (specify)

Primary Language:  English  Spanish  Other (specify)

I give permission to the referring provider to forward my contact and patient information to Alzheimer's Greater Los Angeles. I understand that a representative will contact me and/or my caregiver about support, programs, and other services and will follow up with the referring provider. **Referrals will be entered into our secure database, unless indicated otherwise by checking this box** .

Signature \_\_\_\_\_

Date \_\_\_\_\_

(Patient/Client or Personal Representative/Family Caregiver)

The person being referred provided verbal consent instead of signature  Yes

### REASON FOR REFERRAL (check all that apply)

- Social Work Consultation & Support
- Support for Newly Diagnosed
- Support Groups
- Activity Programs
- Safety Issues
  - Home Safety
  - Driving
  - Wandering (MedicAlert®)
- Research & Clinical Trials Information
- Legal & Financial Considerations
- Healthcare Directives
- Respite Services
- Caregiver Education
- Other (specify) \_\_\_\_\_

### Additional Information

\_\_\_\_\_  
 \_\_\_\_\_

### REQUIRED INFORMATION

Referring Provider Name \_\_\_\_\_ Title \_\_\_\_\_

Provider Organization \_\_\_\_\_  Healthcare organization  
 Non-medical community organization

Phone # \_\_\_\_\_ Fax # \_\_\_\_\_ Email \_\_\_\_\_

How would you prefer to receive follow-up?  Fax  Email  Follow-up unnecessary



## Minnesota Board on Aging

### Dementia Capability Training for Senior LinkAge Line® and Other First Contacts

This three-part web-based video training is designed to provide training to Aging and Disability Resource Centers and other first contacts to:

- Understand the basics of Alzheimer’s disease and related dementias.
- Identify people with possible dementia and/or their care partners over the phone.
- Connect them to the resources they need, including the Alzheimer’s Association via warm handoff (live 3-way phone connection).

All Senior LinkAge Line® staff are required to participate. Participants receive a pre- and post-test.

#### **Part I: The Basics (90 minutes)**

This video conference is an overview for new professionals about dementia, Alzheimer’s disease and the related dementias. It will focus on a description of dementia, risk factors, progress of dementia and resources for people with dementia, family care partners and professional care partners.

**At the end of this session, participants will be able to:**

1. Define dementia, Alzheimer’s disease and related dementias.
2. Describe at least 3 effects of dementia on cognition.
3. List at least 3 resources to support people with dementia and their care partners.

#### **Part II: Normal Cognitive Aging or Problematic Aging—Telling the Difference and Taking Action (90 minutes)**

This videoconference begins with a definition of normal and problematic aging. Then through video interviews of families living with dementia, case studies and a review of the most current research, professionals will hear conversational clues that may provide an alert to a caller’s concerns related to memory loss or dementia.



**At the end of this session, participants will be able to:**

1. Understand normal vs. problematic cognitive aging.
2. Recognize clues in conversation which may be related to cognitive issues.
3. Utilize conversation clues to respond to callers with cognitive issues.

### **Part III: Strategies to Support Families Living With Dementia in the Community (120 minutes)**

This video conference focuses on strategies professionals can use to help support families who are living in the community with a family experiencing memory loss and dementia. Interviews with care partners add personal experience to the power point presentation.

**At the end of this session, participants will be able to:**

1. Describe symptoms and predictors that contribute to long-term care placement based on research evidence.
2. Name practical tools, including technology, to utilize to coach caregivers who are struggling with these challenges.
3. List common community resources (metro and regional) that may help support the person with dementia and caregiver at home.
4. Describe revised SLL Referral Protocol and demonstrate how the process works using case examples.





**DEMENTIA CAL MEDICONNECT PROJECT: CALIFORNIA'S DUALS PILOT**

**CARE NEEDS ASSESSMENT TOOL**

“Caring for someone with Alzheimer’s disease or a related dementia can sometimes be challenging. I am going to ask you some questions to help better plan for care. Some of the questions I ask may be personal, but will help me understand your needs. I’d like to know if you have experienced any of these challenges in the past month, and if so, how much they bothered or upset you when they happened.”

**\*How much does this bother the caregiver?**  
 0 = not at all  
 1 = a little  
 2 = somewhat  
 3 = very much  
 4 = extremely  
 ↓

Challenging Behaviors & ADLs and Functional Needs	Has it happened in the past month?		How much does this bother the caregiver?
<b>CHALLENGING BEHAVIORS</b>			
Sleep disturbances (waking you or other family members up at night)	NO	YES →	
Repetition (doing or saying things over and over)	NO	YES →	
Sadness and/or depression (feeling blue)	NO	YES →	
Combateness (anger, hitting, pushing, fighting, etc.)	NO	YES →	
Hallucinations (seeing or hearing things that are not there)	NO	YES →	
Sundowning (more confusion/restlessness in late afternoon/evening)	NO	YES →	
Suspiciousness/paranoia (accusing/blaming)	NO	YES →	
Screaming and making noises	NO	YES →	
Disinhibition (unwanted sexual behaviors or inappropriate behaviors)	NO	YES →	
<b>ACTIVITIES OF DAILY LIVING AND FUNCTIONAL NEEDS</b>			
Resists bathing or showering	NO	YES →	
Difficulty with dressing and grooming (brushing hair/teeth, shaving, etc.)	NO	YES →	
Difficulty with eating (including chewing, swallowing, dental concerns)	NO	YES →	
Difficulty using the toilet/incontinence (wetting, accidents)	NO	YES →	

Safety & Caregiver Needs	Has the caregiver experienced this?	
<b>SAFETY</b>		
Home safety concerns (falls, guns, knives, stove, leaving the person alone)	NO	YES
Insists on driving	NO	YES
Takes medicine the wrong way	NO	YES
Wanders/gets lost	NO	YES
<b>CAREGIVER NEEDS</b>		
Depression/stress (feeling blue and/or overwhelmed)	NO	YES
Difficulty providing care because of your health	NO	YES
Lacks understanding of dementia	NO	YES
Legal and financial planning (paying the bills, power of attorney, etc.)	NO	YES
Long-term care planning	NO	YES
End-of-life planning	NO	YES

\*Care managers should use clinical judgment to gauge caregiver’s capacity to provide care, level of burden to caregiver, and identified unmet needs. This information will determine which standardized care plans are needed.

**Other needs identified:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_



## Alzheimer's Greater Los Angeles Dementia Care Management Toolkit List of Standardized Care Plans

Once care needs have been identified, care managers can use the standardized care plans listed below to further identify problem areas, determine goals, educate families, teach problem-solving strategies, provide clinical support, and link families to home and community-based services. The plans can be accessed at <http://www.alzqla.org/professionals/dementia-care-management-toolkit/#>; click on 'Standardized Care Plans' and then on the particular care plan you want to read or download.

Note. Standardized care plans are not all-inclusive and are meant to complement and enhance existing care management tools and practices. Clinical judgment should be used when working with individuals and families, and procedures, policies, regulations, laws, and mandates should always be followed.

- [Sleep Disturbances](#)
- [Repetition](#)
- [Sadness & Depression](#)
- [Combativeness](#)
- [Hallucinations](#)
- [Sundowning](#)
- [Suspiciousness & Paranoia](#)
- [Screaming & Making Noises](#)
- [Resists Bathing or Showering](#)
- [Difficulty Eating](#)
- [Difficulty Dressing & Grooming](#)
- [Difficulty Using Toilet & Incontinence](#)
- [Home Safety Concerns](#)
- [Insists on Driving](#)
- [Takes Medicine the Wrong Way](#)
- [Wanders, Gets Lost](#)
- [Caregiver Depression & Stress](#)
- [Difficulty Providing Care Because of Health](#)
- [Lacks Understanding of Dementia](#)
- [Legal & Financial Planning](#)
- [Long Term Care Planning](#)
- [End of Life Planning](#)

These standardized care plans were adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project.



## Online Resources to Help Older Adults, Families, and Others Understand and Engage in Detection of Cognitive Impairment, Diagnostic Evaluation, and Post-Diagnostic Referrals

### Communicating With Your Doctor

- Alzheimer's Association, *Communicating With Your Doctor or Health Care Professionals* (2015); accessible at [http://www.alz.org/documents/national/TS-0019\\_CommunicationWithHealthCareProfessionals\\_FINAL\\_June14.pdf](http://www.alz.org/documents/national/TS-0019_CommunicationWithHealthCareProfessionals_FINAL_June14.pdf)
- Alzheimer's Association, *Preparing for Your Doctor's Visit* (2014); accessible at [http://www.alz.org/national/documents/ED\\_doc\\_checklist.pdf](http://www.alz.org/national/documents/ED_doc_checklist.pdf)

### Brain Health and Aging

- Institute of Medicine, *Cognitive Aging: An Action Guide for Individuals and Families* (2015); accessible at: [https://www.nationalacademies.org/hmd/~/\\_media/Files/Report%20Files/2015/Cognitive\\_aging/Action%20Guide%20for%20Individuals%20and%20Families\\_V3.pdf](https://www.nationalacademies.org/hmd/~/_media/Files/Report%20Files/2015/Cognitive_aging/Action%20Guide%20for%20Individuals%20and%20Families_V3.pdf)
- Administration for Community Living, *Brain Health As You Age: You Can Make a Difference!* (2014); accessible at [http://www.acl.gov/Get\\_Help/BrainHealth/Index.aspx](http://www.acl.gov/Get_Help/BrainHealth/Index.aspx); this website was developed and is updated by the Administration for Community Living, the Centers for Disease Control and Prevention, and the National Institutes of Health.

### Signs and Symptoms of Cognitive Impairment

- National Institute on Aging, *Age Page: Forgetfulness: Knowing When to Ask for Help* (2016); accessible at: <https://www.nia.nih.gov/health/publication/forgetfulness>
- National Institute on Aging, *Understanding Memory Loss: What to Do When You Have Trouble Remembering* (2015); accessible at <https://www.nia.nih.gov/alzheimers/publication/understanding-memory-loss/introduction>; this document is available in English and Spanish.

### Diagnostic Evaluation

- Alzheimer's Association, *Preparing for Your Doctor's Visit* (2014); accessible at [http://www.alz.org/national/documents/ED\\_doc\\_checklist.pdf](http://www.alz.org/national/documents/ED_doc_checklist.pdf)

### After a Diagnosis

- Alzheimer's Association, *Living Well: A Guide for Persons With Mild Cognitive Impairment (MCI) & Early Dementia* (2011); accessible at [http://www.alz.org/documents/mndak/alz\\_living\\_well\\_workbook\\_2011v2\\_web.pdf](http://www.alz.org/documents/mndak/alz_living_well_workbook_2011v2_web.pdf)
- Association for Frontotemporal Degeneration, *The Doctor Thinks It's FTD. Now What: A Guide for Managing a New Diagnosis* (2009); accessible at [http://www.theaftd.org/wp-content/uploads/2009/03/AFTD-40-pg-booklet-NewDiag\\_Website.pdf](http://www.theaftd.org/wp-content/uploads/2009/03/AFTD-40-pg-booklet-NewDiag_Website.pdf)
- Dementia Friendly America, *After a Diagnosis* (2015); accessible at <http://static1.squarespace.com/static/559c4229e4b0482682e8df9b/t/561f2778e4b05fb7f59240d4/1444882296205/DFA-Tools-AfterDiagnosis.pdf>



- National Institute on Aging and the Northwestern University Alzheimer's Disease Center Early-Stage Support Group, *What Happens Next? A Booklet About Being Diagnosed With Alzheimer's Disease or a Related Disorder* (2008 reprint); accessible at <https://www.nia.nih.gov/alzheimers/publication/what-happens-next>
- National Institute on Aging, *Now What? Next Steps After a Diagnosis of Alzheimer's Disease* (2016); accessible at <https://www.nia.nih.gov/alzheimers/publication/now-what>

## Dementia

- UCLA Alzheimer's and Dementia Care Program, *What Is Dementia?* Video presented by David B. Reuben, MD; accessible at <https://www.youtube.com/watch?v=wyO1qQwRHVY>

## Diseases and Conditions That Cause Dementia

### Alzheimer's Disease

- Alzheimer's Association, *Basics of Alzheimer's Disease* (revised 2016); accessible at [http://www.alz.org/national/documents/brochure\\_basicsofalz\\_low.pdf](http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf)
- Alzheimer's Association, *Living With Alzheimer's*; accessible at [https://www.alz.org/living\\_with\\_alzheimers\\_4521.asp](https://www.alz.org/living_with_alzheimers_4521.asp)
- Alzheimer's Association, I Have Alzheimer's Disease webpage, *If you live alone*; accessible at <http://www.alz.org/i-have-alz/if-you-live-alone.asp>
- National Institute on Aging, *Alzheimer's Disease Medications: Fact Sheet* (2015); accessible at <https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/alzheimers-disease-medications-fact-sheet.pdf?ZbjlQhhmxeL53OyaeAIQAMDFWqxAlaKB>
- National Institute on Aging, *Alzheimer's Caregiving Tips: Helping Family and Friends Understand Alzheimer's Disease*; accessible at [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/caregivingtips\\_familyfriends-final\\_7-9-12.pdf?7KwRkvdn6njFP.v0jDzW1pXZqwUfeafL](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/caregivingtips_familyfriends-final_7-9-12.pdf?7KwRkvdn6njFP.v0jDzW1pXZqwUfeafL)

### Vascular Dementia

- Mayo Clinic, *Vascular Dementia* (2014); accessible at <http://www.mayoclinic.org/diseases-conditions/vascular-dementia/basics/treatment/con-20029330>; this website has sections on definitions, symptoms, causes, risk factors, preparing for your doctor visit, and other topics.
- University of California San Francisco, *Vascular Dementia* (2011); accessible at <http://memory.ucsf.edu/education/diseases/vascular>



### Lewy Body Dementia

- Lewy Body Dementia Association, *An Introduction to Lewy Body Dementia: A Special Publication for People Newly Diagnosed With Lewy Body Dementia and Those Still Seeking Answers*; accessible at [http://www.lbda.org/sites/default/files/31056\\_lewy\\_body\\_intro\\_printer\\_proof.pdf](http://www.lbda.org/sites/default/files/31056_lewy_body_intro_printer_proof.pdf)
- Lewy Body Dementia Association, *Lewy Body Dementia Diagnostic Symptoms*, (2015); accessible at [https://www.lbda.org/sites/default/files/diagnostic\\_symptoms\\_checklist\\_2015.pdf](https://www.lbda.org/sites/default/files/diagnostic_symptoms_checklist_2015.pdf); this document includes a one-page list of cognitive symptoms for patients to check the symptoms they are experiencing and a one-page summary for physicians about diagnosing Lewy body dementia.
- National Institute on Aging, *Lewy Body Dementia: Information for Patients, Families, and Professionals* (2015); accessible at <https://www.nia.nih.gov/alzheimers/publication/lewy-body-dementia/introduction>

### Frontotemporal Degeneration (FTD)

- Association for Frontotemporal Degeneration, *Life With FTD: Managing Health Care*; accessible at <http://www.theaftd.org/life-with-ftd/managing-health-care>
- Association for Frontotemporal Degeneration, *Life With FTD: Support for Caregivers*; accessible at <http://www.theaftd.org/life-with-ftd/support-for-caregivers>
- Association for Frontotemporal Degeneration, *Life With FTD: Children and Teens*; accessible at <http://www.theaftd.org/life-with-ftd/children-and-teens>
- National Institute on Aging, *Frontotemporal Disorders: Information for Patients, Families, and Caregivers* (2014); accessible at <https://www.nia.nih.gov/alzheimers/publication/frontotemporal-disorders/introduction>

### Finding Help, Community Services

- Alzheimer's Association, *Community Resource Finder*; accessible at <http://communityresourcefinder.org>
- Family Caregiver Alliance, National Center on Caregiving, *Family Care Navigator*; accessible at <https://www.caregiver.org/family-care-navigator>; this website provides a state-by-state online guide to help families locate government, nonprofit, and private caregiver support programs; the website is not dementia specific.

### Participating in Clinical Trials

- Alzheimer's Association *Trial Match*; accessible at [http://www.alz.org/research/clinical\\_trials/find\\_clinical\\_trials\\_trialmatch.asp](http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp)
- National Institute on Aging, ADEAR: *Find Alzheimer's Disease and Related Clinical Trials*; accessible at <https://www.nia.nih.gov/alzheimers/clinical-trials>
- National Institute on Aging, ADEAR: *Participating in Alzheimer's Research: For Yourself and Future Generations* (2014); accessible at <https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/participating-in-alzheimers-research.pdf>





## Caregiving Tips

- Alzheimer's Foundation of America, *Caregiving Tips*; accessible at <http://www.alzfdn.org/EducationandCare/strategiesforsuccess.html>
- Alzheimer's Greater Los Angeles, *Keeping Home Safe* (2016); accessible at <http://www.alzgia.org/wp-content/uploads/2016/01/Caregiver-Information-Alz-home-safety.pdf>; available in English and Spanish.
- Alzheimer's Greater Los Angeles, *Anger, Frustration & Fighting* (2016); accessible at <http://www.alzgia.org/wp-content/uploads/2016/01/Caregiver-Information-Alz-anger.pdf>; available in English and Spanish.
- Alzheimer's Greater Los Angeles, *Getting Lost* (2016); accessible at <http://www.alzgia.org/wp-content/uploads/2016/01/Caregiver-Information-Alz-getting-lost.pdf>; available in English and Spanish.
- Alzheimer's Greater Los Angeles, *Bathing* (2016); accessible at <http://www.alzgia.org/wp-content/uploads/2016/01/Caregiver-Information-Alz-bathing.pdf>; available in English and Spanish.
- Alzheimer's Greater Los Angeles, *Medications* (2016); accessible at <http://www.alzgia.org/wp-content/uploads/2016/01/Caregiver-Information-Alz-medications.pdf>; available in English and Spanish
- Alzheimer's Greater Los Angeles, *Hallucinations* (2016); accessible at <http://www.alzgia.org/wp-content/uploads/2016/01/Caregiver-Information-Alz-hallucinations.pdf>; available in English and Spanish.
- National Institute on Aging, *Caring for a Person With Alzheimer's Disease* (2015); accessible at [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/caring-for-a-person-with-alzheimers-disease.pdf?ffliK\\_8poO5DBCC\\_NhypDDYUCdpN5UDW](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/caring-for-a-person-with-alzheimers-disease.pdf?ffliK_8poO5DBCC_NhypDDYUCdpN5UDW)
- National Institute on Aging, *About Alzheimer's Disease: Caregiving*; accessible at <https://www.nia.nih.gov/alzheimers/topics/caregiving#pubs>; this website has a list of all the National Institute on Aging Caregiving Tip Sheets.
- National Institute on Aging, *Alzheimer's Caregiving Tips: Managing Personality and Behavior Changes*; accessible at <https://www.nia.nih.gov/alzheimers/publication/managing-personality-and-behavior-changes>
- National Institute on Aging, *Alzheimer's Caregiving Tips: Coping With Agitation and Aggression*; accessible at <https://www.nia.nih.gov/alzheimers/publication/coping-agitation-and-aggression>
- National institute on Aging, *Alzheimer's Caregiving Tips: Changes in Communication Skills*; accessible at <https://www.nia.nih.gov/alzheimers/publication/changes-communications-skills>
- University of San Francisco Medical Center, *Coping Strategies for Vascular Dementia Caregivers*; accessible at [https://www.ucsfhealth.org/education/coping\\_strategies\\_for\\_vascular\\_dementia\\_caregivers/](https://www.ucsfhealth.org/education/coping_strategies_for_vascular_dementia_caregivers/)



## DEMENTIA FRIENDLY AMERICA CLINICAL PRACTICE TOOLS

Dementia Friendly America (DFA) is a Minnesota-based initiative to foster dementia friendly communities across the country. DFA grew out of ACT on Alzheimer's, a statewide collaboration of government and private sector organizations and individuals that is intended to build Minnesota's capacity to respond to Alzheimer's disease and other dementias. ACT on Alzheimer's created clinical practice tools to help health care and social service providers and community-based organizations improve and coordinate care and services for people with dementia and their families. The ACT on Alzheimer's clinical practice tools have been adapted to address DFA's national perspective and audience.

The three DFA clinical practice tools shown in the following appendices incorporate many of the same tools and approaches included in the KAER toolkit. In contrast to the KAER toolkit, which focuses primarily on dementia care provided by PCPs in primary care settings, the DFA tools encompass the broad continuum of dementia care delivered by an array of health care, social service, and community-based providers across care settings. The DFA tools include flow charts that cross the KAER steps and therefore, may be useful to PCPs, other health care providers, health plans, and health care systems as they think about and design systems of dementia care.

### CLINICAL PROVIDER PRACTICE TOOL, 2016 (Appendix DFA-1)

This 6-page tool includes a flow chart for cognitive impairment identification; 1-page guidelines for dementia workup and management, assessment tools, management resources, and references. The tool also includes a 2-page fact sheet on disclosure of dementia diagnoses.

### CARE COORDINATION PRACTICE TOOL, 2016 (Appendix DFA-2)

This 4-page tool includes a flow chart for cognitive impairment identification; a 2-page dementia care plan checklist; and a fact sheet on symptoms of mild cognitive impairment and symptoms and duration of early, middle, and late stage Alzheimer's disease.

### MANAGING DEMENTIA ACROSS THE CONTINUUM (MID TO LATE STAGE), 2015 (Appendix DFA-3)

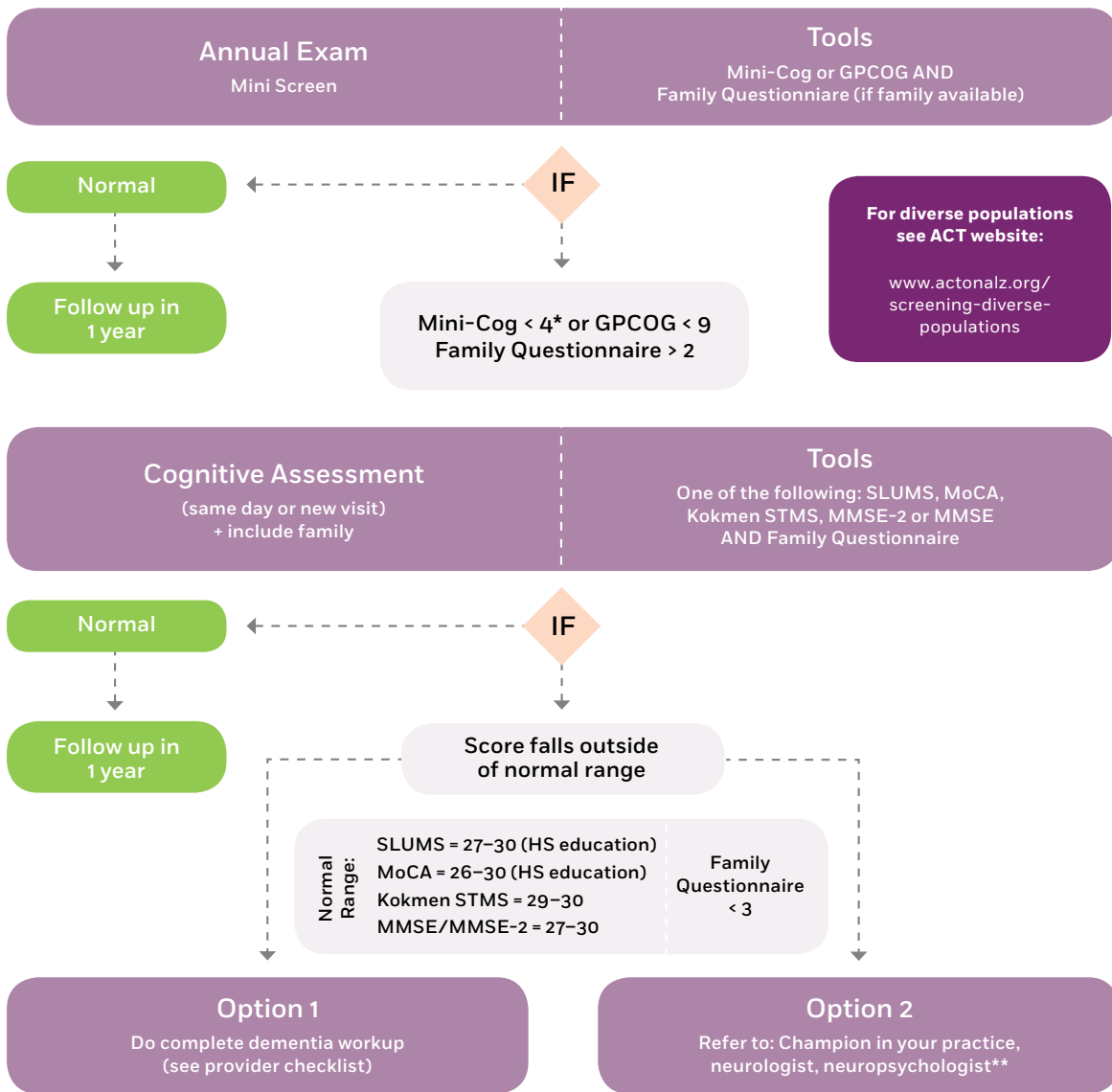
This 6-page tool describes nine tasks in managing care in the mid to late stages of dementia and provides resources to help care providers implement these tasks.

Additional information and materials from the DFA initiative can be accessed at the initiative website, <http://www.dfamerica.org>.



## Clinical Provider Practice Tool

### Cognitive Impairment Identification



For diverse populations see ACT website:  
[www.actonalz.org/screening-diverse-populations](http://www.actonalz.org/screening-diverse-populations)

\*A cut point of <3 on the Mini-Cog has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

\*\*Neuropsychological evaluation is typically most helpful for differential diagnosis, determining nature and severity of cognitive functioning, and the development of an appropriate treatment plan. Testing is typically maximally beneficial in the following score ranges:

SLUMS = 18-27  
 MoCA = 19-27  
 Kokmen STMS = 19-33  
 MMSE/MMSE-2 = 18-28



## Dementia Work-Up

Follow these diagnostic guidelines in response to patient failure on cognitive screening (e.g., Mini-Cog) or other signs of possible cognitive impairment.

### History and Physical

- Person-centered care includes understanding cultural context in which people are living (see [www.actonalz.org/culturally-responsive-resources](http://www.actonalz.org/culturally-responsive-resources))
- Review onset, course, and nature of memory and cognitive deficits (Alzheimer's Association Family Questionnaire may assist) and any associated behavioral, medical or psychosocial issues
- Assess ADLs and IADLs, including driving and possible medication and financial mismanagement (Functional Activities Questionnaire and/or OT evaluation may assist)
- Conduct structured mental status exam (e.g., MoCA, SLUMS, MMSE)
- Assess mental health (consider depression, anxiety, chemical dependency)
- Perform neurological exam focusing on focal/lateralizing signs, vision, including visual fields, and extraocular movements, hearing, speech, gait, coordination, and evidence of involuntary or impaired movements

### Diagnostics

#### Lab Tests

- Routine: CBC, lytes, BUN, Cr, Ca, LFTs, glucose
- Dementia screening labs: TSH, B12
- Contingent labs (per patient history): RPR or MHA-TP, HIV, heavy metals

#### Neuroimaging

- CT or MRI when clinically indicated

#### Neuropsychological Testing

- Indicated in cases of early or mild symptom presentation, for differential diagnosis, determination of nature and severity of cognitive functioning, and/or development of appropriate treatment plan
- Typically maximally beneficial in the following score ranges: MoCA 19-27; SLUMS 18-27; MMSE 18-28

### Diagnosis\*

#### Mild Cognitive Impairment

- Mild deficit in one cognitive function: memory, executive, visuospatial, language, attention
- Intact ADLs and IADLs; does not meet criteria for dementia

#### Alzheimer's Disease

- Most common type of dementia (60–80% of cases)
- Memory loss, confusion, disorientation, dysnomia, impaired judgment/behavior, apathy/depression

#### Dementia With Lewy Bodies/Parkinson's Dementia

- Second most common type of dementia (up to 30% of cases)
- Hallmark symptoms include visual hallucinations, REM sleep disorder,

parkinsonism, and significant fluctuations in cognition

#### Frontotemporal Dementia

- Third most common type of dementia primarily affecting individuals in their 50s and 60s
- EITHER marked changes in behavior/personality OR language variant (difficulty with speech production or loss of word meaning)

#### Vascular Dementia

- Relatively rare in pure form (6-10% of cases)
- Symptoms often overlap with those of AD; frequently there is relative sparing of recognition memory

\* The latest DSM-5 manual uses the term "Major Neurocognitive Disorder" for dementia and "Mild Neurocognitive Disorder" for mild cognitive impairment. This ACT on Alzheimer's resource uses the more familiar terminology, as the new terms have yet to be universally adopted.

### Follow-Up Diagnostic Visit

- **Include family members, friends, or other care partners**
- Review intervention checklist for Alzheimer's disease and related dementias
- Refer to the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 and/or the Eldercare Locator at 1-800-677-1116



## Dementia Management

### Diagnostic Uncertainty & Behavior Management

#### Refer to Specialist as Needed

- Neurologist (dementia focus, if possible)
- Geriatric Psychiatrist
- Geriatrician
- Memory Disorders Clinic

### Counseling, Education, Support & Planning

#### Family Meeting

- Refer to social worker or care coordinator

#### Link to Community Resources

- Refer to the Alzheimer’s Association 24/7 Helpline at 1-800-272-3900 and/or the Eldercare Locator at 1-800-677-1116
- Resources for diverse populations: [www.actonalz.org/screening-diverse-populations](http://www.actonalz.org/screening-diverse-populations)
- Provide After a Diagnosis<sup>1</sup>
- Provide Taking Action Workbook<sup>6</sup>

### Stimulation / Activity / Maximizing Function

#### Daily Mental, Physical and Social Activity

- Provide Living Well Workbook<sup>5</sup> (includes nonpharm therapies for early to mid stage)
- Adult day services (mid to late stage)
- Sensory aids (hearing aids, pocket talker, glasses)

### Safety

*Note: Individuals with dementia are vulnerable adults and may be at a higher risk for elder abuse.*

#### Driving

- Counsel on risks
- Refer for driving evaluation<sup>2</sup>
- Provide At the Crossroads<sup>3</sup>

#### Medication Management

- Family oversight or health care professional

#### Financial / Legal

- Encourage patient to assign durable power of attorney; elder law attorney as needed

### Advance Care Planning

#### Complete Advance Care Plan

- Refer to advance care planning facilitator within system, if available
- Encourage completion of healthcare directive forms<sup>4</sup>

### Medications

- Memory: Donepezil, rivastigmine patch, galantamine and memantine (mid-late stage)
- Mood & Behavior: SSRIs or SNRIs
- Avoid/Minimize: Anticholinergics, hypnotics, narcotics, and antipsychotics (not to be used in Lewy Body dementia)





## Tools

### Mini-Cog

- Public domain: [www.mini-cog.com](http://www.mini-cog.com)
- Sensitivity for dementia: 76-99%
- Specificity: 89-93%

### Montreal Cognitive Assessment (MoCA)

- Public domain: [www.mocatest.org/](http://www.mocatest.org/)
- Sensitivity: 90% for MCI, 100% for dementia
- Specificity: 87%

### St. Louis University Mental Status (SLUMS)

- Public domain: [http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam\\_05.pdf](http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf)
- Sensitivity: 92% for MCI, 100% for dementia
- Specificity: 81%

### Measure/Assess IADLs

- <http://consultgeri.org/try-this/dementia/issue-d13.pdf>

### Family Questionnaire

- [www.actonalz.org/pdf/Family-Questionnaire.pdf](http://www.actonalz.org/pdf/Family-Questionnaire.pdf)

### Mini-Mental Status Exam (MMSE)

- Copyrighted: [www4.parinc.com/Products/Product.aspx?ProductID=MMSE](http://www4.parinc.com/Products/Product.aspx?ProductID=MMSE)
- Sensitivity: 18% for MCI, 78% for dementia
- Specificity: 100%

*Note: The MMSE is not a preferred tool in memory loss assessment. Accumulating evidence shows it is significantly less sensitive than both the MoCA and SLUMS in identifying MCI and early dementia.*

## Dementia Management Resources

1. **After a Diagnosis**  
[www.dfamerica.org/provider-tools/](http://www.dfamerica.org/provider-tools/)
2. **American Occupational Therapy Association**  
[myaota.aota.org/driver\\_search/index.aspx](http://myaota.aota.org/driver_search/index.aspx)
3. **At the Crossroads: Family Conversations About Alzheimer's Disease, Dementia & Driving**  
[www.thehartford.com/alzheimers](http://www.thehartford.com/alzheimers)
4. **National Hospice & Palliative Care Organization**  
Download state-specific advance directive forms at [www.caringinfo.org](http://www.caringinfo.org)
5. **Living Well Workbook**  
[www.alz.org/mnnd/documents/15\\_ALZ\\_Living\\_Well\\_Workbook\\_Web.pdf](http://www.alz.org/mnnd/documents/15_ALZ_Living_Well_Workbook_Web.pdf)
6. **Taking Action Workbook**  
[www.alz.org/i-have-alz/downloads/lwa\\_pwd\\_taking\\_action\\_workbook.pdf](http://www.alz.org/i-have-alz/downloads/lwa_pwd_taking_action_workbook.pdf)

## References: Provider Checklist

Borson, S., Scanlan, J.M., Chen, P., & Ganguli, M. (2003). The Mini-Cog as a screen for dementia: Validation in a population-based sample. *JAGS*, 51(10), 1451-1454.

Borson S, Scanlan JM, Watanabe J et al. Improving identification of cognitive impairment in primary care. *Int J Geriatr Psychiatry* 2006; 21: 349-355.

Ismail Z, Rajii TK, Shulman KI. Brief cognitive screening instruments: an update. *Int J Geriatr Psychiatry*. Feb 2010; 25(2):111-20.

Larner, AJ. Screening utility of the Montreal Cognitive Assessment (MoCA): in place of – or as well as – the MMSE? *Int Psychogeriatr*. Mar 2012;24(3):391-6.

Lessig M, Scanlan J et al. Time that tells: Critical clock-drawing errors for dementia screening. *Int Psychogeriatr*. 2008 June; 20(3): 459-470.

McCarten J, Anderson P et al. Screening for cognitive impairment in an elderly veteran population: Acceptability and results using different versions of the Mini-Cog. *J Am Geriatr Soc* 2011; 59: 309-213.

McCarten J, Anderson P et al. Finding dementia in primary care: The results of a clinical demonstration project. *J Am Geriatr Soc* 2012; 60: 210-217.

Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*. Apr 2005;53(4):695-699.

Scanlan J & Borson S. The Mini-Cog: Receiver operating characteristics with the expert and naive raters. *Int J Geriatr Psychiatry* 2001; 16: 216-222.

Tariq SH, Tumosa N, Chibnall JT, et al. Comparison of the Saint Louis University mental status examination and the mini-mental state examination for detecting dementia and mild neurocognitive disorder—a pilot study. *Am J Geriatr Psychiatry*. Nov 2006;14(11):900-10.

Tsoi K, Chan J et al. Cognitive tests to detect dementia: A systematic review and meta-analysis. *JAMA Intern Med*. 2015; E1-E9.



## Increasing Disclosure of Dementia Diagnosis

### Divergence Between Common Perceptions About Dementia Diagnosis and Published Data

Physicians have cited many barriers to diagnosing dementia, including doubts about the value of diagnosis given limited treatment options, concern over risk of misdiagnosis, and lack of knowledge of local dementia support services.<sup>7</sup> However, based on published data, perceptions that disclosure of dementia diagnosis is not preferred or causes psychological distress among individuals and family members should be challenged.

#### A majority of patients want to know if they have Alzheimer’s Disease (AD)

A recent 5-country survey<sup>9</sup> examining public attitudes about AD found that more than 80% of all adults (N=2,678) and 89% of US adults (N=639) responded that if they had memory or confusion symptoms, they would go to a doctor to determine if the cause was AD. This US finding is consistent with previously published reports over the last 2 decades.<sup>10,11</sup>

“ In gaining knowledge and developing a treatment plan, individuals may realize that they can take an active role in managing the illness, enhancing a sense of self-efficacy where before they might have felt helpless.”

#### Most family members appreciate the benefits of diagnosis

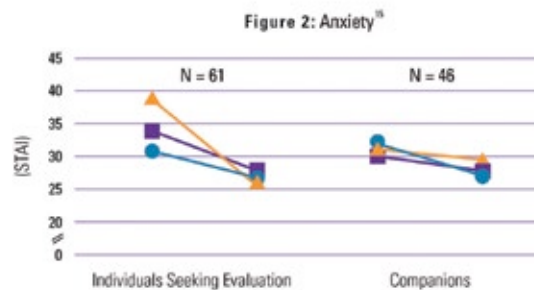
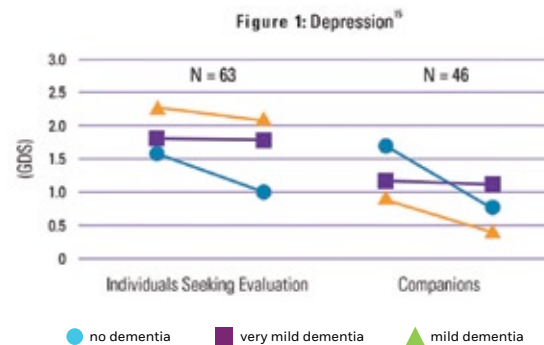
Connell and colleagues surveyed 178 adults who had a family member with AD.

- More than 75% of family members rated the following benefits of diagnosis as being very or extremely important: 1) let family know what was wrong with relative; 2) allowed family to get information about AD; and 3) allowed family to plan for the future.
- Only 6% of all respondents strongly agreed that “it is easier to not know what the diagnosis is.”

#### Diagnosis does not cause psychological stress in most patients and their families

Physician conjecture that a dementia diagnosis may lead to depression or even suicide has been reported.<sup>12</sup> Empirical findings on the issue are primarily limited to retrospective or review studies in populations with comorbid depression, a well-known risk factor for suicide.<sup>13,14</sup> To examine psychological stress, Carpenter and colleagues evaluated 90 individuals and their companions before a dementia evaluation and after dementia disclosure using the Geriatric Depression Scale (GDS) and the State-Trait Anxiety Inventory (STAI).<sup>15</sup>

- No clinically significant changes were noted in depressive symptoms in either the persons diagnosed with dementia or their companion (Figure 1).
- Anxiety decreased or remained unchanged after diagnostic feedback for most groups (Figure 2).





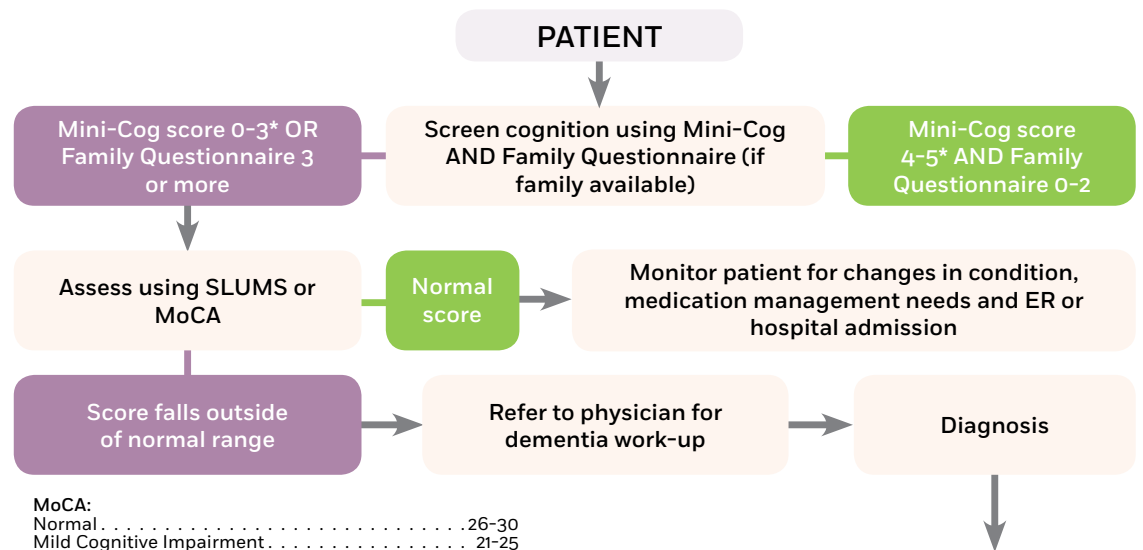
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## Care Coordination Practice Tool

### Cognitive Impairment Identification and Dementia Care Coordination\*\*



<b>MoCA:</b>	
Normal . . . . .	26-30
Mild Cognitive Impairment . . . . .	21-25
Moderate . . . . .	15-20
Severe . . . . .	0-14
<b>SLUMS (high school education)</b>	
Normal . . . . .	27-30
Mild Cognitive Impairment . . . . .	21-26
Dementia . . . . .	1-20
<b>SLUMS (Less than high school education)</b>	
Normal . . . . .	25-30
Mild Cognitive Impairment . . . . .	20-24
Dementia . . . . .	1-19

**Family Questionnaire**  
[www.actonalz.org/pdf/Family-Questionnaire.pdf](http://www.actonalz.org/pdf/Family-Questionnaire.pdf)

**Mini-Cog**  
[www.mini-cog.com](http://www.mini-cog.com)

**Montreal Cognitive Assessment (MoCA)**  
[www.mocatest.org](http://www.mocatest.org)

**St. Louis University Mental Status (SLUMS)**  
[http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam\\_05.pdf](http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf)

**DEMENTIA CARE COORDINATION**

- Identify care partner
- Conduct comprehensive assessment of patient
- Provide disease education
- Develop care plan based on patient’s diagnosis and stage of disease (MCI, early, middle, late), needs and goals
- Arrange services and supports
- Determine visit frequency
- Develop plan for communication
- Monitor patient for changes in condition, medication management needs and emergency room or hospital admission
- Re-evaluate and modify care plan as needed

\*A cut point of <3 on the Mini-Cog has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

\*\*The latest DSM-5 manual uses the term "Major Neurocognitive Disorder" for dementia and "Mild Neurocognitive Disorder" for mild cognitive impairment. This ACT on Alzheimer’s resource uses the more familiar terminology, as the new terms have yet to be universally adopted.



## Dementia Care Plan Checklist

With the patient and care partner, create a person-centered plan to meet identified needs, address barriers and set goals based on the patient's values.

### Conduct comprehensive assessment of patient (include care partner).

- Person-centered care includes understanding cultural context in which people are living ([www.actonalz.org/cultural-competency-awareness](http://www.actonalz.org/cultural-competency-awareness))
- Screening and diagnosis of diverse populations ([www.actonalz.org/screening-diverse-populations](http://www.actonalz.org/screening-diverse-populations))

### Educate the patient and care partner about diagnosis and disease process.

- Contact Alzheimer's Association 24/7 Helpline at 1-800-272-3900 or visit [www.alz.org](http://www.alz.org)
- Refer to Taking Action Workbook ([www.alz.org/i-have-alz/downloads/lwa\\_pwd\\_taking\\_action\\_workbook.pdf](http://www.alz.org/i-have-alz/downloads/lwa_pwd_taking_action_workbook.pdf))
- Culturally responsive resources ([www.actonalz.org/culturally-responsive-resources](http://www.actonalz.org/culturally-responsive-resources))

### Develop care plan based on patient's diagnosis and stage of disease, needs and goals.

#### Medication Therapy and Management

- Discuss prescribed and over-the-counter medications
- Refer to pharmacist for medication review and to simplify medication regimen
- Work with patient's health care team to create a medication management plan
- Educate patient and care partner on medication management aids (pill organizers, dispensers, alarms)

*Patients in middle and late stages will require medication oversight from care partner or health care professional.*

#### Maximize Abilities

- Work with patient's health care team to treat conditions that may worsen symptoms or lead to poor outcomes, including depression and co-existing medical conditions (e.g., diabetes, blood pressure, sleep dysregulation)
- Encourage patient to stop smoking and/or limit alcohol
- Refer to occupational therapy to maximize ability for self care
- Encourage lifestyle changes that may reduce disease symptoms or slow their progression (e.g., establish routines for person with disease and care partner)

#### Care Partner Education and Support (if patient has a care partner)

- Refer to support groups, respite care, caregiver education and training programs, and caregiver coaching services.
- Call the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 or visit [www.alz.org](http://www.alz.org)
- Contact the Eldercare Locator at [www.eldercare.gov](http://www.eldercare.gov) or 1-800-677-1116

#### Health, Wellness and Engagement

- Encourage regular physical activity and healthy eating
- Contact the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 for engagement programs
- Encourage socialization and participation in activities the patient enjoys

See *Living Well Workbook for recommendations* ([www.alz.org/mnnd/documents/15\\_ALZ\\_Living\\_Well\\_Workbook\\_Web.pdf](http://www.alz.org/mnnd/documents/15_ALZ_Living_Well_Workbook_Web.pdf)).





## Dementia Care Plan Checklist (cont.)

### Home and Personal Safety

- Refer to an occupational therapist and/or physical therapist to address fall risk, sensory/mobility aids and home modifications
- Obtain MedicAlert® + Alzheimer's Association Safe Return® (call 1-800-272-3900 or visit [www.alz.org/care/dementia-medic-alert-safe-return.asp](http://www.alz.org/care/dementia-medic-alert-safe-return.asp))
- Refer to occupational therapy for driving evaluation ([http://myaota.aota.org/driver\\_search/index.aspx](http://myaota.aota.org/driver_search/index.aspx))
- Educate patient and care partner about safe driving (see At the Crossroads at [www.thehartford.com/advance50/publications-on-aging](http://www.thehartford.com/advance50/publications-on-aging) or Dementia and Driving Resource Center at [www.alz.org/driving](http://www.alz.org/driving))

### Legal Planning

- Refer to an elder law attorney
- Encourage patient to assign durable power of attorney and health care directive

### Advance Care Planning

- Encourage patient and family to discuss and document preferences for care when patient is not able to make decisions (download state specific advance directive forms at [www.caringinfo.org](http://www.caringinfo.org))
- Call the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 or visit [www.alz.org](http://www.alz.org)

*In middle and late stages, discuss palliative care and hospice with patient and care partner.*

## Arrange services and supports.

- Visit the Eldercare Locator at [www.eldercare.gov](http://www.eldercare.gov) or call 1-800-677-1116 to get connected to aging services such as financial assistance, home delivered meals, transportation, adult day services and long-term care options in every community across the US
- Contact the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 or [www.alz.org](http://www.alz.org) for information, education and support
- Culturally responsive supports and resources: [www.actonalz.org/culturally-responsive-resources](http://www.actonalz.org/culturally-responsive-resources)

## Determine visit frequency and plan for communication.

- Schedule regular check-ins with the patient and care partner (consider monthly face-to-face visits until relationship is established)
- Educate patient and care partner to contact care coordinator for changes in condition, assistance with medication management and emergency room or hospital admission

## Re-evaluate and modify care plan as needed.



## Mild Cognitive Impairment and Stages of Alzheimer’s: Symptoms and Duration of Disease

**Alzheimer’s symptoms vary.** The information below provides a general idea of how abilities change during the course of the disease. Not everyone will experience the same symptoms nor progress at the same rate. Find additional information on the stages of Alzheimer’s at: [www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp)

<p><b>Mild Cognitive Impairment (MCI)</b></p> <p><a href="http://www.mayoclinic.com/health/mild-cognitive-impairment/DS00553">www.mayoclinic.com/health/mild-cognitive-impairment/DS00553</a></p>	<ul style="list-style-type: none"> <li>• Mild forgetfulness</li> <li>• Increasingly overwhelmed by making decisions, planning steps to accomplish a task or interpreting instructions</li> <li>• Mild difficulty finding way in unfamiliar environments</li> <li>• Mild impulsivity and/or difficulty with judgment</li> <li>• Family and friends notice some or all of these symptoms</li> <li>• IADLs only mildly compromised; ADLs are intact</li> </ul>
<p><b>Alzheimer’s Disease Early Stage</b></p> <p>2-4 years in duration</p>	<ul style="list-style-type: none"> <li>• Increased short-term memory loss</li> <li>• Difficulty keeping track of appointments</li> <li>• Trouble with time/sequence relationships</li> <li>• More mental energy needed to process information</li> <li>• Trouble multi-tasking</li> <li>• May write reminders, but lose them</li> <li>• Mild mood and/or personality changes</li> <li>• Increased preference for familiar things</li> <li>• IADLs more clearly impaired; ADLs slightly impaired</li> </ul>
<p><b>Alzheimer’s Disease Middle Stage</b></p> <p>2-10 years in duration</p>	<ul style="list-style-type: none"> <li>• Significant short-term memory loss; long-term memory begins to decline</li> <li>• Fluctuating disorientation</li> <li>• Diminished insight</li> <li>• Changes in appearance</li> <li>• Learning new things becomes very difficult</li> <li>• Restricted interest in activities</li> <li>• Declining recognition of acquaintances, relatives</li> <li>• Mood and behavioral changes</li> <li>• Alterations in sleep and appetite</li> <li>• Wandering</li> <li>• Loss of bladder control</li> <li>• IADLs and ADLs broadly impaired</li> </ul>
<p><b>Alzheimer’s Disease Late Stage</b></p> <p>1-3 years in duration</p>	<ul style="list-style-type: none"> <li>• Severe disorientation to time and place</li> <li>• No short-term memory</li> <li>• Long-term memory fragments</li> <li>• Loss of speech</li> <li>• Difficulty walking</li> <li>• Loss of bladder/bowel control</li> <li>• No longer recognizes family members</li> <li>• Inability to survive without total care</li> </ul>

**Resources**

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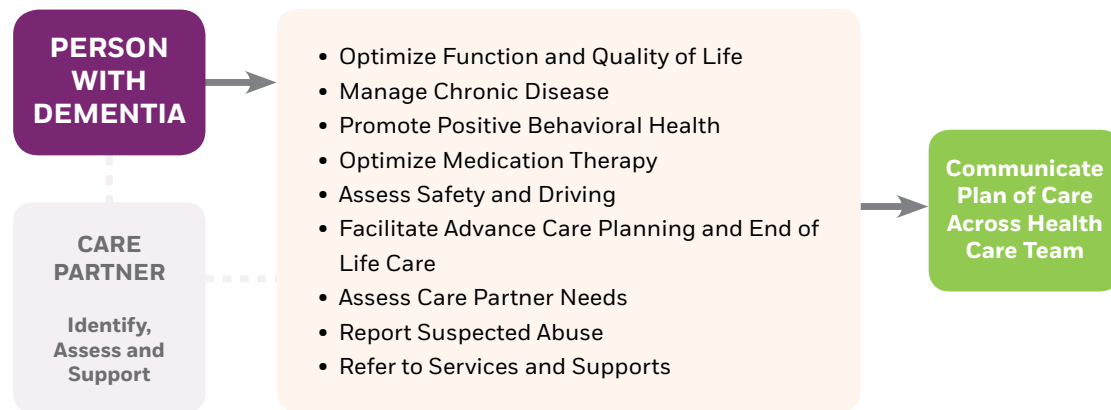
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## Managing Dementia Across the Continuum (Mid to Late Stage\*)



Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities: [www.mnmed.org/Portals/mma/MMA Events/CME/Schoephoerster.pdf](http://www.mnmed.org/Portals/mma/MMA%20Events/CME/Schoephoerster.pdf)

### Optimize Function and Quality of Life

- Assess cognitive and functional status
- Identify preserved capabilities and preferred activities; encourage socializing and participating in activities
- Refer to an occupational therapist and/or physical therapist to maximize independence
- Encourage lifestyle changes that may reduce disease symptoms or slow their progression (e.g., establish routines for person with disease and care partner)
- Work with health care team to appropriately treat conditions that can worsen symptoms or lead to poor outcomes, including depression and existing medical issues

### Manage Chronic Disease

- As dementia progresses, modify treatment goals and thresholds
- Create an action plan for chronic conditions (e.g., CHF) and geriatric syndromes to prevent potentially harmful hospitalization
- Schedule regular health care provider visits, encourage care partner presence

\* The latest DSM-5 manual uses the term “Major Neurocognitive Disorder” for dementia and “Mild Neurocognitive Disorder” for mild cognitive impairment. This ACT on Alzheimer’s resource uses the more familiar terminology, as the new terms have yet to be universally adopted.



## Promote Positive Behavioral Health

- Key steps to promoting positive behavioral health include:
  1. Rule out delirium for any acute changes in behavioral expressions and other symptoms
  2. Define and categorize the target behavioral expression and other symptom (Examples: hallucinations, delusions, physical aggression, spontaneous disinhibition, mood-related)
    - Identify and address unmet need(s) (**see Figure 1: Screening, Identifying, and Managing Behavioral Symptoms in Patients With Dementia on page 4**)
    - Only treat conditions that are bothersome or negatively affecting the quality of life of the person with the disease
  3. Initiate non-pharmacologic therapies aimed at reducing the target symptom
    - **See Table 1: Potential Nonpharmacologic Strategies on page 5**
    - **See Table 2: General Nonpharmacologic Strategies for Managing Behavioral Symptoms on page 6**
    - Give the patient “tasks” that match his/her level of competency
    - Train caregivers to validate, redirect, and re-approach
    - Reinforce that routine is essential
    - Control the level of stimulation in the person’s environment
    - Be proactive: Write orders for non-pharmacologic interventions
    - Ask caregivers to re-administer a behavior tool (e.g., Cohen Mansfield) to assess the efficacy of the therapy
  4. Consider pharmacologic interventions only when non-pharmacologic interventions consistently fail and the person is in danger of doing harm to self or others, or when intolerable psychiatric suffering is evident
    - Note there is no FDA-approved medication for Behavioral and Psychological Symptoms of Dementia (BPSD), nor strong scientific evidence to support any particular class of medications. If you use any medications, document informed consent in the medical record and counsel caregivers to monitor for degraded functional or cognitive status, sedation, falls or delirium.
    - Regularly attempt to wean or discontinue the medication as soon as possible.
    - Regularly monitor target behaviors to evaluate efficacy of medication, if started.

## Optimize Medication Therapy

- Identify all prescriptions and over-the-counter medications being used, including vitamins and herbal remedies
- Avoid or minimize anticholinergics, hypnotics (benzodiazepines, zolpidem), H2-receptor antagonists, and antipsychotics**
- Evaluate the medications for over and underuse and inappropriate prescribing
- Periodically reassess the value of any medications, including those being used for cognitive symptoms; consider a slow taper if continued benefit is unclear
- Recommend a care partner or health care professional oversees/dispenses medications as needed

## Assess Safety and Driving

### Continue to discuss home safety and fall risk

- Refer to an occupational therapist and/or physical therapist, if indicated, to address fall risk, sensory/mobility aids and home modifications

### Continue to discuss safe driving

- Refer to driving rehabilitation specialist for clinical and/or in-vehicle evaluation
- Report an at-risk driver



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

- Continue to discuss care goals, values and preferences with person with the disease and family
- Discuss the role of palliative care and hospice in addressing pain and suffering
- Encourage completion of healthcare directive and financial surrogacy documents
- Complete POLST, when appropriate (and routinely re-evaluate/modify plan of care as appropriate)

### Assess Care Partner Needs

#### Identify care partner/caregiver and assess needs

#### Encourage self care of care partner

- Offer suggestions to the care partner for maintaining health and well-being
- Encourage caregiver support services (e.g., respite) in the care plan for the person with dementia
- Provide education on behavioral expressions and stages of dementia

### Report Suspected Abuse

- Report suspected abuse, neglect (including self neglect), or financial exploitation
  - Under many state statutes, licensed health care professionals and professionals engaged in the care of a vulnerable adult are mandated to report suspected maltreatment of a vulnerable adult

### Refer to Services and Supports

- Visit the Eldercare Locator at [www.eldercare.gov](http://www.eldercare.gov) or call 1-800-677-1116 to get connected to aging services such as financial assistance, home delivered meals, transportation, adult day services and long-term care options in every community across the US.
- Contact the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 or [www.alz.org](http://www.alz.org) for information, education and support.
- Culturally responsive supports and resources: [www.actonalz.org/culturally-responsive-resources](http://www.actonalz.org/culturally-responsive-resources).





## Mid To Late Stage Resources

### Managing Dementia Across the Continuum

#### Professional Resource

- Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities: [www.mnmed.org/Portals/mma/MMA%20Events/CME/Schoephoerster.pdf](http://www.mnmed.org/Portals/mma/MMA%20Events/CME/Schoephoerster.pdf)

### Optimize Function and Quality of Life

#### Professional Resources

- Instrumental Activities of Daily Living (IADL): [http://consultgerirn.org/uploads/File/trythis/try\\_this\\_23.pdf](http://consultgerirn.org/uploads/File/trythis/try_this_23.pdf)
- Activities of Daily Living (ADL): [http://consultgerirn.org/uploads/File/trythis/try\\_this\\_2.pdf](http://consultgerirn.org/uploads/File/trythis/try_this_2.pdf)
- FAST Scale: <http://geriatrics.uthscsa.edu/tools/FAST.pdf>
- MN Live Well at Home: [www.mnlivewellathome.org](http://www.mnlivewellathome.org)
- Patient Health Questionnaire (PHQ-9): [www.sfaetc.ucsf.edu/docs/PHQ20-20Questions.pdf](http://www.sfaetc.ucsf.edu/docs/PHQ20-20Questions.pdf)

#### Family Resource

- Stages of Alzheimer's: [www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp)

### Promote Positive Behavioral Health

#### Professional Resources

- ABC of Behavior Management: [www.dementiamanagementstrategy.com/Pages/ABC\\_of\\_behaviour\\_management.aspx](http://www.dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management.aspx)
- ACT on Alzheimer's Dementia Curriculum and Dementia Trainings for Direct Care Staff: [www.actonalz.org/dementia-education](http://www.actonalz.org/dementia-education)
- Confusion Assessment Method (CAM) for identifying delirium: [www.healthcare.uiowa.edu/igec/tools/cognitive/CAM.pdf](http://www.healthcare.uiowa.edu/igec/tools/cognitive/CAM.pdf) (Adapted from: Inouye SK, et al. Ann Intern Med. 1990; 113: 941-948. Confusion Assessment Method. Copyright 2003, Hospital Elder Life Program, LLC. Not to be reproduced without permission.)
- Delirium Information: [www.uptodate.com/contents/delirium-beyond-the-basics](http://www.uptodate.com/contents/delirium-beyond-the-basics)
- Cohen Mansfield Agitation Inventory: [www.dementia-assessment.com.au/symptoms/CMAI\\_Scale.pdf](http://www.dementia-assessment.com.au/symptoms/CMAI_Scale.pdf)
- Pain Assessments: [www.geriatricpain.org/Content/Assessment/Impaired/Pages/default.aspx](http://www.geriatricpain.org/Content/Assessment/Impaired/Pages/default.aspx)
- Coping with Behavior Change in Dementia: A Family Caregiver's Guide: <http://whisppub.com/coping-with-behavior-change-in-dementia/>
- Validation Therapy: [www.youtube.com/watch?v=CrZXz10FcVM](http://www.youtube.com/watch?v=CrZXz10FcVM)

#### Family Resources

- Teaching Families About Delirium: [www.viha.ca/NR/rdonlyres/28BFF246-F1F9-4BB8-8145-83FB04C1F545/0/pamphlet\\_family\\_09.pdf](http://www.viha.ca/NR/rdonlyres/28BFF246-F1F9-4BB8-8145-83FB04C1F545/0/pamphlet_family_09.pdf)
- Coping with Behavior Change in Dementia: A Family Caregiver's Guide: <http://whisppub.com/coping-with-behavior-change-in-dementia/>



## Manage Chronic Disease

### Professional Resource

- Guiding Principles for the Care of Older Adults with Multimorbidity:  
[www.americangeriatrics.org/health\\_care\\_professionals/clinical\\_practice/multimorbidity](http://www.americangeriatrics.org/health_care_professionals/clinical_practice/multimorbidity)

### Family Resource

- Geriatric Syndromes and Resources:  
[www.healthinaging.org/resources/resource:guide-to-geriatric-syndromes-part-i/](http://www.healthinaging.org/resources/resource:guide-to-geriatric-syndromes-part-i/)

## Optimize Medication Therapy

### Professional Resources

- AGS Beers Criteria (2012):  
[www.americangeriatrics.org/files/documents/beers/2012BeersCriteria\\_JAGS.pdf](http://www.americangeriatrics.org/files/documents/beers/2012BeersCriteria_JAGS.pdf)
- Drugs with Possible Anticholinergic Effects:  
[www.indydiscoverynetwork.org/resources/antichol\\_burden\\_scale.pdf](http://www.indydiscoverynetwork.org/resources/antichol_burden_scale.pdf)
- START (Screening Tool to Alert Doctors to the Right Treatment):  
<http://ageing.oxfordjournals.org/content/36/6/632.full.pdf+html>
- STOPP (Screening Tool of Older Persons' Potentially inappropriate Prescriptions):  
<http://ageing.oxfordjournals.org/content/37/6/673.full.pdf+html?sid=cabc290d-e3ec-4c69-8dec-a27016271785>

### Family Resource

- Improve Dementia Care by Reducing Unnecessary Antipsychotic Drugs:  
[www.actonalz.org/pdf/ReduceDrugs.pdf](http://www.actonalz.org/pdf/ReduceDrugs.pdf)

## Assess Safety and Driving

### Professional Resources

- American Geriatrics Society Clinic Practice Guideline – Prevention of Falls in Older Persons:  
[www.americangeriatrics.org/health\\_care\\_professionals/clinical\\_practice/clinical\\_guidelines\\_recommendations/2010/](http://www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/2010/)
- Finding a Driving Assessment Program: [http://myaota.aota.org/driver\\_search/index.aspx](http://myaota.aota.org/driver_search/index.aspx)
- Practice Parameter Update – Evaluation and Management of Driving Risk in Dementia:  
[www.neurology.org/content/early/2010/04/12/WNL.0b013e3181da3b0f.full.pdf](http://www.neurology.org/content/early/2010/04/12/WNL.0b013e3181da3b0f.full.pdf)
- AMA Physician's Guide to Assessing and Counseling Older Drivers:  
[www.nhtsa.gov/people/injury/olddrive/olderdriversbook/pages/contents.html](http://www.nhtsa.gov/people/injury/olddrive/olderdriversbook/pages/contents.html)
- National Council on Aging Falls Prevention Resource Center: [www.ncoa.org/center-for-healthy-aging/falls-resource-center/](http://www.ncoa.org/center-for-healthy-aging/falls-resource-center/)

### Family Resources

- Minnesota Falls Prevention: [www.mnfallsprevention.org/consumer/index.html](http://www.mnfallsprevention.org/consumer/index.html)
- Obtain MedicAlert® + Alzheimer's Association Safe Return®  
[www.alz.org/care/dementia-medic-alert-safe-return.asp](http://www.alz.org/care/dementia-medic-alert-safe-return.asp)
- At the Crossroads: [www.thehartford.com/sites/thehartford/files/at-the-crossroads-2012.pdf](http://www.thehartford.com/sites/thehartford/files/at-the-crossroads-2012.pdf)
- Dementia and Driving Resource Center: [www.alz.org/care/alzheimers-dementia-and-driving.asp](http://www.alz.org/care/alzheimers-dementia-and-driving.asp)
- STEADI Initiative: Older Adult Fall Prevention: [www.cdc.gov/steady/patient.html](http://www.cdc.gov/steady/patient.html)



## Advance Care Planning and End of Life Care

### Professional Resources

- Hospice Criteria Card (2013): [http://geriatrics.uthscsa.edu/gerifellowship/documents/updated\\_08\\_2013/Hospice%20Card%20%20JSR%20SSR%202013.07.10.pdf](http://geriatrics.uthscsa.edu/gerifellowship/documents/updated_08_2013/Hospice%20Card%20%20JSR%20SSR%202013.07.10.pdf)
- POLST (Provider Orders for Life Sustaining Treatment): [www.polst.org](http://www.polst.org)

### Resources for Professionals and Family

- National Hospice and Palliative Care Organization - download state specific advance directive forms at [www.caringinfo.org](http://www.caringinfo.org)
- Advance Care Planning Resources: [www.nhdd.org/public-resources/#where-can-i-get-an-advance-directive](http://www.nhdd.org/public-resources/#where-can-i-get-an-advance-directive)
- End of Life Decisions: [www.alz.org/national/documents/brochure\\_endoflifedecisions.pdf](http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf)

## Assess Care Partner Needs

### Professional Resources

- Caregiver Self Assessment: [www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment\\_english.pdf](http://www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_english.pdf)
- Zarit Burden Interview: [www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf](http://www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf)

### Family Resources

- Alzheimer's Association: 1-800-272-3900 or [www.alz.org/care/](http://www.alz.org/care/)
- Eldercare Locator: [www.eldercare.gov](http://www.eldercare.gov) or 1-800-677-1116
- Culturally responsive supports and resources: [www.actonalz.org/culturally-responsive-resources](http://www.actonalz.org/culturally-responsive-resources)

## Report Suspected Abuse

### Professional Resource

- U.S. Preventative Task Force recommendations for screening for elder abuse: [www.uspreventiveservicestaskforce.org/3rduspstf/famviolence/famviolrs.htm](http://www.uspreventiveservicestaskforce.org/3rduspstf/famviolence/famviolrs.htm)

### Resources for Professionals and Family

- National Adult Protective Services Association: [www.napsa-now.org](http://www.napsa-now.org)
- National Committee for the Prevention of Elder Abuse: [www.preventelderabuse.org/elderabuse/](http://www.preventelderabuse.org/elderabuse/)





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