



Assessment of Cognitive Complaints Toolkit

For Alzheimer's Disease

Instruction Manual

PRODUCED BY THE
CALIFORNIA
ALZHEIMER'S DISEASE
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DISEASE PROGRAM

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The project was supported by a grant from the California Department of Public Health, Alzheimer's Disease Program. The Assessment of Cognitive Complaints Toolkit is released in the public domain.

This toolkit was developed for use by healthcare providers and should not be used by non-professionals to diagnose or determine significance of cognitive complaints without the involvement of an experienced professional. Interpretation of the answers to these questions requires expert knowledge and must be done in the context of knowing the general health history. If, in reviewing this toolkit, you identify concerning problems, you should discuss it with your physician. Similarly, if you have concerns about your memory or cognition, you should discuss them with your physician even if reviewing this toolkit has led you to believe they are not worrisome.

The California Alzheimer's Disease Centers (CADCs)

The California Alzheimer's Disease Centers (CADCs) are a statewide network of ten dementia care Centers of Excellence at university medical schools, established by legislation in 1984. The CADCs effectively and efficiently improve dementia health care delivery, provide specialized training and education to health care professionals, and advance the diagnosis and treatment of Alzheimer's disease and dementia. The CADCs also provide an important ongoing economic stimulus, attracting fiscal resources to meet the growing needs of Californians affected by dementia. These include industry and federal support for clinical trials and research; foundation and federal support for training programs, fellowships, and research grants; and private philanthropy. Each CADC plays a critical role in building a vital workforce for the growing needs of the state through training physicians, nurses, physician's assistants, health care professionals and research investigators. The CADCs serve the diverse population of California by providing culturally and linguistically appropriate care to Latinos, African Americans, Asians and Pacific Islanders, and LGBTQ individuals. Community education and outreach are also provided by the CADCs in the form of lectures, workshops, forums, and support groups that are open to the public.



CADC Locations and Contact Information

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UC Davis – Sacramento
UC Davis Medical Center
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PLEASE READ THIS SECTION BEFORE USING THE TOOLKIT

NOTE THE DATE: The science and care of neurodegeneration are evolving rapidly, including the development of new diagnostic markers and new treatments. The CADCs will regularly update the toolkit to have it reflect the most recent developments. If the version you are looking at is more than a year old, or if you think there are major developments that do not seem to be addressed in the version you are working with, look to see if there is a more recent version, which should be available on the California Department of Public Health Alzheimer's Disease Program website.

Last Toolkit Revision Date: August 1, 2025

What is in this toolkit?

The toolkit contains three separate components:

1. The Instruction Manual (this document/section)
2. The Reference and Interpretation Manual
3. The Patient Assessment Forms

This **instruction manual** contains essential background information, including:

- The goals and intended use of this toolkit and how to use it.
- An overview of the causes of dementia and how to recognize them.
- Definitions and classifications of cognitive impairment severity
- Clinical guidelines and rationales for diagnosing cognitive impairment
- Strengths and limitations of this toolkit.
- Resources for patients and families.

To have the best understanding of how and why to use this toolkit, it is not necessary, though it is recommended, to read the whole instruction manual. In order to use the toolkit at all, it is **necessary to read at least the first section of the instruction manual from here until the section on the toolkit background (i.e., through page 10, less than six pages).**

The **reference and interpretation manual** contains outlines of the procedures for assessment, interpretations for all of the elements that are part of the assessment, and a decision support guide section with a decision tree to help finalize diagnosis and planning. Clinicians will need to familiarize themselves with these interpretations and have access to them during an assessment to interpret their findings. The need to consult the reference and interpretation manual will vary depending on the patient's symptoms and the clinician's experience with the toolkit. This component also contains scripts for discussing your diagnosis with the patient and information about billing for the assessment.

Lastly, the **patient assessment forms** component contains forms that can be printed or copied for individual patient assessments to guide the evaluation and document the information collected and the assessment results.

Note that the **Table of Contents, above, is hyperlinked**, so that if you click on a topic it will take you to that part of the document. This allows quick navigation and perusal of topics.

Detection versus diagnosis

Practitioners can have different goals regarding cognitive complaints.

Detection involves the initial identification of patients who may have significant cognitive or behavioral changes. This step can be prompted by observations from clinic staff, a question or concern from a patient or family member. Detection can be accomplished in a few minutes by asking a few targeted questions and, if necessary, using brief cognitive tests. Detection is a preliminary step that allows the clinician to flag a significant concern. However, detection alone does not constitute a diagnosis.

Diagnosis involves taking a more thorough history to identify the severity of the impairment, its impact on daily function, and its cause. This full assessment takes more time, but it is necessary to establish a diagnosis, identify potentially reversible factors, and plan treatment. This can be done within the primary care setting for many patients, or through a referral to an expert.

Goals of the toolkit

This toolkit is designed to help clinicians **detect and diagnose cognitive and behavioral changes** in middle aged and older patients particularly in situations when specialty access is limited. While specialists are often involved in diagnosis, their numbers are insufficient to meet the growing need.

This toolkit empowers primary care clinicians to take the lead, offering clear guidance on history-taking, targeted physical exams, and brief cognitive testing. Its primary focus is diagnosing mild cognitive changes or dementia due to typical Alzheimer's disease (AD), while also helping to identify signs that suggest alternative causes.

In most settings where specialty expertise (neurology, neuropsychology, psychiatry, or geriatrics) is available, referral of patients with atypical symptoms is appropriate. Referral of patients with mild cognitive changes or dementia likely due to AD should be considered as well, and depends on the goals of the referral.

Toolkit components

The toolkit is divided into sections to support different tasks. These include:

A. Detection of Significant Cognitive or Behavioral Complaints

A workflow and recommended questions for **detecting** significant cognitive complaints during a routine visit, such as an annual Medicare Wellness Evaluation (see Guidelines for Assessment section below for additional detail). One way to implement these questions is as part of the routine health risk assessment (HRA) recommended by the CDC for primary care. Based on the outcome of this brief assessment, the clinician can identify patients who need a full evaluation of their complaint, or the clinician can be reassured that no additional assessment is necessary.

B. Full Cognitive Assessment

For practitioners wishing to pursue a thorough evaluation without making unnecessary referrals, the toolkit provides guidance on interviewing a patient and an informant, doing a neurological examination, doing brief cognitive testing **that is appropriate for the patient's level of education**, ordering and interpreting basic lab tests and imaging, ordering biomarkers for Alzheimer's disease, and on using these data to come up with a diagnosis or to identify patients needing referral.

C. Diagnostic Disclosure and Counseling

The **Reference and Interpretation Manual** includes specific suggestions for wording on how to discuss the following situations:

1. The diagnosis of dementia and mild cognitive impairment
2. Driving
3. Medications for treatment
4. Managing behavioral symptoms
5. Research opportunities, focusing on clinical trials

D. Guidance on Making a Referral

This **instruction manual** provides a few details useful to provide to the center receiving the referral to help plan appropriate clinical assessments and staffing.

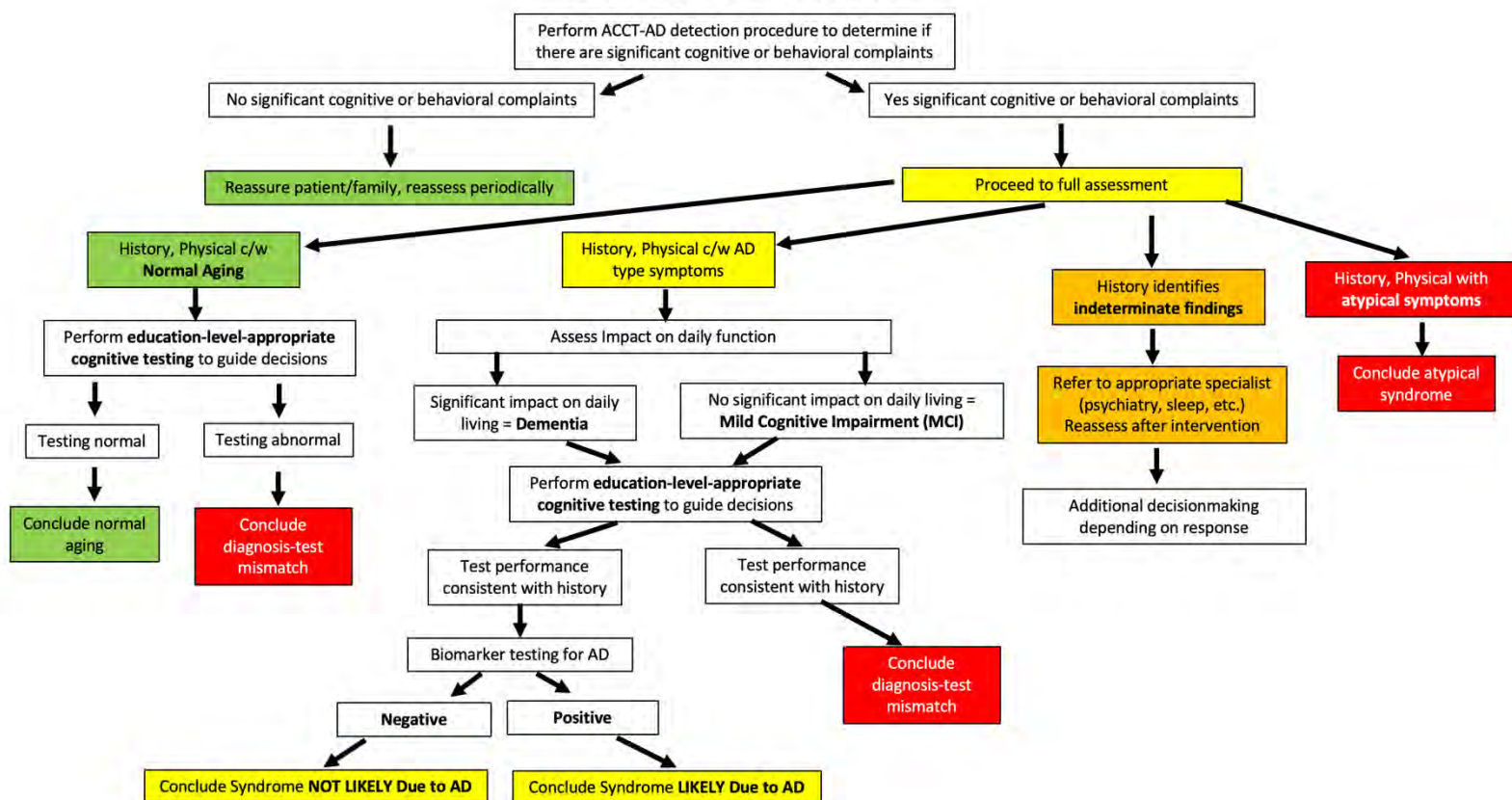
Approach to Assessment

For both the detection and the full assessment of cognitive concerns, **the toolkit primarily relies on the clinical history and assumes the availability of a knowledgeable informant** (spouse, family member, friend...) who can provide collateral history. The assessments involve collecting information from both the patient and the informant to arrive at an accurate diagnosis. This is because there is no accepted, objective testing that can capture all of the information needed to arrive at a specific diagnosis regarding the cause of cognitive impairment, and history can be unreliable in patients with cognitive impairment.

Use of the toolkit can result in the following conclusions (see the workflow diagram below and the **Outcome scenarios and Decision Tree** in the decision support section in the **Reference and Interpretation Manual** for more details):

1. The complaints are normal for age and do not need further assessment.
2. The complaints are more than would be expected for age. In this case, the toolkit helps to establish the severity of the problem, which is separated into two levels:
 - a. Changes that do not affect (or have a minimal effect on) daily function and thus are not severe enough to be called dementia. Such symptoms are typically called mild cognitive impairment (MCI).
 - b. Changes that impair at least some daily functions, and thus are severe enough to be called dementia
 - c. **It is strongly advised to read the section below in this instruction manual on mild cognitive impairment versus dementia.**
3. Regardless of severity, the complaints and findings are organized into three categories:
 - a. Complaints and findings that are consistent with AD as the cause
 - b. Complaints and findings potentially indicate another neurodegenerative cause, and suggest that referral to a specialist is appropriate
 - c. Complaints and findings that suggest another neurological, or non-neurological cause may account for the symptoms, and thus addressing these issues is necessary before a final determination about neurodegeneration can be made. Examples would include symptoms that developed suddenly (e.g., a stroke), or symptoms of sleep apnea, or significant mood symptoms,

ACCT-AD Assessment Workflow



The backbone of this toolkit is the approach to the clinical history, which provides the bulk of the information needed to make a diagnosis. **The toolkit provides specific wording for open-ended questions.** These questions are **provided in the Patient Assessment Forms section**, and they are worded in the way that the experts who created this toolkit would inquire about this symptom. The toolkit also provides wording for **additional prompts to use if the patient or informant needs some guidance on how to answer the question (e.g., they said, “What do you mean?” or they give an answer that is not relevant).** The prompts do not need to be delivered if the patient and informant have given a clear and relevant answer to the open-ended question. To help classify cognitive and behavioral complaints, we identified common responses to each question and provided **color-coded interpretations in the Reference and Interpretation Manual.**

Each potential outcome is coded according to whether that finding is **consistent with normal aging (green, not worrisome)**, **consistent with AD (yellow)**, **not consistent with normal aging or AD, and therefore a potential indicator of another cause of dementia (red)**, or **indeterminate or potentially due to a non-neurological cause (orange)**. The same color coding is used to interpret outcomes from all elements of the assessment, including the physical exam, cognitive tests, and lab testing and imaging. When clinicians are new to the toolkit, they may find themselves consulting the reference and interpretation manual fairly frequently, but as they become familiar with the common outcomes, they should find themselves doing so less often.

For example, in the excerpt below from the interpretation table for the assessment of language symptoms, the question and prompts are highlighted in gray, and the potential responses are colored based on their potential significance.

LANGUAGE		Prompts:
Are you having difficulty expressing yourself or difficulty understanding words or conversation?		Can't find the word or name you want to use? Difficulty understanding what people are saying to you? Difficulty pronouncing words that were easy for you to pronounce in the past?
NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS NO REFERRAL	REFERRAL INDICATED
- Occasionally can't find a word or name, but it comes back later. Does not disrupt a conversation or ability/desire to participate in conversation. - No comprehension problems.	- Consistent TROUBLE FINDING WORDS. Sometimes says wrong words, e.g. lib for fib, or clark for clock. Might have trouble finishing sentences. LESS PARTICIPATION in group conversations. - Reading activity declining. Note: Typical of AD if these complaints are not the presenting symptom but occur in the context of progressive memory concerns and/or other cognitive difficulties.	WORD FINDING IS THE PRIMARY and first presenting symptom, which impacts ability to communicate. - May be described as a "memory problem" but is actually memory for words. FREQUENT WORD FINDING PAUSES, word searching, increased effort to get words out, relying on words like "thing," "stuff," and less ability to use detailed language to tell a story. - May cause embarrassment and/or dropping out of activities.
		REFERRAL INDICATED - The primary and first presenting symptom is DIFFICULTY UNDERSTANDING SINGLE WORDS OR PHRASES; can't remember what some words mean. Interpretation - Concerning for FTD, semantic variant and other temporal lobe disorders.

You **should know the answers to ALL of the history questions** in the assessment in order to make your diagnosis. If you make a diagnosis of normal aging or mild cognitive impairment or dementia due to AD, none of the outcomes should be red. Any red answers or red findings are not typical for normal aging or AD, and referral to a specialist is recommended. If you identify red responses, you can stop at that point before making a diagnosis and inform the patient that you are making a referral to a specialist. It can be helpful to proceed to complete more of the assessment, including the neurological exam, to better characterize your findings for the referring provider. Labs and imaging can be deferred for specialist ordering and interpretation. Refer to the section on making a referral for additional guidance.

The toolkit also includes guidance on limited cognitive testing. It is important that **cognitive tests used are appropriate for the patient's level of education**. Using a test that is not appropriate will likely produce scores that are inconsistent with the other clinical and likely do not reflect the patient's actual cognitive status. **If an appropriate cognitive test is not available, it is best to rely primarily on the history for your assessment, rather than try to interpret an inappropriate test.** Expert referral, for example to a neuropsychologist, is warranted in this setting. **This toolkit provides guidance and recommendations on cognitive testing for**

individuals with low levels of formal education for some languages (see Table of Contents).

The questions on the full evaluation assume you know the patient's medical history, basic family history, social history, and medication regimen. If this is a new evaluation, consider that you will have to add time to collect these data. **The full assessment can be completed over several visits to accommodate patient and provider schedules. Also, the questions need not all be asked by a primary provider, but can potentially be collected by another member of the practice. It is important to recognize, however, that not all questions are perfectly formulated for every patient, so the person evaluating the responses must have enough training to know if the patient understood the question and provided a relevant answer.**

Using this approach, the toolkit recommends the following steps for evaluation:

Step One: Complete ACCT-AD procedures for detection of cognitive or behavioral concerns

- Practitioners should use this workflow at a routine visit to elicit concerns in patients at risk for neurodegenerative disease (see Assessment Recommendations below) using the **forms provided in the Patient Assessment Forms section.**
- The process mainly involves a brief set of questions for the patient and informant and limited cognitive testing for use when a reliable informant is unavailable. An informant is critical, because many patients have poor insight into their problems. The informant may need to be interviewed separately if the patient is angered by discussions about their possible impairments. **Optional pre-visit questionnaires to assist with assessment are provided in the Patient Assessment Forms section.**
- The details of the procedure are provided in the **Reference and Interpretation Manual**, in the section entitled STEP ONE: DETECTING COGNITIVE CONCERNS.
- **The Reference and Interpretation Manual** includes tables to guide the interpretation of the outcomes of all questions and any testing.
- If concerns arise, the practitioner should proceed to the Full Cognitive Assessment or refer the patient to a specialist.

Step Two: Complete full cognitive assessment

The full cognitive assessment can be completed over a series of appointments if necessary.

- Practitioners should use this workflow to perform a full assessment of concerns that arose at a routine visit from the detection questions or for another reason. Full assessment **forms are provided in the Patient Assessment Forms section.**
- The process involves a more extensive clinical history from the patient and informant, physical examination, limited cognitive testing, and limited lab testing and imaging. **Optional pre-visit questionnaires to assist with assessment are provided in the Patient Assessment Forms section.**
- The details of the procedure are provided in the **Reference and Interpretation Manual**, in the section entitled STEP TWO: FULL COGNITIVE ASSESSMENT.
- **The Reference and Interpretation Manual** includes tables to guide interpretation of the outcomes of all questions and any testing.
- Based on this assessment, the practitioner can render an accurate diagnosis, or they may identify findings that suggest referral to a specialist is necessary.

Step Three: Interpretation

- The toolkit **decision support guide and decision tree** assist with integration of the findings to arrive at a plan for disclosure and management.

Step Four: Diagnostic disclosure and care planning

- The toolkit provides **scripts for disclosure**.
- The toolkit provides **scripts for discussing driving safety**, which should be utilized for anyone diagnosed with dementia.

Toolkit limitations

There are situations where the assumptions underlying this toolkit will not be met. In all of these situations, the toolkit should be used with caution, and in most of these situations, we recommend referral to a local specialist such as a neurologist, psychiatrist, or geriatrician. Below is a brief listing of these situations. If referral is not possible, we provide potential options in the Toolkit limitation details section of this instruction manual, along with more detailed reasoning behind these recommendations.

- No Informant Available, or Informant Has Very Limited Knowledge about Patient
- Patient and Family Speak No or Limited English (see below for some exceptions)
- Patient with low level of formal education or literacy (see Cognitive testing with low literacy and language constraints below in this instruction manual for some exceptions)
- Patients with major mental illness

END OF THE INTRODUCTORY SECTION

INFORMATION REGARDING TOOLKIT BACKGROUND AND DEMENTIA

Why was this toolkit developed?

Estimates published in 2024 indicate that there were 6.9 million Americans over the age of 65 suffering from Alzheimer's disease. Research suggests that almost half of people are not told of their diagnosis. Specialty physicians are most often relied on to provide work-up and diagnosis; however, the numbers of these specialists are not sufficient to meet the overwhelming need. In 2016, the ten California Alzheimer's Disease Centers (CADC) were charged by Senate Bill 833 with providing guidance to improve the detection and diagnosis of Alzheimer's disease by primary care providers. The CADCs comprise a group of expert clinicians and researchers, with diverse knowledge in the assessment and management of these conditions. To create this toolkit, the CADCs drew upon peer-reviewed evidence, best practices, Medicare and Medicaid policy, and reimbursement standards in the primary care setting.

This toolkit is designed to provide primary care providers with the tools necessary to recognize normal cognition, diagnose Alzheimer's disease, identify other cognitive problems and make decisions about referral. It differs from many other toolkits that have been published for this purpose because: 1) it provides concrete detailed guidance on how to implement all of the components of the diagnostic process, 2) it focuses not just on the broad diagnosis of dementia, but the specific diagnosis of Alzheimer's disease and differentiation of Alzheimer's from other causes of dementia, and 3) it provides step-by-step support for follow-up conversations about diagnosis and care.

Specific diagnosis of neurodegenerative disease in the primary care setting has value for several reasons:

- Early identification of treatable entities: Waiting times for expert assessment are long. Early, thorough assessment increases the likelihood of identifying potentially treatable conditions that may explain the symptoms
- Continuity of care: Completion of workups for cognitive complaints in a primary care setting will allow more patients to maintain continuity of care within the setting of their primary care practice, decreasing the need for communication across care providers. This enables better coordination of care and monitoring of symptoms and treatments by the primary care practice.
- Care planning: Early and accurate diagnosis allows patients and families to plan effectively for the future, in addition to helping the clinician anticipate necessary changes in the management of non-dementia health issues.
- Initiation for Treatment: The specific diagnosis determines currently available treatment. There are specifically approved therapies for AD, including disease modifying treatments that address the underlying protein disorder that cause disease. These treatments are most likely to be effective if initiated earlier in the disease process. They would not be appropriate for neurodegeneration caused by non-AD disorders. Future treatments will also be targeted at the specific proteins that cause each of the neurodegenerative syndromes.
- Diagnosis can guide polypharmacy decisions. Some forms of dementia, such as Dementia with Lewy Bodies, are associated with a very high likelihood of adverse effects from specific medications such as antipsychotics.
- Implications for prognosis. For example, patients with FTD have shorter survival than patients with AD, and some dementia patients are at much higher risk of developing motor problems, including parkinsonism in FTD and DLB and motor neuron disease in FTD. Patients with DLB often develop unique problems with sleep and neuropsychiatric

symptoms, and patients with DLB and particularly PSP are at very high risk of falls. There are many other similar prognostic implications.

- Participation in clinical trials or other research. Discovering treatments and cures for neurodegenerative disease requires patients to participate in research, both in observational research to understand these diseases better and in drug trials. A specific diagnosis can direct the provider to the types of research for which a patient would be eligible.

Toolkit limitation details

There are situations where the assumptions underlying this toolkit will not be met. In all of these situations, we recommend referral to a specialist such as a neurologist, psychiatrist, or geriatrician, or a California Alzheimer's Disease Center (CADC). If referral is not possible, we provide possible options to be considered.

➤ **No Informant Available, or Informant Has Limited Knowledge about Patient**

If, based on the preliminary cognitive questions or your initial brief assessment, you suspect the patient has significant cognitive problems, you must try hard to identify a knowledgeable informant to participate in the full evaluation. Without an informant, the history may be less reliable, because people with dementia will often deny significant symptoms. If an informant is not available, the assessment should begin with standardized cognitive testing (MoCA/MMSE/SLUMS/3MS) that is appropriate for the patient's level of education. If the score is low (see Decision Tree), the clinician should be aware that much of the history will be suspect, and they might seek additional resources to ensure the patient's well-being (e.g., home visit by social worker). Consideration of referral to an occupational therapist who can perform a functional assessment may also be helpful.

➤ **Patient and Family Speak No or Limited English**

Standardized cognitive testing is difficult in this situation. Although tests such as the Montreal Cognitive Assessment (MoCA) have been translated into many languages, it may be difficult to reliably use a translated version, even with a family member or a professional interpreter to assist. The toolkit provides guidance recommendations for testing of some individuals in languages other than English. If these recommendations do not address the patient's language, referral to a neuropsychologist can be very helpful in this situation. Michels and Graver provide an in-depth discussion of neuropsychological evaluation in primary care (<https://www.aafp.org/afp/2010/0901/p495.html>). If referral is not possible, the best course would be to rely on the detailed history rather than the standardized cognitive test.

➤ **Patient with low level of formal education or literacy**

Patients with low levels of formal education (did not complete elementary school) will sometimes have achieved reasonable literacy skills, for example through work experiences. Despite this, formal cognitive testing may misrepresent the patient's cognitive status. Ideally, these patients should be referred to a neuropsychologist for formal cognitive assessment. Michels and Graver provide an in-depth discussion of neuropsychological evaluation in primary care (<https://www.aafp.org/afp/2010/0901/p495.html>). The toolkit recommends specific basic cognitive tests for low levels of education in a few languages, and guides practitioners in their use. Beyond these tests, referral is advised, and if that is not possible, the best course would be to rely on the detailed history rather than standardized cognitive testing.

➤ **Patients with major mental illness**

Cognitive complaints may be common in people with major depression, bipolar affective disorder or chronic schizophrenia. Use of high doses of antipsychotic or anticholinergic medications may be associated with feelings of sluggishness or cognitive slowing. In patients who have had relatively mild psychiatric symptoms over the course of their life (e.g., mild depression not interfering with daily activities or bouts of serious depression with good recovery, and currently not severely depressed), the diagnostic assessment can proceed as outlined in this document. In patients who have had significant mental illness (e.g., preventing normal schooling or resulting in significant disability), referral to a specialist is advised. If referral is not possible, the evaluation should proceed with a focus on trying to identify changes from baseline (e.g., loss of previously stable level of function).

➤ **Patients with a history of major developmental differences**

Patients with a history of significant developmental differences can certainly develop cognitive changes due to neurodegenerative disease later in life. In fact Down's syndrome due to Trisomy 21 is associated with a very high risk of early age of onset AD. Evaluation of changes in this context can be complex, including the need for appropriate cognitive tests, and should best be done in an expert setting. If a referral is not possible, the history should focus strongly on identifying insidious functional decline. For patients with mild developmental differences, such as a history of attention deficit disorder with limited impact on educational attainment or daily functioning, a referral for full assessment may not be necessary, though it is reasonable. Formal cognitive assessment by a neuropsychologist can be very helpful in this setting. Michels and Graver provide an in-depth discussion of neuropsychological evaluation in primary care (<https://www.aafp.org/afp/2010/0901/p495.html>).

Definition of Key Terms

- Cognitive and behavioral concerns: your judgment that there is possible cognitive decline based on patient or informant- expressed concern or your own observation of change in cognition or behavior.
- Cognitive Impairment: Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. It can be documented using standardized cognitive tests, but such tests are only reliable if they have been validated for the patient's level of education, language, and cultural background.
- Neurocognitive disorder/syndrome/disease: a disorder of cognition or behavior that results from neurologic dysfunction due to injury or disease.
- Neurodegenerative disorder: a progressive disorder of the nervous system characterized clinically by insidious onset, gradual progression, and eventual functional impairment in most cases, and pathologically by neuronal morphological changes and neuronal loss, and usually by accumulation of microscopic collections of proteins within and/or outside of neurons.
- Dementia, also called Major Neurocognitive Disorder in DSM-V: a neurocognitive disorder that is severe enough to interfere with the ability to function at work and or other daily activities. A deterioration of intellectual faculties, such as memory, concentration and judgment, or socioemotional behavior resulting from an organic disease or disorder of the brain.
- Alzheimer's disease: Alzheimer's disease (AD) is usually considered the most common cause of dementia. The most common symptoms in AD are forgetting of recent events and conversations. A dementia where the earliest and most prominent symptoms are this type of forgetfulness is often called a "typical" dementia syndrome.
- Atypical dementia: Dementia where symptoms other than memory are the earliest and most important symptoms. Atypical dementias can begin with declines in language, visuospatial, or socioemotional function. Any dementia where motor symptoms are early or very prominent would also be considered atypical. In addition, any dementia where the symptoms begin before the age of 65 would be considered early age of onset, and therefore atypical. When a dementia syndrome is atypical, it suggests that the cause may not be Alzheimer's (see table below), although Alzheimer's can also present with atypical symptoms.
- Mild Cognitive Impairment (MCI), also called Minor Neurocognitive Disorder in DSM-V: Deficits in memory or other cognitive functions that do not significantly impact daily functioning.
- Cognitive testing: Cognitive testing checks for problems with cognition. Cognition is a combination of processes that involve storing, utilizing, and manipulating information. Tests of cognitive function typically assess domains such as memory, language, executive function, and visuospatial function. A problem with cognition is called cognitive impairment, which can range from mild to severe. Cognitive tests are only reliable if they have been validated for the patient's level of education, language, and cultural background.
- Functional Impairment: Functional impairment refers to the loss of ability to independently conduct activities of daily living (ADLs). Such activities are usually divided into instrumental ADLs (IADLs), such as working, bill paying and other finances, cooking, shopping, and other home activities, and basic ADLs, such as dressing and hygiene. Functional impairment is a required criterion for the diagnosis of major neuropsychiatric disorders/dementias.
- Biomarkers: Biologically based measures that capture some element of the biology of disease. These typically include brain imaging, measurements of proteins or other molecules in cerebrospinal fluid (CSF) or blood. Biomarkers can be used to detect the presence of a disease, to track the evolution of the disease or both. Some biomarkers are informative about a certain aspect of a disease (such as the severity of neurodegeneration), but are not very specific, whereas others are targeted as specific biology that helps to identify a cause for symptoms.

Causes of dementia and principles underlying diagnosis

This toolkit is primarily designed as a practical tool for assessment of cognitive complaints. It can also be used as a training tool for less experienced clinicians. It is not designed as a comprehensive review of the causes of dementia, but in this section, we provide a brief background on dementia. Interested readers can consult several other sources such as the Gerontological Society of America's KAER Toolkit (<https://www.geron.org/programs-services/alliances-and-multi-stakeholder-collaborations/cognitive-impairment-detection-and-earlier-diagnosis>) and the Health Resources and Services Administration's Training Curriculum: Alzheimer's disease and Related Dementias (<https://bhwh.hrsa.gov/grants/geriatrics/alzheimers-curriculum>).

- **Dementia** is a general term used to refer to a situation where a patient has suffered from a progressive decline in cognitive and/or behavioral function over at least six months, and they have reached the point where they are unable to independently perform activities that they were able to independently accomplish in the past. Determining when an individual has reached this point can be difficult and subjective, and the level of cognitive impairment sufficient to reach this threshold may be different in people who are working versus those who have retired, and may differ based on educational and occupational background. Despite this variation, impact on daily function, called “**functional impairment**,” remains the **standard requirement** for a diagnosis of dementia. The term dementia has been replaced in the DSM-V manual with the term **major neurocognitive impairment**, but the term dementia is still commonly used in neurology and by many psychiatrists. It is generally accepted that, if a patient's cognitive and behavioral changes have progressed to the point of dementia, there is a very high likelihood that the cause is a neurological disease.
- Because the term dementia only represents a description of the course of cognitive decline and its severity, it does not represent a specific or complete diagnosis. A diagnosis of dementia is generally used to imply a likely neurological etiology, and there is a list of potential causes (Galasko, 2013). The most common cause of dementia is **neurodegenerative disease**. Neurodegenerative disease is a general term for a class of disorders characterized by progressive accumulation of injurious proteins in central nervous system tissues that leads to neuronal dysfunction and death. Examples of neurodegenerative diseases include Alzheimer's disease (AD) and Parkinson's disease. While AD is the most common, there are a number of other neurodegenerative causes. In particular, in patients with dementia onset before age 65, the likelihood of a non-AD dementia is at least fifty percent (Garre-Olmo, 2010).
- Most of the proteins that cause neurodegenerative disease cannot be identified in living patients. Therefore, diagnosis must be inferred from the clinical presentation. Inferring diagnosis is possible because each type of protein has a tendency to affect certain portions of the nervous system early in the course of the disease and then spread to other parts of the nervous system over time. Thus, a careful history to document the symptoms (and, by extension, the neural systems) involved earliest and those involved later in the course is critical to arrive at a **specific diagnosis**.
- Unfortunately, many of the important features in neurodegenerative disease, such as hallucinations and changes in socioemotional behavior, cannot be captured in objective tests, such as neuropsychological testing. Conversely, deficits in neuropsychological tests can be similar across types of dementia. Thus, although cognitive testing can be an important component of the diagnostic assessment, it cannot substitute for a thorough clinical history. In addition, a physical neurological examination is critical because some neurodegenerative disorders include involvement of specific motor systems whereas others do not. The Dementia Table provides a brief summary of the major neurodegenerative syndromes that are commonly seen in clinical practice and the main clinical features that distinguish them.

Dementia Causes Table

Dementia Table

Brief summary of the major neurodegenerative syndromes that are commonly seen in clinical practice and the main clinical features that distinguish them.

	Alzheimer's Disease (AD)	Vascular Dementia (VaD)	Lewy Body Dementia (DLB)	Behavioral Fronto-temporal Dementia (bvFTD)	Corticobasal Degeneration (CBD)	Progressive Supranuclear Palsy (PSP)	FTD Language Variants
Onset	Gradual Usually after age 65	Maybe sudden or stepwise	Gradual	Gradual, usually before age 65	Gradual, between 60–80 (mean 64)	Gradual, between 50–80 (mean 63)	Gradual
Causative Protein	Beta amyloid and tau	N/A	Alpha-synuclein	Tau, TDP-43, FUS	Tau	Tau	TDP-43, tau
Typical First Symptom	Memory difficulties	Depends on ischemia	Varies: hallucinations or visuospatial	Behavior or personality changes	Unilateral motor changes	Falls	Language
Cognitive Domains, Symptoms	Memory, language, visuospatial	Depends on anatomy of ischemia	Memory, visuospatial, fluctuating symptoms	Executive: $\nleftrightarrow$ memory	Executive: $\nleftrightarrow$ memory	Spared memory, frontal subcortical deficits	Language, Loss of knowledge of word meaning
Psychiatric/Behavioral	Delusions are common	Depression, irritability	Hallucinations, usually visual	Disinhibition, apathy	Disinhibition, apathy	Depression, impulsivity	Compulsions
Motor Symptoms	Rare early, apraxia later	Correlates with location of ischemia	Parkinsonism	Some rare cases with motor neuron disease	Alien limb, unilateral dystonia	Falls, supranuclear gaze palsy, axial rigidity, dysarthria, dysphagia	Effortful speech
Progression	Gradual, over 8 to 10 years	Stepwise with further ischemia	Gradual, but faster than AD	Gradual, but faster than AD	Gradual, motor symptoms	Gradual, mean survival 6–9 years	Gradual
Laboratory Tests	Normal	Normal	Normal	Normal	Normal	Normal	Normal
Imaging	Possible global atrophy, small hippocampal volumes	Cortical or subcortical white matter lesions on MRI	Possible global atrophy	Atrophy in frontal and temporal lobes	Asymmetrical parietal and frontal atrophy	Midbrain atrophy	Left fronto-insular or anterior temporal atrophy

Dementia versus mild cognitive changes

Main points:

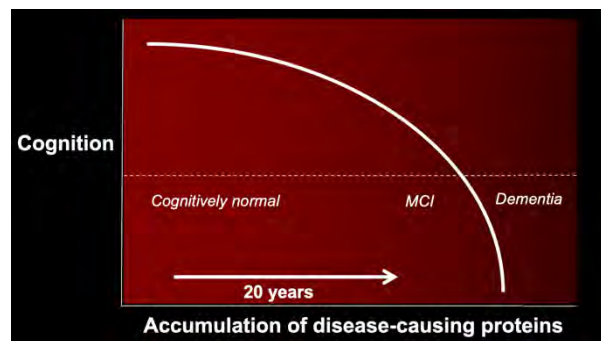
- MCI is cognitive impairment with little or no functional impairment.
- MCI is often caused by neurodegenerative disease, but not always.
- It is important to diagnose MCI because it can help providers follow patients more carefully and can help prepare patients and families for the future.
- MCI can be diagnosed using the same tools this toolkit provides as the assessment for dementia.

The term dementia is specifically used as a descriptive term to denote the presence of cognitive and behavioral changes that have become severe enough to impair the ability to complete daily functions independently. For example, if the patient previously was able to work, pay bills, file tax returns, and/or shop and cook for the home, and someone else (e.g., a spouse or a child) has had to take over those tasks because errors were occurring, then a diagnosis of dementia is warranted. In the DSM-V, this is currently referred to as a **Major Neurocognitive Disorder**. The importance of recognizing dementia is that normal aging does not cause severe enough cognitive change to result in a dementia syndrome. The assumption is that there is a disease that is causing the problem, even if this cannot be confirmed with additional diagnostic testing.

Because of the critical importance of diagnosing dementia, this ACCT-AD toolkit includes specific questions meant to elicit evidence of impairment in daily functions. It is important that the changes in daily function should only be considered evidence of dementia if the patient was continuing to try to accomplish these tasks but could not do it, forcing others to take over. If a patient, for instance, was worried about their cognitive abilities and voluntarily decided to stop working, this would not constitute evidence of dementia.

Many patients exhibit memory or other cognitive changes that are noticeable to them or to their friends and/or their family, and longitudinal follow-up reveals that many of these patients go on to develop dementia. The term "Mild Cognitive Impairment" (MCI) is commonly used to denote this early functional and cognitive decline. The symptoms of MCI can be similar to those in typical AD, with predominant memory problems for recent events, conversations, etc., but not causing functional impairment, or they may be more suggestive of other neurodegenerative disorders. Writing notes, using reminders and calendars, and having good organizational habits are often the reason that patients with MCI do not have functional impairment.

Studies using imaging and other biological markers have demonstrated that many patients with MCI already show the biology of AD or other neurodegenerative diseases. Because of these findings, models of the natural history of neurodegenerative disease usually indicate that the biology of these diseases starts when people have normal cognition, and the diseases evolve through a period of MCI before causing dementia, as depicted in the figure to the right.



On the other hand, many patients with MCI are stable for many years, and may never worsen, or sometimes even improve. In these cases, it is assumed that the complaints were due to normal aging or another condition that improved. The causes can range from cerebrovascular changes to mood and other psychiatric disorders, to various medications and other medical conditions that affect the brain. Usually, such causes are apparent in the medical history, but not always. Therefore, to assume that MCI always represents an early stage of neurodegenerative disease would not be accurate. With the development of biomarkers for neurodegenerative disease (most of which currently identify AD), it will become increasingly possible to link MCI and dementia to the neurodegenerative cause in each patient that is affected by neurodegeneration.

It is important to recognize MCI because such patients are at increased risk of progression to dementia over time, and therefore should be monitored more closely. Also, drugs aimed at addressing the underlying protein disorders that cause neurodegeneration are likely to be more effective at the MCI stage than at the dementia stage.

The evaluation for cognitive impairment in MCI should include the same assessment that is done for dementia, including history, physical examination, blood testing and imaging, and biomarker testing for neurodegeneration as appropriate. Because of the possibility that their symptoms might be due to a neurodegenerative disease that will worsen, such patients should be encouraged to consider appropriate steps such as signing advanced directives and ensuring that people close to them keep track of their functional abilities and monitor important activities such as finances.

Lastly, the identification of MCI is important because it provides patients and families with the most accurate medical assessment of their complaint. To tell a patient with significant cognitive changes that they have dementia due to a neurodegenerative disease when the evidence does not support it would mean giving a devastating diagnosis prematurely and/or unnecessarily. Conversely, to tell such a person that they are normal would not be accurate and would not be satisfying to many patients and families who know that something is wrong. Diagnosing MCI and explaining that there are uncertainties about prognosis provides the patient with the most accurate knowledge we can currently offer.

The syndrome called MCI has been associated with a number of other labels, some of the most common being Cognitive Impairment No Dementia, and **Minor Neurocognitive Disorder** (the term used in DSM-V). Many approaches further characterize MCI in terms of the nature of the complaints, for instance amnesic MCI for those with primarily memory complaints, and non-amnesic MCI for those with other types of complaints such as executive, visuospatial, etc. There is substantial debate about the proper use of these terms, and many experts limit the term MCI for those who have objective evidence of decline, based on cognitive testing. The tests recommended in this toolkit can provide such evidence. However, many patients with MCI would score normally on these basic tests and show memory impairment on more detailed tests of memory. For the purposes of this toolkit, we advise use of the term MCI based on the clinician's judgment that the patient is experiencing significant decline in cognitive function (but not to the point of dementia), even if they score normally on the basic cognitive tests recommended here. If the clinician wants more data on whether the patient has impairment on cognitive tests, referral to a neuropsychologist is recommended.

With the development of biomarkers for neurodegenerative disease (most of which currently identify AD), it will become increasingly possible to link an MCI and to the neurodegenerative cause. Use of biomarkers for this purpose are discussed in this toolkit.

Role of other medical (non-neurodegenerative) conditions

There are many conditions other than neurodegenerative disease that can contribute to cognitive impairment. Common entities include effects of medications, sleep apnea, psychiatric conditions, substance abuse, and many chronic diseases. These entities may be detected in the past medical history, social history, or history of present illness and the temporal relationship between these factors and the cognitive symptoms is key. It should be noted, however, that even when these conditions are present, they might not be the primary cause. When a history indicates a progressive cognitive and behavioral impairment that is typical of Alzheimer's disease, for example, that is often the cause. If the clinician identifies a complicating condition and makes plans to treat it, they must be alert to the possibility that the condition will not improve or will worsen, in which case a neurodegenerative disorder must still be considered. When the problem is more mild, and consistent with the mild cognitive impairment diagnosis, such non-neurological medical conditions have a higher likelihood of accounting for the complaints, but the patient must still be followed to ensure that the symptoms improve.

Vascular disease affecting the brain is a special case to consider. If a patient has a history of sudden onset of neurological complaints, including cognitive complaints, this may represent a stroke or other non-neurodegenerative condition, and immediate referral to a neurologist is recommended. On the other hand, chronic disease of the small vessels in the brain can cause brain pathology that is known to be associated with cognitive complaints, including dementia. This is discussed more in a dedicated section below.

Vascular cognitive impairment

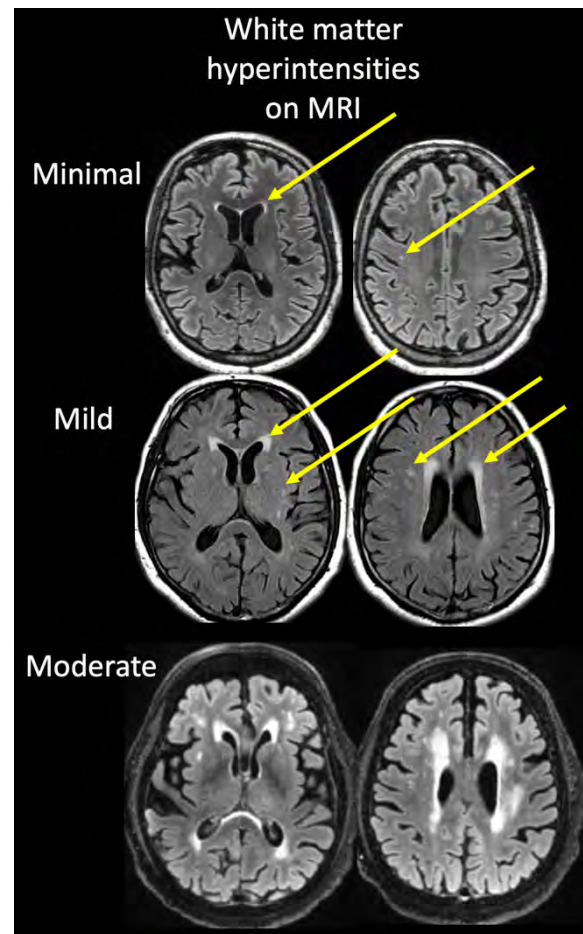
Main points:

- Strokes can cause changes in cognitive function, usually evident from the history as sudden in onset, with improvement or stability thereafter.
- Small vessel disease can cause cerebral injury indicated by white signal in the white matter on T2 weighted MRI.
- Small vessel disease can cause cognitive impairment. It is unlikely to be the only cause when changes are severe enough to be called dementia.
- Pure small vessel disease can cause mild cognitive changes, but many of these patients still have neurodegenerative disease.
- If the small vessel related changes are read by a radiologist as mild, they are unlikely to be making a major contribution to cognitive changes.
- Any patients with insidiously progressive cognitive or behavioral changes should be considered as having possible neurodegenerative disease, even if they have evidence of significant vascular disease.

Cerebrovascular disease associated with aging and other vascular risk factors (e.g., diabetes, hypertension) can cause a number of changes in the brain that affect cognition. The clearest association is when there is a change in cognition after an ischemic or hemorrhagic stroke. Strokes can cause aphasia, memory loss, visuospatial changes, or other cognitive changes, depending on the location in the brain.

Stroke-related cognitive impairment is usually clear from the history. It should have a sudden onset, and the severity should be worst at the onset and gradually improve to some degree over weeks to months, and then remain stable. Progressive worsening suggests another etiology, even if the patient or family endorses relatively sudden onset. MRI or CT scanning should reveal evidence of a stroke, either a cortical stroke or a subcortical lacunar event (relatively small spherical lesion) in a location that can account for the patient's symptoms. If MRI is obtained less than a week after the event, it could show evidence of a recent stroke. If a stroke is more than a few days old, it is difficult to determine its age from imaging.

Another common cause of cognitive impairment is chronic low-grade ischemia from cerebrovascular disease affecting small vessels. The effects of this phenomenon can be seen as increased signal intensity (white signal) in the subcortical white matter on T2-weighted MRI sequences, including FLAIR images (see figure), or low intensity in the white matter on CT scanning. The lesions accumulate around the lateral ventricles in the cerebral hemispheres, and in deeper white matter closer to the cerebral cortex. Lacunar lesions, often around the basal ganglia, can also be seen, even where there is no history of any stroke-like event. Research has shown that the larger the volume of the white matter signal hyperintensity (e.g., in cc's), the more likely there will be cognitive impairment. The presence of lacunes is also associated with increased



likelihood of cognitive impairment. However, the correlation is not very strong, and many older people can have a significant degree of this type of abnormality on MRI and not experience any cognitive or behavioral symptoms.

The term *vascular dementia* is often used in the setting where an older patient has dementia and this type of signal change on MRI. This term could be taken to imply that the patient's dementia is caused solely by these lesions or related processes. However, post-mortem studies have shown that about 90 percent of patients that received a diagnosis of dementia in life have neurodegenerative changes, most commonly Alzheimer's disease and potentially additional changes. Thus, patients with dementia and evidence of significant vascular disease very often have *mixed dementia*. In patients with mild cognitive impairment, the likelihood of "pure" vascular changes is currently thought to be closer to 30 percent. These data come from US studies with limited representation from ethnically and socioeconomically diverse people, so it is possible that more inclusive studies may alter these statistics. Because a significant degree of vascular injury is a potential cause of cognitive impairment, but is often a contributor, rather than the sole cause of cognitive decline, the term *vascular cognitive impairment* is often used. Clinically, cognitive impairment due to small vessel changes is subtly different than typical Alzheimer's disease, with more executive dysfunction, but the memory complaints often sound very similar to Alzheimer's. In patients with pure vascular changes, the progression may be slower, and possibly more step-wise, but these are not reliable features for diagnosis of the etiology of the cognitive changes.

The ability to attribute someone's cognitive changes to vascular disease depends on the presentation. If there is a clear temporal relationship between a stroke and the cognitive change, and the deficit has remained stable or improved, and there is a lesion on imaging that could explain the specific symptom (e.g., left inferior frontal lesion in aphasia), then it is reasonable to assume that the infarct is the cause. In the absence of this clear linkage, attributing the changes to small vessel disease is not an exact science. Standard scoring systems for white matter signal hyperintensity are available, but rarely used in clinical practice. These abnormalities are usually described with terms such as mild, or "scattered foci", moderate, or severe, with no precise definitions for these terms. It is reasonable to assume that if the changes are read as mild, they are not likely to be making a major contribution, except possibly in patients with very mild complaints. This is true regardless of whether the patient has vascular risk factors. At the other extreme, in patients with dementia even moderate or severe changes are unlikely to be the sole cause. Because we have limited biological markers for neurodegenerative diseases (but see below), it is not possible to rule out neurodegenerative disease. If the initial history or longitudinal follow-up indicates insidiously progressive worsening, the patient should be considered to have possible neurodegenerative disease, even if there is evidence of significant vascular disease on imaging. For diagnostic purposes, the decisions about how to assess such a patient's cognitive decline should be the same as if there were no vascular changes. If the nature of the complaints is similar to Alzheimer's disease, it is reasonable to diagnose the patient with an Alzheimer's type of clinical complaint and identify the presence of cerebrovascular changes as a potential contributor (or possible cause in the setting of mild cognitive impairment). If the evaluation reveals any features suggesting an atypical syndrome or other conditions requiring assessment, they should be addressed in the same way, regardless of whether vascular disease is present.

Biomarkers for neurodegenerative disease

Main points:

- Biomarkers for Alzheimer's disease are available using PET, CSF or blood testing
- Asymptomatic patients should not be tested due to uncertainties in interpretation
- Biomarkers should only be obtained and interpreted in the context of a full diagnostic assessment

The landscape of biomarker testing is rapidly evolving. We will update this section regularly to reflect recent developments (the date of the last revision will be documented in a designated section near the beginning of the toolkit, accessible through the table of contents).

Neurodegenerative diseases are caused by accumulation of toxic proteins, with many different types of proteins associated with disease (pages 12-13 above). Some have biomarkers in the clinic, with others in the research pipeline. Although biomarkers are clinically available, their interpretation is dependent on the clinical presentation, and therefore **they should only be ordered as part of a thorough clinical assessment**. Due to implications for prognosis and treatment eligibility, all clinicians should understand their appropriate use, and therefore they have been incorporated into decision guidance for this toolkit.

Extensive research has shown that the biological changes of Alzheimer's disease, in particular amyloid plaques, are detectable 10-20 years before clinical symptoms, and a substantial proportion of older patients with normal cognitive function have abnormal biomarker tests. Asymptomatic patients with abnormal tests are at increased risk of cognitive impairment, but given that amyloid plaques precede symptoms by a decade or more, many patients won't develop symptoms within their lifetime. Two ongoing studies are looking at amyloid-targeting treatment for primary prevention, but no current data support use in asymptomatic patients. Given these uncertainties, **testing asymptomatic patients with AD biomarkers is not recommended**. The ACCT-AD toolkit decision trees provide guidance on the use of AD biomarkers.

MRI and CT scanning: Neither CT scanning nor MRI can detect the presence of neurodegenerative proteins. The main use of these techniques is to assess for evidence of non-neurodegenerative pathologies, including tumors, trauma, and cerebrovascular disease (see section on Vascular Cognitive Impairment). The degree and pattern of brain atrophy, and other findings, can be used to support a diagnosis, particularly for frontotemporal dementia and other rare disorders, but this is currently not applied in a standardized way outside of expert centers. **When an MRI or CT is ordered, it is advisable that the requisition include that there is a suspicion of dementia (and the suspected cause), and for MRI the sequences include FLAIR (which detects vascular-related injury and other pathology), diffusion weighted imaging (which is useful for acute stroke and rapidly progressive dementia), and susceptibility weighted imaging (which is very sensitive for hemorrhages).**

FDG-PET: FDG-PET can show regional patterns of hypometabolism that aid in diagnosis (e.g., frontal hypometabolism with frontotemporal dementia, temporoparietal hypometabolism with PET). Differentiating between Alzheimer's disease and frontotemporal dementia is the only CMS-approved context for FDG-PET scanning in assessment for neurodegenerative disease. However, subtle patterns can be difficult to interpret, and FDG-PET is probably most appropriate in expert settings.

Other types of PET scans and CSF: FDA-approved PET radiotracers are available to detect either amyloid plaques or tau tangles, the pathological hallmarks of AD. FDA-approved assays are available for CSF markers of amyloid plaques and tau tangles, namely A β ₄₂ (the main constituent of amyloid plaques) and hyperphosphorylated and total tau, with reduced A β ₄₂ and elevated tau strongly predictive of Alzheimer's disease. **CSF being sent for AD testing requires special polypropylene tubes**, as A β ₄₂ sticks to the walls of standard tubes in lumbar puncture kits. CSF sent in standard tubes will be rejected by testing labs. It is important to discuss this requirement with the clinician collecting the sample to make sure they are aware of the need for special handling. Biomarker-confirmed AD using PET scanning or CSF testing is required by most expert centers to support treatment with anti-amyloid therapies.

Blood testing: Blood tests for various forms of A β and phosphorylated tau have recently become clinically available. Research has shown that these tests accurately predict the presence of Alzheimer's pathology in the brain, with the best performing tests having accuracy on par with CSF. Currently, the gold standard blood test is phosphorylated tau 217 (p-tau217), which is FDA-approved. A β tests are also available and may improve accuracy in early stages in combination with p-tau217, but are insufficiently accurate as standalone tests. Due to the newness of the tests, regulatory approval and insurance coverage varies.

Alzheimer's disease biomarker interpretation: PET, CSF, or blood tests for AD must be interpreted in light of the clinical presentation. In patients with a dementia syndrome suggestive of AD, positive biomarkers can confirm that Alzheimer's disease is present and contributing to their symptoms, although mixed pathology is common and a positive test does not rule out other contributors. In patients with mild cognitive changes, the interpretation is more complex. For patients with progressive decline and impairment on cognitive testing, a positive test indicates that Alzheimer's disease is present and may be contributing, and therefore their risk of progressing to dementia over the next few years is increased, although how quickly this happens varies widely. For patients with subjective concerns that are not progressing, the prognostic significance of a positive test is less clear, and, due to comparatively low prevalence of AD in this cohort, the diagnostic performance of testing is lower, making interpretation even less certain. For these reasons, as mentioned above, screening asymptomatic patients is not recommended. If asymptomatic patients do obtain positive test results, they should be counseled that although these findings may suggest that Alzheimer's disease is affecting them, the likelihood of a false positives is higher and the prognostic significance, even if accurate, is not clear. A program for regular follow-up should be established.

Lewy body disease: Tests to detect pathological alpha-synuclein protein, the main constituent of Lewy bodies, have become available in both the CSF and skin. Although research suggests high diagnostic performance for both of these methods, additional interpretation beyond confirming the presence of Lewy bodies as a probable pathology in the brain has not been established. Testing for alpha-synuclein should probably only be considered in expert settings at present.

Neurofilament Light Chain (NfL): NfL is another protein that can be measured in the CSF or blood. The protein is considered a non-specific indicator of neurological injury, and can be elevated in many situations, including head trauma and multiple types of neurological disorders, including neurodegeneration. Interpretation of a potentially elevated NfL level should only be done in the context of an expert evaluation.

Genetic testing for neurodegenerative disease

Main points:

- Genetic mutations can cause strongly heritable neurodegenerative disease, including Alzheimer's
- Genetic neurodegenerative diseases are usually atypical, with very early age of onset, which should prompt referral
- *APOE-ε4* is a genetic "risk factor" for Alzheimer's disease, so it increases lifetime risk of the disease but is not in itself diagnostic or determinative, so testing is generally not recommended
- *APOE-ε4* increases the risk of amyloid-related imaging abnormalities (ARIA) with amyloid-targeting antibodies, so testing is recommended when such treatments are being considered
- Genetic testing should include genetic counseling, likely in the context of an expert assessment

Mutations: Many genetic factors influence the risk of neurodegenerative disease, including many common variants that slightly increase or decrease the risk. Neurodegenerative disease can also be caused by autosomal dominant mutations, which are essentially determinative for developing the disease given a long enough lifespan. For some diseases, like Huntington's disease, autosomal dominant mutations are the main causes. In Alzheimer's disease, autosomal dominant mutations account for only about one or two percent of all cases. In these families, the mutations lead to disease in ~50% of family members, on average, and the age of onset is very young (often 30s or 40s). For other disorders, such as frontotemporal dementia, autosomal dominant mutations account for a larger portion, possibly 20-30%. Genetic testing for neurodegenerative disease should be driven by clinical suspicion, especially a strong family history of atypical or early presentations, and features suggesting genetic causes of neurodegenerative disease are marked as "red flags" in this toolkit. Genetic testing should be done as part of an expert assessment and include genetic counseling to review the implications for the patient and their family.

Apolipoprotein E (*APOE*): The *APOE* gene codes for several variants, named *APOE-ε2*, *APOE-ε3*, and *APOE-ε4*. *APOE-ε4* increases the lifetime risk of developing Alzheimer's disease, including at an earlier age (e.g., late 50s, early 60s), and carrying two *APOE-ε4* alleles further increases that risk. However, carrying *APOE-ε4* is not considered a cause of Alzheimer's disease, and many patients, even some with two *APOE-ε4* alleles, never develop dementia from Alzheimer's disease. Therefore, *APOE-ε4* has limited diagnostic or prognostic value, and so *APOE-ε4* testing is not recommended for these purposes.

However, *APOE-ε4* has been associated with an increased risk of amyloid-related imaging abnormalities (ARIA), including cerebral edema and hemorrhages, in the setting of amyloid-targeting antibodies (see Treatment for Neurodegenerative Disease Section). Therefore, *APOE* testing is recommended if patients are considering such treatments in order to inform the patient about the risk of side effects. Such testing and counseling should be done in the context of an expert assessment, and include genetic counseling.

Treatment of Neurodegenerative Diseases

Main points:

- New treatments for Alzheimer's disease are available that slow the rate of clinical decline.
- Only early symptomatic stages have evidence for benefit, typically mild cognitive impairment or mild dementia, with the best response associated with earlier initiation and rapid clearance
- The most common side effect from amyloid-targeting antibodies is ARIA, which is usually mild, transient, and asymptomatic, though it can be severe and debilitating in rare cases
- Thorough patient evaluation and risk stratification with *APOE* is recommended prior to treatment

A thorough discussion of treatment is beyond the scope of the toolkit, which is intended to guide diagnosis, but the toolkit does aim to guide decisions about referral, and the availability of new treatments in expert settings will likely impact such decisions. We therefore include a brief discussion of treatment, focusing on aspects that have the most influence on referral decisions. We will update this section regularly to reflect recent developments (the date of the last revision will be documented in a designated section near the beginning of the toolkit, accessible through the table of contents).

It must be emphasized that management of neurodegenerative diseases includes non-pharmacological and pharmacological approaches. Non-pharmacological management often involves ancillary health providers, e.g., social workers, psychologists, or physical, occupational, or speech therapists (among other specialties). Referral to these providers is highly recommended.

For decades, the only pharmacological tools were for symptom management, typically medicines that alter neurotransmitter function in the brain. FDA-approved treatments include drugs aimed at boosting memory, such as cholinesterase inhibitors (e.g., donepezil, galantamine, rivastigmine) and glutamine receptor antagonists (memantine), and a few drugs aimed at management of behavioral symptoms (e.g., brexipiprazole). Other antidepressants and antipsychotics, while not-FDA approved, are commonly used to manage behavioral and psychiatric symptoms in this setting. Initiation and management of these symptomatic medications is within the scope of practice of a primary care practitioner, with referral decisions based on whether behavioral problems have become exceptionally difficult to manage.

New treatments that target specific neuropathology in Alzheimer's disease are now available. Two monoclonal antibodies that target amyloid have full FDA-approval: lecanemab and donanemab. Another amyloid-targeting antibody, aducanumab, had conditional approval but has now been withdrawn from the market. As a class, amyloid-targeting antibodies clear plaques from the brain and slow the rate of progression by ~25% in early stages (mild cognitive impairment and mild dementia), with better efficacy seen when started in the earliest symptomatic stages. Notably, as the disease progresses, risk increases and benefit decreases, so patients with moderate or severe dementia should not be treated. Two ongoing trials are assessing these medicines for primary prevention, but given that there is currently a lack of evidence for benefit, asymptomatic patients should not be treated, even if they have a positive test for amyloid.

Treatment requires intravenous infusion every two weeks (lecanemab) or every month (donanemab). Infusion reactions are typically mild and self-limiting. The major side effect is related to immune-mediated clearance of amyloid and called amyloid-related imaging abnormalities (ARIA). ARIA refers to changes seen on MRI that reflect brain swelling (ARIA-E) or bleeding (ARIA-H). ARIA is more common in *APOE*- $\epsilon 4$ carriers (especially homozygotes), patients with cerebrovascular disease (especially cerebral amyloid angiopathy), and patients with uncontrolled hypertension. Anticoagulation may increase risk. ARIA is typically mild, asymptomatic, and resolves after a treatment pause, however ARIA can in rare cases cause severe, even life-threatening, symptoms. Management of ARIA typically includes increased monitoring with possible treatment pause, but severe symptomatic ARIA may require additional measures (e.g., hospital admission, steroids, treatment discontinuation).

Due to the need for careful patient selection, complex administration, and intensive monitoring for side effects, this new class of drugs is available only in expert settings. However, patients with Alzheimer's disease may benefit from treatment, so if a primary care provider and their patient agree, they should be evaluated as a potential candidate, and referred for consideration of treatment if eligible. For a higher likelihood of a successful referral, the clinical diagnosis should be Alzheimer's disease (preferably with biomarker confirmation if available), at an appropriate clinical stage (symptomatic but not yet in moderate dementia), with imaging to rule out structural causes and contraindications (preferably an MRI with FLAIR, DWI, and heme sequences).

Assessment Recommendations and Guidelines

Detection of Symptoms

- When does a provider know that a patient needs an assessment of cognitive symptoms?
Current expert guidelines do not recommend routine formal cognitive testing of patients based on arbitrary cutoffs such as age ([US Preventative Services Task Force-screening for cognitive impairment](#)). Rather, the clinician should be alert to signs that cognitive changes may be occurring. These can include:
 - The patient brings up cognitive concerns in a visit.
 - The patient's informant (caregiver, family member or friend) brings up cognitive concerns to the provider or medical staff.
 - The medical staff and/or provider notice that there may be cognitive concerns (missed appointments, medication mistakes, etc.).
- In addition, current guidelines suggest that a few brief, routine questions can be used to identify patients with cognitive concerns. One example of when these might be used is in the context of a health risk assessment (HRA) that would be performed in the context of the Medicare Annual Wellness Visit. The CDC provides additional direction on the potential contents and approaches for performing an HRA.
- The CDC guidelines anticipate that the HRA questions can be obtained in many ways, including paper or online questionnaires, in person, and other options.
- There are no requirements to use specific questions, and different sources recommend different versions (e.g. Alzheimer's Association Cognitive Screen Toolkit).
- The ACCT-AD toolkit provides questions and procedures that can be used for detection of significant cognitive complaints.
- While ACCT-AD Detection Questions may be suitable for detecting concerns using pre-visit questionnaires and similar approaches, the ACCT-AD toolkit recommends that a trained medical staff person ask these questions in person, because there is currently not enough data to indicate these questions are adequately sensitive when self-administered. These questions should be asked of a patient and informant, and if no informant is available, they should be supplemented with a brief cognitive test.

Diagnosis of Cause: Full Evaluation

- Expert guidelines recommend that, if the detection procedures or similar tools detect a concern about significant cognitive and/or behavioral changes, that a full assessment be conducted. The full assessment provides the opportunity to quantify the severity of the problem and its impact on daily function, to obtain a detailed inventory of all of the problems beyond the primary complaint, to identify medical issues that may be contributing or causing the cognitive and behavioral changes, and, if the conclusion is that the patient may be suffering from mild cognitive changes or dementia due to a neurodegenerative disease, to specify the potential cause of the symptoms.

Referral

- Once a probable etiology for the symptoms has been established, the clinician should decide whether a referral is needed, what kind of expert should be consulted, and what the goals are for the referral.

Cognitive testing information

The following PowerPoint tutorials are available upon request. We have provided PDF versions of these PowerPoints in Section 3: Patient Assessment Forms.

Cognitive testing for Primary Care Practices

Mini-Cog

MMSE-Mini-Mental State Exam

MoCA-Montreal Cognitive Assessment

SLUMS-St. Louis University Mental Status exam

3MS- Modified Mini-Mental State

Cognitive testing with low literacy and language constraints

The guidelines provided in the toolkit regarding the use of cognitive testing are based on the available data and experience of toolkit developers. Unfortunately, the majority of the available data on cognitive testing are based on cohorts of relatively highly educated individuals residing in highly developed countries. It is well known that educational and cultural factors influence scores on cognitive testing. The toolkit guidelines regarding use of cognitive testing must be modified for assessment of patients with low levels of education and patients that do not speak English fluently. Patients in the US and California come from many cultures and speak many languages, and the available data regarding cognitive testing varies across these many cultures and languages. For many of these cultural and language settings, the toolkit cannot currently recommend a specific approach, and as discussed in the toolkit limitations section, the detection of cognitive and behavioral changes in someone with low education and/or in a patient who is not fluent in English is a justifiable reason for referral to an expert for evaluation. However, the toolkit developers have been able to identify appropriate tests for use in some commonly encountered situations, and have provided the following recommendations for tests in these circumstances. In addition to the specific test, cutoff values for each test must be modified for those with low education, and these alternate cutoffs are provided in the **Reference and Interpretation Manual**.

CONTEXT	Brief Cognitive Test for Detection	Cognitive Testing for Full Assessment
Spanish >6 yrs. of education	Mini-Cog	Montreal Cognitive Assessment (MoCA)
Spanish with 6 or fewer years of education	Modified version of the Mini Mental State Exam (MMSE)	Modified version of the Mini Mental State Exam (MMSE)
Chinese >6 yrs. of education	Brain Health Test (BHT)	Montreal Cognitive Assessment (MoCA)
Chinese with 6 or fewer years of education	Brain Health Test (BHT)	Montreal Cognitive Assessment-basic (MoCA basic)

The Use of Interpreters for Cognitive Tests with Language and Cultural Barriers

Formal standardized assessment of cognition is *one* component of a thorough assessment of cognitive complaints. Even beyond the patient's language and education, several other factors can influence the validity of cognitive testing, including the difference between the clinician and patient in terms of language, culture, nation of origin, and the patient's knowledge and attitudes about cognitive testing. The best practice for reducing these confounds is to ensure that the patient is assessed in their own language by a person with training in cognitive testing, and with an understanding and appreciation of how the patient's culture, education level, language, and dialect may affect the assessment tools used. Unless the clinician is fully bilingual, a multidisciplinary partnership must be used to assess the patient. **If language, culture, or other factors are likely to affect the results of cognitive testing, the physician is better off not obtaining any formal cognitive testing and relying on the history. If these confounds are present and cognitive testing is felt to be critical, then the clinician should refer to a neuropsychologist.**

Clinicians often attempt to bridge the gaps of language and culture by using interpreters. This is only advisable if specific criteria are met. These criteria are more likely to be achievable if a practice works regularly with specific individuals that provide interpretation. The following is a limited guide to determine if formal cognitive assessment with an interpreter is appropriate or if referral is necessary:

- 1) The **individual who will be testing the patient must have some training and experience with the planned approach for cognitive assessment**, and be familiar with the testing materials so they can administer the examination in a standardized and valid manner. A clinician should specifically ask the interpreter about their fluency with testing methods and materials (and preferably ensure that they have reviewed the training materials provided by this toolkit or similar training).
- 2) Using an **interpreter or a family member as an intermediary creates potential administration issues**. Cognitive scoring assumes that testing was done in accordance with rules that govern when stimuli or testing instructions can be given, and whether and when prompts and encouragement can be used. If these rules are not adhered to, scores will not be valid. Thus, the clinician must ensure that the person being the intermediary is instructed to only translate what the clinician says, with as little change or elaboration as possible, and does not interact with the patient in any other way during testing. Because of these issues, use of a family member to interpret for cognitive assessment is rarely appropriate.
- 3) The **measure used to assess cognition should be validated in the patient's language, culture, education level, and country of origin at minimum, and provide interpretive "cut points"** based on alignment with gold standard approaches. Dialect can also impact the appropriateness of a measure to a specific patient or group of patients.
- 4) The clinician should discuss with the interpreter if there were any barriers to the patient's understanding, appreciation, or engagement with regard to the testing process, and if there are any educational, cultural or linguistic reasons for this.

If, considering these issues, the clinician decides to pursue cognitive testing through an interpreter, the following considerations can guide how the testing should be used for decision-making:

- 1) The clinician should assess whether the test results align with what else they know about the patient's cognition. If there is discrepancy between the cognitive assessment results and other components of the assessment (especially discrepancies that may change the diagnosis or interventions) a clinician should rely more heavily on the history, and refer to a specialist if feasible.
- 2) In cases where the cognitive results are in a borderline zone (e.g. very close to a "cutpoint" between diagnosis or diagnoses), a referral would be appropriate.

Guidance on Neurological exam

The assessment of any patient with cognitive complaints must include a neurological examination. For those who need review of how to conduct and interpret a neurological examination, there are many resources available. Some good ones include:

➤ **The book entitled, Clinical Neuroanatomy Made Ridiculously Simple by Stephen Goldberg**

This book presents clinical neuroanatomy with mnemonics, humor, and case presentations. It includes tutorial on how to localize neurologic injuries and interactive quiz of classic neurologic cases. Windows/Macintosh CD and book.

➤ **The website at neuroexam.com**

This website is an interactive online guide to the main components of the neurologic examination with video demonstrations. It is based on the book Neuroanatomy through Clinical Cases by Hal Blumenfeld, MD, PhD, Yale University School of Medicine.

Resources for care

Family and Caregiver resources

Dementia care

Caregiving Resources

- The Alzheimer's Association: 800-272-3900; www.alz.org/
- Family Caregiver Alliance: 800-445-8106; www.caregiver.org/
- National Institute of Aging: <https://www.alzheimers.gov>
- NIH Senior Health: <https://nihseniorhealth.gov/>
- National Caregivers Library: www.caregiverslibrary.org/
- Next Step in Care: <http://www.nextstepincare.org/>
- VA Caregiver Support Program: <http://www.caregiver.va.gov>
- Arizona Center on Aging: <http://aging.arizona.edu/program/elder-care-resource-interprofessional-providers>
- Alzheimer's Greater Los Angeles: <http://www.alzgla.org/>

Finding Local Resources

- Contact your local Area Agency on Aging to see if individual consultations are available: <http://www.n4a.org/>
- If you are in California, contact your local Caregiver Resource Center for an individual consultation: <https://www.caregiver.org/californias-caregiver-resource-centers>
- Search for educational events in your area using the Alzheimer's Association's Community Resource Finder: <http://www.communityresourcefinder.org/>

Information about Long Term Care

- Long Term Care.gov: <http://longtermcare.gov/>
- California Association for Nursing Home Reform (CANHR): <http://www.canhr.org/>

Finding Legal Help

- American Bar Association: <http://www.americanbar.org/>
- Low-cost and free legal help for California seniors: <http://www.aging.ca.gov/programsproviders/Legal/>
- LawHelpCA.org: www.lawhelpCA.org
- California Association for Nursing Home Reform (CANHR) Legal Referral Service: <http://www.canhr.org/LRS/>

Home Safety

- CDC Falls: <http://www.cdc.gov/homeandrecreationalsafety/falls/>
- Safe Return: <http://www.alz.org/care/dementia-medic-alert-safe-return.asp>
- Alzheimer's Association: <https://www.alz.org/media/Documents/alzheimers-dementia-home-safety-checklist-ts.pdf>

- Dementia Enabling Environments: <http://www.enablingenvironments.com.au/>
- Tech Enhanced Life: <https://www.techenhancedlife.com/>

Self-Care Resources

- Find Support Groups: http://www.alz.org/apps/we_can_help/support_groups.asp
- Mindfulness Activities: <http://ggia.berkeley.edu/>
- Silver Sneakers Exercise Program: <https://www.silversneakers.com/>
- NIH “Go 4 Life”: <https://go4life.nia.nih.gov/>
- Sit and Be Fit: <http://www.sitandbefit.org/>

Activities

- Activities from Alzheimer’s Australia: <https://vic.fightdementia.org.au/about-dementia/i-am-a-carer-family-member-or-friend/activities-for-people-with-dementia>
- Daily Plan from Alz.org <https://www.alz.org/care/alzheimers-dementia-daily-plan.asp>
- Alz Store: <http://www.alzstore.com/>
- S & S Worldwide Store: <http://www.ssw.com/>
- Senior Center Without Walls: <http://www.seniorcenterwithoutwalls.org/>
- Creative Caregiving Lessons/ Videos: <http://creativecaregiving.creativeaging.org/>

Caregiving Videos

- Conversations with Caregivers YouTube Channel: bit.do/conversationswithcaregivers
- Cure PSP How To YouTube Channel: <https://www.youtube.com/user/CurePSPHowTo>
- Family Caregiver Alliance YouTube Channel: <https://www.youtube.com/user/CAREGIVERdotORG>
- AARP Home Alone Alliance Video Series: <http://www.aarp.org/ppi/info-2017/home-alone-alliance.html> <https://www.youtube.com/user/CAREGIVERdotORG>
- UCLA Caregiver Education: <http://dementia.uclahealth.org/caregiver-education>
- Pines of Sarasota YouTube Channel: <https://www.youtube.com/user/PinesofSarasota>
- VA Caregiver Videos: <http://www.ruralhealth.va.gov/vets/resources.asp#dem>

SECTION 2: REFERENCE AND INTERPRETATION MANUAL



Assessment of Cognitive Complaints Toolkit

For Alzheimer's Disease

Reference and
Interpretation Manual

PRODUCED BY THE
CALIFORNIA
ALZHEIMER'S DISEASE
CENTERS AND FUNDED
BY THE CALIFORNIA
DEPARTMENT OF PUBLIC
HEALTH, ALZHEIMER'S
DISEASE PROGRAM

Overall process for assessment

- A reliable informant should accompany the patient to all appointments for the evaluation of cognitive impairment.
- It is very important that this informant be involved in the patient's cognitive assessment to provide collateral input.
- If this is not possible, we recommend considering other options to ensure an accurate history and evaluation, i.e., via telephone or rescheduling patient when informant would be available.

To go directly to desired step, click on the link

[Step One: Complete ACCT-AD questions for detection of cognitive and behavioral concerns](#)

- See procedure details in section on STEP ONE: DETECTING COGNITIVE CONCERNS

[Step Two: Complete full cognitive evaluation](#)

The full cognitive evaluation can be completed over a series of appointments if necessary.

- See procedure details in section on STEP TWO: FULL COGNITIVE EVALUATION

[Step Three: Interpretation](#)

- Decision support guide
- Decision Tree

[Step Four: Diagnostic disclosure and care planning](#)

- Disclosure and Scripts
- Discussing driving safety

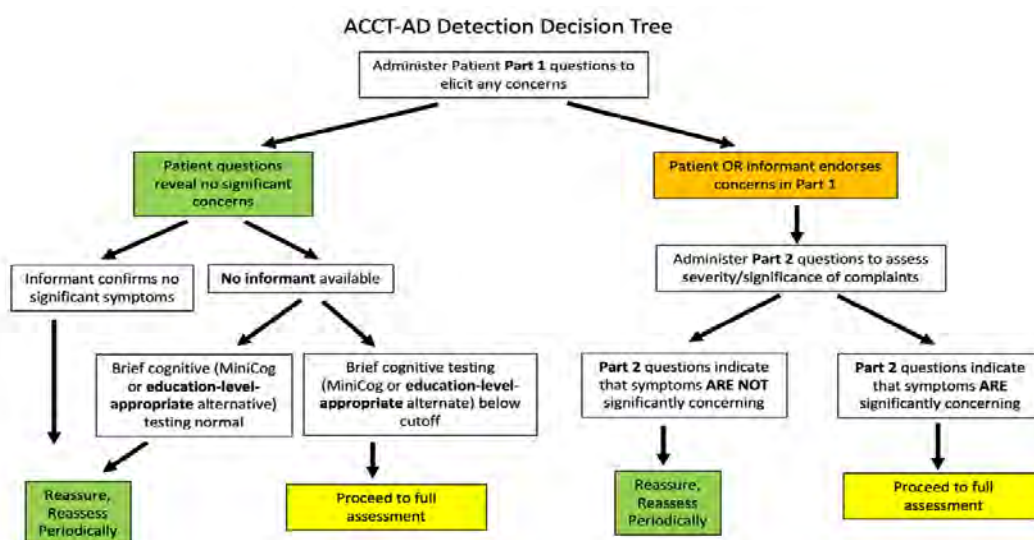
STEP ONE: DETECTING COGNITIVE CONCERNS

It is recommended that the detection questions should be routinely asked of patients over the age of 65 about once a year unless a cognitive complaint has already been identified and diagnosed.

While ACCT-AD detection questions may be suitable for detecting concerns using pre-visit questionnaires and similar approaches, the ACCT-AD toolkit recommends that a trained medical staff person ask these questions in person, because there is currently not enough data to indicate that these questions are adequately sensitive when self-administered. As detailed below, these questions should be asked of a patient and informant, and if no informant is available, they should be supplemented with a brief cognitive test.

Procedure

- Administer detection questions to patient AND informant (can be together or separate) using **ACCT-AD detection questions**. Questionnaire can be found in the 'patient assessment forms' section.
- If patient AND informant do not identify any 'indeterminate' (orange) responses in Part 1, reassure patient and bring back in a year to repeat **ACCT-AD detection questions**.
- If patient or informant DO identify any 'indeterminate' (orange) responses in Part 1, proceed to part 2. If patient OR informant identify any 'yes' (yellow) response in Part 2, **proceed to full assessment** or refer to dementia specialist.
- If patient did not identify any 'indeterminate' (orange) responses in Part 1 and no informant is available, complete **Mini-Cog®** test (see instruction manual for information on the **Mini-Cog®**) or alternate test in non-English and/or low education context to confirm no cognitive concerns. If no concerns, reassure patient and bring back in a year to repeat **ACCT-AD detection questions**. If concerns, proceed to or arrange full assessment or refer to dementia specialist.
- Before pursuing full cognitive evaluation, consider whether patient has characteristics that are affected by TOOLKIT LIMITATIONS. If so, consider whether full cognitive evaluation needs to be amended or if referral to dementia specialist is justified.



INTERPRETATION TABLES: Detection questions

Patient component- Part 1

PATIENT COMPONENT- Part 1 MEMORY, LANGUAGE AND PERSONALITY CHANGES	
MEMORY 1. Do you think your memory or thinking has changed in the last 5–10 years?	Prompts: Remembering recent events, like family event, dinner, movie, book. Remembering recent conversations
ANSWER-NO GO TO QUESTION 2 I often go into a room and forget why I'm there. I have more difficulty remembering names. Interpretation Normal aging if confirmed with informant or negative min-cognitive testing	ANSWER-YES REQUIRES FOLLOW-UP IN PART 2 Yes, any other complaint Interpretation Could be cognitive impairment
LANGUAGE 2. Have you noticed changes in your language?	Prompts: Trouble finding words or understanding conversations
ANSWER-NO GO TO QUESTION 3 I have occasional problems coming up with a word. Interpretation Normal aging if confirmed with informant or negative mini cognitive testing	ANSWER-YES REQUIRES FOLLOW-UP IN PART 2 I think that it's harder for me to get my point across. Interpretation Could be cognitive impairment
PERSONALITY 3. Have you noticed changes in your personality?	Prompts: More irritable/anger more easily Trouble getting along with people
ANSWER-NO GO TO INFORMANT QUESTIONS (If answers to 1 and 2 are also no, otherwise proceed to part 2), or proceed to brief cognitive testing if no informant Interpretation Normal aging if confirmed with informant or negative mini-cognitive testing	ANSWER-YES REQUIRES FOLLOW-UP IN PART 2 I might be a little less patient. My family thinks I'm more difficult to get along with Interpretation Could be cognitive impairment.

- If there are indications of impairment (yes responses), continue to the patient component-Part 2.
- If there are no indications, skip to informant component-Part 1 to confirm patient's responses.
- If there are no indications and no informant is available, perform Mini-Cog®. If score is normal, end 'HRA cognitive questions', reassure patient and repeat in one year.
- If the patient has any errors on the Mini-Cog®, proceed to a 'Full Cognitive Evaluation'.

Patient component- Part 2

**PATIENT COMPONENT-Part 2/Significance of Cognitive Complaints
MEMORY, LANGUAGE AND PERSONALITY CHANGES**

MEMORY

Do you think your memory changes are worse than your peers?

Prompts:

ANSWER

GO TO NEXT QUESTION

All my friends complain about the same thing. Actually, I think my memory is still better than my peers.

Interpretation

Normal aging

ANSWER-YES

BRING BACK FOR FULL ASSESSMENT

My friends don't seem to have as much trouble as I do with remembering appointments. I often rely on my friends to remember our dates.

Interpretation

Concerning for cognitive impairment.

MEMORY

Have you stopped doing anything because of these changes?

Prompts:

ANSWER

GO TO NEXT QUESTION

I might rely on my phone or calendar more.

Interpretation

Normal aging

ANSWER-YES

BRING BACK FOR FULL ASSESSMENT

I am worried about my performance at work. I have given control of the calendar to my spouse. I am asking my family to help with bills/finances.

Interpretation

Concerning for cognitive impairment

MEMORY

Has anybody commented to you about these changes in your memory?

Prompts:

ANSWER-NO

GO TO NEXT LANGUAGE (If indicated in Part 1), otherwise proceed to informant portion or proceed to brief cognitive testing if no informant

My children occasionally say I repeat a story.

Interpretation

Normal aging

ANSWER-YES

BRING BACK FOR FULL ASSESSMENT

My wife tells me that I am always asking her what the schedule is. My friends comment that I often miss appointments.

Interpretation

Concerning for cognitive impairment

**PATIENT COMPONENT-Part 2/Significance of Cognitive Complaints
MEMORY, LANGUAGE AND PERSONALITY CHANGES**

LANGUAGE Do you think your language changes are worse than your peers?	Prompts:
--	----------

ANSWER-NO GO TO NEXT QUESTION
All my friends complain about the same thing. Actually, I think my vocabulary is not very limited.
Interpretation
Normal aging

ANSWER-YES BRING BACK FOR FULL ASSESSMENT
My friends comment that I don't speak as easily as in the past. My wife is always saying that I don't seem to be able to participate in discussions as well as the past. I am hesitant to talk on the phone because of my speech (or comprehension).
Interpretation
Concerning for cognitive impairment.

LANGUAGE Have you stopped doing anything because of these language changes?	Prompts:
---	----------

ANSWER-NO GO TO NEXT QUESTION
My life is very busy.
Interpretation
Normal aging if confirmed with informant or negative mini cognitive testing

ANSWER-YES BRING BACK FOR FULL ASSESSMENT
I stopped participating in my book club. I still go but speak less at social occasions.
Interpretation
Concerning for cognitive impairment

LANGUAGE Has anybody commented to you about these changes in your language?	Prompts:
---	----------

ANSWER-NO GO TO NEXT PERSONALITY (If indicated in Part 1), otherwise proceed to informant portion or proceed to brief cognitive testing if no informant
No.
Interpretation
Normal aging

ANSWER-YES BRING BACK FOR FULL ASSESSMENT
My wife says I use words like "thingy" more than I used to.
Interpretation
Concerning for cognitive impairment

**PATIENT COMPONENT-Part 2/Significance of Cognitive Complaints
MEMORY, LANGUAGE AND PERSONALITY CHANGES**

PERSONALITY

Do you think your personality changes are worse than those of your peers

Prompts:

ANSWER-NO

GO TO NEXT QUESTION

We are all just getting crabby.
We all are doing less than we used to.

Interpretation

Normal aging

ANSWER-YES

BRING IN FOR FULL ASSESSMENT

I seem to be much less patient than my friends.
I'm much less interested in doing things than my friends.

Interpretation

Concerning for cognitive impairment

PERSONALITY

Have you stopped doing anything because of these personality changes?

Prompts:

ANSWER-NO

GO TO NEXT QUESTION

I'm busier than ever.

Interpretation

Normal aging

ANSWER-YES

BRING IN FOR FULL ASSESSMENT

My wife doesn't like to go out to dinner with me anymore.
I am just not interested in hobbies the way I used to be.

Interpretation

Concerning for cognitive impairment

PERSONALITY

Has anyone commented on these personality changes to you?

Prompts:

ANSWER-NO

GO TO INFORMANT PORTION, or proceed to brief cognitive testing if no informant

Interpretation

Normal aging

ANSWER-YES

BRING IN FOR FULL ASSESSMENT

My friends think that I tend to get angry more easily.

Interpretation

Concerning for cognitive impairment

- If there are indications (yes responses), do a 'Full Cognitive Evaluation'.
- If there are no indications, proceed to informant component-Part 1 to confirm patient responses.
- If there are no indications and no informant is available, perform Mini-Cog®. If Mini-Cog® score is normal, end 'HRA Cognitive questions', reassure patient and repeat in one year.
- If the patient has any errors on the Mini-Cog®, proceed to a 'Full Cognitive Evaluation'.

Informant component- Part 1

INFORMANT COMPONENT-Part 1 Questions for Memory, Language & Personality Change	
MEMORY 1. Do you think the patient's memory or thinking has changed in the last 5–10 years?	Prompts: Remembering recent events, like a family event, dinner, movie, or book Remembering recent conversations
ANSWER-NO GO TO QUESTION 2 Yes, they often go into a room and forget why they're there. They have more difficulty remembering names. Interpretation Normal aging if confirmed with informant or negative mini-cognitive testing	ANSWER-YES REQUIRES FOLLOW-UP IN PART 2 Yes, any other complaint Interpretation Could be cognitive impairment
LANGUAGE 2. Have you noticed changes in their language?	Prompts: Trouble finding words or understanding conversations
ANSWER-NO GO TO QUESTION 3 They have occasional problems coming up with a word. Interpretation Normal aging if confirmed with informant or negative mini-cognitive testing	ANSWER-YES REQUIRES FOLLOW-UP IN PART 2. Yes. I think that it's harder for them to get their point across. Interpretation Could be cognitive impairment
PERSONALITY 3. Have you noticed changes in their personality?	Prompts: More irritable/anger more easily Trouble getting along with people
ANSWER-NO GO TO PART 2 if any responses yes, OR END HERE if all responses are no, decide if full assessment needed No. Interpretation Normal aging if confirmed with informant or negative mini cognitive testing	ANSWER-YES REQUIRES FOLLOW-UP IN PART 2 They might be a little less patient. Our family thinks they're more difficult to get along with. Interpretation Could be cognitive impairment.

- If there are indications (yes responses), proceed to informant component-Part 2.
- If there are no indications, end DETECTION QUESTIONS here, reassure patient and repeat in one year.

Informant component- Part 2

**INFORMANT COMPONENT-Part 2/Significance of Cognitive Complaints
MEMORY, LANGUAGE AND PERSONALITY CHANGES**

MEMORY

Do you think their memory changes are worse than their peers?

Prompts:

**ANSWER-NO
GO TO NEXT QUESTION**

All their friends complain about the same thing. Actually, I think their memory is still better than our peers.

Interpretation

Normal aging if confirmed with informant or negative mini cognitive testing

**ANSWER-YES
BRING IN FOR FULL ASSESSMENT**

Their friends don't seem to have as much trouble as they do with remembering appointments. They often rely on their friends to remember their dates.

Interpretation

Concerning for cognitive impairment.

MEMORY

Have they stopped doing anything because of these memory changes?

Prompts:

**ANSWER-NO
GO TO NEXT QUESTION**

They might rely on phone or calendar more.

Interpretation

Normal aging

**ANSWER-YES
BRING IN FOR FULL ASSESSMENT**

I am worried about their performance at work. They have given control of the calendar to me/their spouse. They have asked for help with bills/finances.

Interpretation

Concerning for cognitive impairment

MEMORY

Has anybody commented to you about these changes in their memory?

Prompts:

**ANSWER-NO
GO TO LANGUAGE (if indicated in informant part 1) otherwise END HERE**

Their children occasionally say they will repeat a story.

Interpretation

Normal aging

**ANSWER-YES
BRING IN FOR FULL ASSESSMENT**

They are always asking me what the schedule is. I notice that they often miss appointments.

Interpretation

Concerning for cognitive impairment

**INFORMANT COMPONENT-Part 2/Significance of Cognitive Complaints
MEMORY, LANGUAGE AND PERSONALITY CHANGES**

LANGUAGE

Do you think their language changes are worse than their peers?

Prompts:

**ANSWER-NO
GO TO NEXT QUESTION**

All their friends complain about the same thing.
Their vocabulary is more limited.

Interpretation

Normal aging

**ANSWER-YES
BRING IN FOR FULL ASSESSMENT**

They don't speak as easily as in the past.
They don't seem to be able to participate in discussions as well as the past.
They are hesitant to talk on the phone because of their speech (or comprehension).

Interpretation

Concerning for cognitive impairment.

LANGUAGE

Have they stopped doing anything because of these language changes?

Prompts:

**ANSWER-NO
GO TO NEXT QUESTION**

Their life is very busy.

Interpretation

Normal aging

**ANSWER-YES
BRING IN FOR FULL ASSESSMENT**

They stopped participating in their book club.
They still go but speak less at social occasions.

Interpretation

Concerning for cognitive impairment

LANGUAGE

Have you notices any changes in their language?

Prompts:

**ANSWER-NO
GO TO PERSONALITY (if indicated in informant part 1) otherwise END HERE**

Interpretation

Normal aging

**ANSWER-YES
BRING IN FOR FULL ASSESSMENT**

They use words like "thingy" more than they used to.

Interpretation

Concerning for cognitive impairment

INFORMANT COMPONENT-Part 2/Significance of Cognitive Complaints MEMORY, LANGUAGE AND PERSONALITY CHANGES

PERSONALITY	Prompts:
--------------------	----------

Do you think their personality changes are worse than those of their peers?

ANSWER-NO GO TO NEXT QUESTION
--

We are all just getting crabby.
We all are doing less than we used to.

Interpretation

Normal aging

ANSWER-YES BRING IN FOR FULL ASSESSMENT
--

They seem to be much less patient than their friends.
They are much less interested in doing things than their friends.

Interpretation

Concerning for cognitive impairment

PERSONALITY	Prompts:
--------------------	----------

Have they stopped doing anything because of these personality changes?

ANSWER-NO GO TO NEXT QUESTION
--

They are busier than ever.

Interpretation

Normal aging

ANSWER-YES BRING IN FOR FULL ASSESSMENT
--

I don't like to go out to dinner with them anymore.
They are just not interested in hobbies like they used to be.

Interpretation

Concerning for cognitive impairment

PERSONALITY	Prompts:
--------------------	----------

Has anyone commented on these personality changes to you?

ANSWER-NO END HERE, decide if full assessment needed

Interpretation

Normal aging

ANSWER-YES BRING IN FOR FULL ASSESSMENT
--

Their friends think that they tend to get angry more easily.

Interpretation

Concerning for cognitive impairment

- If there are indications (yes responses), do a 'Full Cognitive Evaluation'.
- If there are no indications, reassure patient and repeat in one year.

Brief Cognitive test

Mini-cog®

Using the Mini-Cog®¹

“The Mini-Cog® is a 3-minute instrument that can increase detection of cognitive impairment in older adults. It can be used effectively after brief training in both healthcare and community settings. It consists of two components, a 3-item recall test for memory and a simply scored clock-drawing test. As a screening test, however, it does not substitute for a complete diagnostic workup.

Scoring the Mini-Cog®

The Mini-Cog® is scored in two parts: 1) 3-item recall, and 2) clock drawing. These are added together for a total score.

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.

<https://mini-cog.com/>

http://mini-cog.com/wp-content/uploads/2018/03/Standardized-English-Mini-Cog-1-19-16-EN_v1-low-1.pdf

¹ Information obtained from mini-cog.com

Low literacy and non-fluency in English-Brief Cognitive tests

The toolkit cannot currently recommend appropriate forms of cognitive testing for all of the wide varieties of cultural and language contexts encountered in practice. However, the toolkit has identified reasonable approaches for the common contexts in the table below. In these contexts, the identified test can be used in place of the Mini-Cog® for the detection procedures. In these contexts, the test should be delivered in the patient's native language by a fluent speaker of that language, and not through an interpreter. For low levels of education, the cutoff score will be different than for those with higher levels of education.

The Spanish version of the Mini-Cog® is available at <https://mini-cog.com/>. The toolkit provides a version of the MMSE suitable for use in low-literacy Spanish speaking individuals from South and Central America, and the Brain Health Test for use in Chinese speaking individuals in the **Patient Assessment Forms section**. Instructions for use and scoring of the Brain Health Test in Chinese can be found at can also be found in this section.

For Chinese speakers we have identified the Brain Health Test (Tsai PH, et al.- <https://pubmed.ncbi.nlm.nih.gov/29694392>) which has been used by researchers in Taiwan. They have determined that it is equally applicable for people with lower and higher levels of education. Some people did feel uncomfortable with the clock drawing task, particularly those with low education. Developers have determined that the test can still be used skipping the clock drawing task. With the clock drawing task, the maximum score is 12; without it the score is 10. The cut-offs for normal vs concern with cognitive impairment are adjusted accordingly per table below.

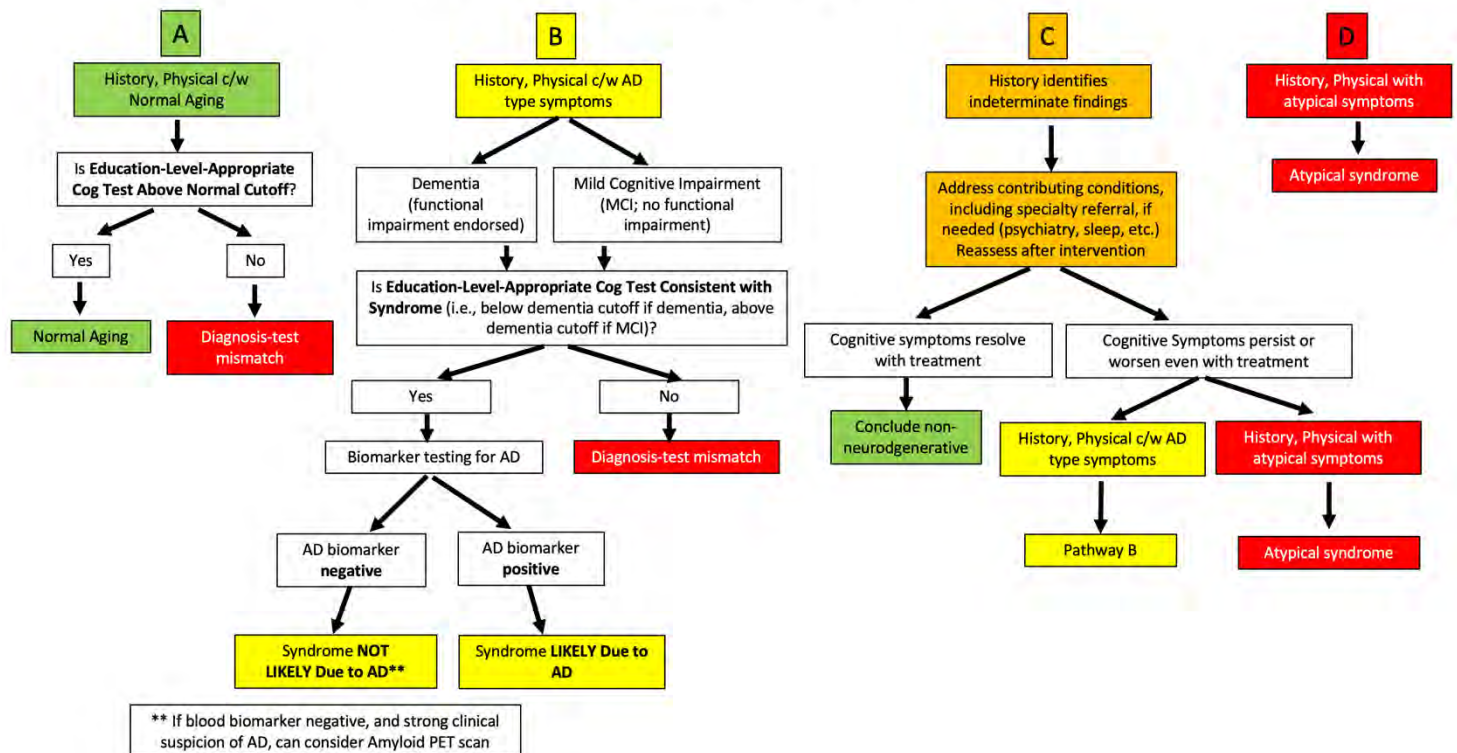
CONTEXT	Brief Cognitive Test	Score cutoff
Spanish >6 yrs. of education	Mini-Cog	Same as for English speakers
Spanish with 6 or fewer years of education	Mini Mental State Exam (MMSE)	Cutoff of 14
Chinese, all education levels	Brain Health Test (BHT)	11/12 with clock drawing 9/10 without clock drawing

STEP TWO: FULL COGNITIVE ASSESSMENT

Procedure

- A. Can administer pre-visit patient questionnaire, **provided in Patient Evaluation Forms section**
 - a. Can be administered as self-report survey, on paper, online, or delivered in person by clinic staff
 - b. Patient and informant to complete, can be separate or together (by their choice and convenience)
 - c. Provider and/or care team should review responses prior to evaluation
 - d. Note **TOOLKIT LIMITATIONS** to decide whether full cognitive evaluation needs to be amended, or pursued through specialty evaluation, vs performed in primary care
- B. Pursue full cognitive evaluation, using **form provided in Patient Evaluation Forms section**
 - a. Patient and informant attend appointment for accurate history and evaluation
 - b. Go through all questions, even those not endorsed in pre-visit questionnaire
 - c. Refer to **Reference and Interpretation Manual as needed** for interpretation of patient/informant responses
- C. Complete **education-level-appropriate standardized cognitive test** (MoCA, MMSE, 3MS, SLUMS, etc., as desired), using cutoffs and interpretations provided in the **Reference and Interpretation Manual as needed**
 - a. See cognitive testing section of **Instruction Manual** for links to standardized cognitive testing tutorials.
- D. Complete physical, including neurological exam
- E. Pursue labs and Imaging-if indicated
- F. Obtain **biomarkers for Alzheimer's disease**, if appropriate according to the decision tree
- G. Move on to Step 3, Interpretation, using **Decision Tree** to finalize diagnosis. The decision tree is copied below.

Full Assessment **Diagnostic** Decision Tree (candidate)



INTERPRETATION TABLES: Full Cognitive Evaluation

History of Present Illness

Chief Complaint

CHIEF COMPLAINT	Comments:
We'll talk more in detail, but can you give me a brief overview of the main things that brought you here?	Gives an idea of main problem (memory, language, behavior, etc.)

NORMAL AGING OR MILD COGNITIVE IMPAIRMENT, depending on answers to rest of questions	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
Having trouble with memory	Having trouble with memory	PERSONALITY HAS CHANGED Interpretation - Uncommon chief complaint in Alzheimer's Disease (AD); could be Frontotemporal Dementia (FTD). After HPI, continue with full evaluation. Indications for Referral (for Diagnostic Purposes) - If behavior is indeed main problem, should refer as possible FTD or atypical dementia. REFERRAL INDICATED - I'm having TROUBLE SPEAKING, getting my words out. Interpretation - Word finding trouble could be typical of AD but is not usually chief complaint. Could be progressive aphasia. After HPI, continue with full evaluation (pay special attention to language questions). Indications for Referral (for Diagnostic Purposes) - If language is indeed main problem, should refer as possible progressive aphasia.

Duration

DURATION/EARLY SYMPTOMS	Comments:
To have a good understanding of what's going on, it helps to start at the beginning. What were the first symptoms you noticed, and how long ago was that?	First symptoms indicate which neurological systems are involved first. Each disease has its own characteristic first symptom that indicates a specific system involved, and progresses to involve other systems over time.

NORMAL AGING OR MILD COGNITIVE IMPAIRMENT, depending on answers to rest of questions	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED	
		Symptoms just noticed a few months ago or less, patient now has SIGNIFICANT IMPAIRMENT (e.g., out of work, not doing activities at home).	
		Interpretation Concerning for rapidly progressive dementia (RPD) or other encephalopathy.	
		Indications for Referral (for Diagnostic Purposes) Immediate referral to neurology for workup that would include imaging, EEG, LP, and comprehensive lab assessment, possible body scanning. Cancer/ paraneoplastic, autoimmune and infection are top concerns.	
		REFERRAL INDICATED Symptoms waxing and waning over a few months, also with sleepiness.	
		Interpretation Concerning for delirium or Lewy Body Dementia (LBD).	
		Indications for Referral (for Diagnostic Purposes) Begin metabolic assessment for delirium. If negative, refer immediately.	
		REFERRAL INDICATED Non-episodic memory problems emerge as early symptoms.	
		Interpretation If early symptoms are <u>not</u> memory, this could signify atypical AD or non-AD. Continue with full evaluation (pay special attention to questions focused on earliest symptoms).	
		Indications for Referral (for Diagnostic Purposes) Referral appropriate if early symptoms were not memory.	

Clarification of symptoms

CLARIFICATION OF SYMPTOMS For symptoms that the patient or informant reports, clarify any general statements such as: “I forget things” or “I have problems with a task.” Typically, it is necessary to ask for examples. ▪ If they forget things, ask: “Can you give me an example of the kinds of (things, words, events, etc.) you forget?” • If they have problems with tasks, ask: “When you are trying to do [task], what happens?”	Comments: People use terms like memory differently. For instance, someone who complains of memory problems might mean: ▪ word retrieval ▪ forgetting what you are doing after a few seconds ▪ forgetting events after minutes/days/hours ▪ difficulties with day-to-day activities (e.g. tasks) -For an AD diagnosis, “memory” issues related to forgetting recent events are of concern.
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Evolution –changes in symptoms

History of Present Illness EVOLUTION Have these symptoms worsened or changed over time? If yes, ask, “What makes you say things are worse?” or “What are you noticing that makes you think it’s getting worse?”	Comments: Avoid asking, “Why do you think they are worse?” This often results in theories about cause, such as “because I think my brain is deteriorating” or “because I’m stressed.” Focus on specific examples of what has changed or gotten worse.
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NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE • Used to FORGET once in a while, now forgets MORE FREQUENTLY; memory recall seems shorter (e.g., repeating questions after a short time)	REFERRAL INDICATED NO
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Evolution-new symptoms

EVOLUTION	Comments:
Have any new symptoms developed that weren't there at the beginning?	As new parts of the brain become involved, new symptoms emerge.

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT , or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE - Used to forget, now has other concerns, e.g. TROUBLE FINDING WORDS, difficulty finding the way around familiar places, more TROUBLE ORGANIZING, difficulty REMEMBERING STEPS to tasks. Interpretation - Typical of AD, indicates spread of disease to temporal, parietal and frontal regions. TYPICAL OF AD TYPE SYMPTOMS REFERRAL PER DECISION TREE - Starting to notice behavioral changes, e.g. GETTING IRRITABLE, MILD DELUSIONAL THINKING (e.g., thinks people might be stealing), decreased motivation. Interpretation - Typical behavioral features in AD. TYPICAL OF AD TYPE SYMPTOMS REFERRAL PER DECISION TREE - Developing profound problem with LANGUAGE AND COMMUNICATION. - Developing UNUSUAL BEHAVIOR, such as bizarre delusions (thinks they are someone else, thinks someone is not who they are), hallucinations, and abnormal social interactions with strangers. Interpretation - When reported late in the disease progression, can still be AD, but may indicate atypical syndrome or mixed pathology. Indications for Referral (for Diagnostic Purposes) - Continue with full evaluation. Pay attention to the language questions. If any concerning symptoms emerge, refer as indicated.	REFERRAL INDICATED NO
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Non –Neurodegenerative cause

POTENTIAL NON-NEURODEGENERATIVE CAUSES	Prompts:
Are there any particular events that were associated with the onset or worsening of the symptoms, like medical illness, accidents or major life stresses?	Was there evidence of problems/symptoms before the event (illness, accident, major life stresses)?
	Have these problems/symptoms worsened since the event occurred?

REFERRAL INDICATED
• If onset clearly relates to surgery, accident, etc. • If symptoms occurred prior to illness/event and/or have significantly worsened since the event.

Severity / Impact on Function

Instrumental activities of daily living

INSTRUMENTAL ACTIVITIES OF DAILY LIVING Has there been a change from baseline in ability to manage household due to problems with memory or thinking?	Prompts: Are you able to manage shopping? Do you have problems leaving items on the stove? Do you have any problems following recipes? Do you manage your own medications? Are you able to pay your bills on time? Are you able to complete household chores or projects? Are you still driving? Do you have trouble completing tasks at work? Have you lost your job because of trouble completing tasks at work?
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NORMAL AGING OR MILD COGNITIVE IMPAIRMENT, depending on answers to rest of questions	TYPICAL OF AD TYPE DEMENTIA REFERRAL PER DECISION TREE	REFERRAL INDICATED
• Still able to do [activity] but may take me longer. • No problems taking my medications, I use a pillbox. • Still paying bills, may take a bit longer. • Still driving, no accidents or concerns [check with informant if possible].	• Often buys duplicate items or forgets to buy items. • Burns food, not able to follow recipes or not cooking anymore. • Missing doses of medications. • Missing bill payments, making poor financial decisions, no longer doing financial tasks, has transferred responsibility to another. • Neglects household chores, difficulty operating household appliances. • Has gotten lost. • Notable scratches on car.	• Is able to perform activities, but does not seem interested or does not care about doing them.
Interpretation	Interpretation	Interpretation
• Could be consistent with normal aging. • Could also be consistent with mild cognitive changes but not dementia. • Could still be neurodegenerative.	• Consistent with AD. • Need to confirm with informant as patients may deny. • Informant reports concerns or a loss of independence.	• Not typical of AD. May reflect apathy due to Frontotemporal Dementia (FTD) rather than their ability to perform activity.
Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)
• Reassure if rest of assessment suggests normal aging, • Consider referral if rest of assessment points to mild cognitive changes due to typical AD or another cause.	• Typical of AD/No referral. • If no informant, consider home visit or Occupational Therapy (OT) evaluation to confirm.	• Refer to dementia specialist.

Basic activities of daily living

BASIC ACTIVITIES OF DAILY LIVING	Prompts:
Have there been changes in ability to manage basic activities of daily living due to changes in memory or thinking?	Still able to bathe without prompting or help? Still able to dress appropriately without help? Still managing bladder and bowel without accidents?

NORMAL AGING OR MILD COGNITIVE IMPAIRMENT, depending on answers to rest of questions	TYPICAL OF DEMENTIA DUE TO AD TYPE SYMPTOMS REFERRAL PER DECISION TREE	REFERRAL INDICATED
- Still able to bathe; dress appropriately and independently, though maybe less often. - Continent of bowel and bladder.	- Not bathing as regularly, forgetting to bathe. - Not changing clothes as often as previously. - Not dressing appropriately for the weather. - May have occasional bladder accidents early in disease progression.	Difficulty getting clothing on due to changes in perception rather than memory, especially if out of proportion to other deficits (early in the disease progression).
Interpretation	Interpretation	Interpretation
- Could be consistent with normal aging. - Could also be consistent with mild cognitive changes but not dementia. - Could still be neurodegenerative.	Typical of AD.	May be typical of Lewy Body Dementia (LBD) or Posterior Cortical Atrophy (PCA) with prominent visual difficulties.
	Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)
	Typical of AD/No referral. Note: changes due to physical limitations should be considered independent of assessment for AD.	Refer to dementia specialist.

Memory

MEMORY Do you have any problems with your memory or thinking?	Prompts: Misplacing items often (e.g., phone, keys)? Relying more on notes? Having more trouble with recent memory (conversations, recent events) compared to remote memory? Asking repetitive questions?
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NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
- Occasionally misplaces an item or forgets a word but it is not disruptive. - Occasionally walks into a room and forgets why but reason always comes back fairly quickly. - Retrieval of events/information may be slower than before but can retrieve desired information most of the time.	- Never forgets important events, but has LOSS OF DETAILS (e.g., remembered making an appointment but forgot what day). RELYING ON NOTES, CALENDARING, OR OTHERS to remember information they used to manage on their own. RECENT INFORMATION/EVENTS FORGOTTEN compared to relatively intact memory of information/events from long ago. MISPLACING ITEMS is a regular occurrence, disruptive to daily schedule. REPETITIVE questions or storytelling. - Symptoms are gradually and PROGRESSIVELY WORSENING.	

Language

LANGUAGE	Prompts:
Are you having difficulty expressing yourself or difficulty understanding words or conversation?	Can't find the word or name you want to use? Difficulty understanding what people are saying to you? Difficulty pronouncing words that were easy for you to pronounce in the past?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT , or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
- Occasionally can't find a word or name, but it comes back later. Does not disrupt a conversation or ability/desire to participate in conversation. - No comprehension problems.	- Consistent TROUBLE FINDING WORDS. Sometimes says wrong words, e.g. lib for fib, or clark for clock. Might have trouble finishing sentences. LESS PARTICIPATION in group conversations. - Reading activity declining. <u>Note:</u> Typical of AD if these complaints are not the presenting symptom but occur in the context of progressive memory concerns and/or other cognitive difficulties.	WORD FINDING IS THE PRIMARY and first presenting symptom, which impacts ability to communicate. - May be described as a "memory problem" but it's actually memory for words. FREQUENT WORD FINDING PAUSES, word searching, increased effort to get words out, relying on words like "thing," "stuff," and less ability to use detailed language to tell a story. - May cause embarrassment and/or dropping out of activities.
		REFERRAL INDICATED The primary and first presenting symptom is DIFFICULTY UNDERSTANDING SINGLE WORDS OR PHRASES; can't remember what some words mean.
		Interpretation Concerning for FTD, semantic variant and other temporal lobe disorders.

Executive functions

EXECUTIVE FUNCTIONS	Prompts:
Do you have difficulty planning, starting or finishing complicated tasks at home or at work?	Are you keeping your home or office as neat/organized/clean as you used to? Are you having problems finishing a task because you get distracted easily?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED See indeterminate below
	- Papers in office are now SCATTERED, DISORGANIZED. - They used to be able to FIX ANYTHING/DO COMPLICATED CRAFTS BUT NOW GET CONFUSED or the end result is not as good as before. DON'T DO THINGS IN AN ORGANIZED WAY e.g. <u>can't</u> figure out how to pack correct clothing for a trip but <u>can</u> plan a gathering or trip. - Gets CONFUSED ABOUT STEPS in cooking a recipe. - Gets EASILY DISTRACTED, doesn't finish tasks. - Comes home with items not on their shopping list or they WENT TO THE WRONG PLACE or they forgot to go to a location. - Problems with bills: LATE PAYMENTS - Missed payments - Paid twice. - Utility notices for cutoff	

INDETERMINATE
No longer takes on tasks because they feel overwhelmed when they think about doing it.
Interpretation
- Could be seen in AD, but not a specific indicator of any neurological illness (not diagnostically significant on its own). - Could be mood related or related to apathy/socioemotional function. Common in depression.
Indications for Referral (for Diagnostic Purposes)
Consider other causes (e.g., depression) and refer to a provider who handles mood issues (e.g., psychiatrist, psychologist).

Visual-Spatial

Getting lost

VISUAL-SPATIAL	Prompts:
Do you get lost while walking or driving?	Difficulty finding familiar places (walking or driving) i.e., grocery store, post office, friend's house, etc. Do you get lost in a familiar store or restaurant?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED NO
• Yes, we visited DC, and he had difficulty navigating. • Not familiar with DC, never been there.	• CALLED FROM THE PARKING LOT of a store when he was going to the neighborhood post office and was not sure what he should do. • Have had to call security at the mall at least twice because they COULD NOT FIND THEIR CAR. • Would not be able to go to store in car to get something. • Went on a trip to visit a place they know well, TOOK THE WRONG ROAD or roundabout way, was very delayed and did not stay in touch. • COULD NOT FIND THEIR WAY to the restroom at the restaurant where eat regularly.	
Interpretation	Interpretation	
• Not necessarily related to dementia/AD.	• Common in AD, could represent memory problems rather than visuospatial, but common in early AD.	

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Seeing/judging distances

VISUAL-SPATIAL Do you have difficulty seeing things properly or judging distances properly?	Prompts: Does your motor vehicle show evidence of damage? Do you have difficulty figuring out how to position yourself to sit in a chair? Do you complain of difficulty seeing while reading? Do you complain that your eyes don't work? Do you have trouble seeing things that are right in front of you?
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NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
	SOME THESE SYMPTOMS ARE PRESENT, but are not as prominent as memory, which is central to typical AD.	YES, THIS WAS THE EARLIEST AND MOST PROMINENT SYMPTOM. This could indicate an atypical form of AD, such as Posterior Cortical Atrophy (PCA). YES, THEY COMPLAIN THAT THEY CAN'T READ BECAUSE THEY HAVE TROUBLE SEEING. Visuospatial complaints are not usually severe enough in typical AD to affect reading. In addition, patients with Progressive Supranuclear Palsy (PSP) can complain of reading trouble because of eye tracking difficulty. YES, THEY HAVE HAD THEIR EYES CHECKED, AND THE EYE DOCTOR SAYS THAT NOTHING IS WRONG, BUT THEY JUST DON'T SEEM TO SEE THINGS THAT ARE IN FRONT OF THEM. Visuospatial complaints are not usually severe enough in typical AD to provoke a visit to the eye doctor. In addition, patients with PSP can complain of visual trouble because of eye tracking difficulty.

Difficulty recognizing people

VISUAL-SPATIAL	Prompts:
Do you have difficulty recognizing people?	

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
They have difficulty remembering the names of people at church but recognize faces.	They have DIFFICULTY REMEMBERING THE NAMES of people at church and do not recognize faces.	They think that someone important in their life (e.g. THEIR SPOUSE) IS SOMEONE ELSE.
Interpretation	Interpretation	Interpretation
Normal aging. Does not indicate facial recognition problems.	Consistent with AD. If prominent and progressive, may be a form of word-finding trouble consistent with AD.	Common in late AD. If this is an early and prominent symptom, it may indicate another diagnosis, such as Lewy Body Dementia (LBD).
		Indications for Referral (for Diagnostic Purposes)
		Referral if early and most prominent symptom.

Depression

DEPRESSION	Prompts:
Has your mood changed?	Crying a lot? Hopeless about life or about the future? Feeling worthless or bad about yourself?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED See indeterminate below
	• CRIES SOMETIMES WHEN FRUSTRATED because they forget something or make a mistake.	
	Interpretation	
	• Not necessarily indicative of depression. • Common complaint in early AD.	
	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	
	• Gets irritable, angry more easily than before. • Feels down a lot. • Cries a lot because they feel sad, hopeless. • Often thinks they would like to be dead (or having more active suicidal thoughts).	
	Interpretation	
	• Not necessarily indicative of depression. • Common in/may co-occur with AD and many other dementias.	

INDETERMINATE
• Doesn't want to do anything, MAKES EXCUSES NOT TO DO ACTIVITIES.
Interpretation
• Indicates apathy, common in AD and many other dementias, not diagnostically significant on its own). • May be consistent with depression if there are other indicators of depression-related low mood.
Indications for Referral (for Diagnostic Purposes)
• Consider other causes (e.g. depression) and refer to a provider who handles mood issues (e.g. psychiatrist, psychologist).

Apathy

APATHY	Prompts:
Have you lost motivation or energy to do things you used to enjoy?	Decreased interest in social activities? Decreased interest in church or community groups? Decreased interest in hobbies?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED See indeterminate below
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INDETERMINATE
DOESN'T WANT TO DO ANYTHING, makes excuses not to do activities.
Interpretation
- Indicates apathy, common in AD and many other dementias, not diagnostically significant on its own). - May be consistent with depression if there are other indicators of depression-related low mood.
Indications for Referral (for Diagnostic Purposes)
Consider other causes (e.g., depression) and refer to a provider who handles mood issues (e.g., psychiatrist, psychologist).

Irritability/Anger

IRRITABILITY/ANGER		Prompts:	
Do you become angry more easily?		Gets angry about things that would not have bothered them in the past?	

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED NO
	GETS ANGRY AND YELLS even in public, usually directed at family, sometimes at strangers (e.g., waiters, store clerks).	
	Interpretation	
	May occur with AD or other dementias. Proceed with evaluation.	

Disinhibition

DISINHIBITION	Prompts:
Sometimes we have patients who seem to forget how to behave in public. Has this been an issue?	Doing things that are embarrassing to family? e.g., calling people fat in public when they might hear? Telling dirty jokes in inappropriate situations? Telling personal things about self or family to strangers? Eating off other people's plates at restaurants?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
	GETS ANGRY AND MIGHT YELL, even in public, usually directed at family, sometimes at strangers (e.g., waiters, store clerks).	- Some SURPRISINGLY RUDE BEHAVIOR (e.g., leaves family gatherings or dinner table abruptly, ignores some relatives at social gatherings). - Any answer that clearly suggests FORGETTING SOCIAL RULES (see prompts).
	Interpretation May occur with AD or other dementias. If loss of inhibition is driven by anger, it is mainly directed at family. This is a non-specific and non-diagnostic general sign of irritability. Proceed with evaluation.	Interpretation Very concerning for Frontotemporal Dementia (FTD)

Delusions

DELUSIONS Have there been any problems with beliefs that are unusual or not realistic?		Prompts: Someone is out to get you? You have special powers or special relationships with famous or powerful people?
NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
	- Thinks PEOPLE ARE STEALING from them. - Thinks spouse is HAVING AN AFFAIR. - Thinks people who have DIED ARE STILL ALIVE.	- Thinks they HAVE SPECIAL POWERS, come from another planet. - Complex BIZARRE BELIEF systems (e.g., vast government conspiracy against them).
	Interpretation Common in moderate AD.	Interpretation Unusual in AD. Typical of non-degenerative psychiatric syndromes. Literature not clear on which dementias this goes with.

Hallucinations

HALLUCINATIONS		Prompts:	
Have you been seeing or hearing anything that might not be there (or others can't see or hear)?			
NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED	
	HEARING VOICES, name called, sounds in house. Interpretation - Significance unclear. Follow over time for changes, as this would not dissuade from AD diagnosis.	SEEING PEOPLE, SEEING LITTLE PEOPLE, ANIMALS. SEEING SHAPES AND PATTERNS on uniform surfaces (e.g., wall looks wavy or has patterns). Interpretation - Unusual in AD. Suggestive of Lewy Body Dementia (LBD). Often occurs at night, when in bed.	

Obsessions/Compulsions

OBSSESSIONS/COMPULSIONS Have you become fixated on certain ideas that you can't get out of your head, or have you developed specific rituals?	Prompts: Obsessions with certain political or religious ideas? Obsessions about timing or routine being adhered to precisely? Obsessions with specific games, movies, or specific forms of entertainment?
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NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
		- Driven to PERSISTENTLY DO CERTAIN ACTIVITIES all the time (e.g., play specific games, watch specific programs). RIGID FIXATION ON TIME, everything has to happen exactly as planned (e.g., meals at specific times). FIXATED ON CERTAIN PEOPLE (e.g., famous people, certain types of people).
		Interpretation Concerning for Frontotemporal Dementia (FTD).

Sleep

SLEEP	Prompts:
Any changes in sleep?	Waking up a lot in the middle of the night? Can't fall asleep?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED NO
Gets up a lot to urinate, but falls back to sleep.	AWAKE MORE AT NIGHT, often confused or disoriented. Sleeping during the day.	
Interpretation		
No relation to dementia		

Acting out dreams

SLEEP	Prompts:
Any problems acting out dreams (yelling, screaming, hitting)?	

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
Sometimes talks in their sleep		Yes, MOVES IN BED, HITS, YELLS OUT.
Interpretation		Interpretation
Probably no relation to dementia		Suggests REM sleep behavior disorder, associated with Lewy Body Dementia (LBD).

Snoring/breathing stoppages

SLEEP	Prompts:
Do you snore? Evidence of breathing stoppages? Sleepy during the day?	

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED See indeterminate below
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INDETERMINATE
Yes, SNORING, BREATHING STOPPAGES.
Interpretation
No relation to dementia, but consider referral for sleep apnea. Can explain mild cognitive complaints.
Indications for referral (for diagnostic purposes)
Consider referral to sleep center for sleep apnea assessment.

Eating behaviors

EATING BEHAVIORS	Prompts:
Have there been changes in your eating habits?	Eating more or less than usual? Unintentional weight gain or weight loss? Wanting to eat specific foods all the time? Wanting to eat sweets or carbohydrates more than you used to?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
A bit more liberal with fattening foods.	FORGETS TO EAT or forgets they've eaten. May lose weight.	CRAVING SWEETS, hoarding candies or other foods. - Eating voraciously, finishing everything on plate without thinking about it. - Stuffing mouth. - Fixated on certain foods or faddish dietary habits.
Interpretation		Interpretation
Probably no relation to dementia.		Concerning for Frontotemporal Dementia (FTD), consider referral.

Loss of Empathy

LOSS OF EMPATHY Do you seem less concerned about others' needs, problems?	Prompts: Not reacting appropriately in emergency/when someone needs help. Not reacting emotionally when someone has a particularly sad or happy event (e.g., a loss, major achievement).
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NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
		- Any CHANGE IN BEHAVIOR THAT SEEMS LIKE A MARKED DIFFERENCE compared with before - Any change in behavior that fits in ONE OR MORE OF THE PROMPT CATEGORIES Note: If changes can be solely accounted for by depression (e.g., frank admission of sadness or anhedonia by patient), refer to a mood specialist (e.g., psychiatrist or psychologist).

Judgment/Gullibility

JUDGMENT/GULLIBILITY	Prompts:
Do you seem to be more open to scams or solicitations?	Buying lots of magazines or online offers? Fooled by suspicious business arrangement?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
	Someone has TAKEN ADVANTAGE OF them (e.g., taking money from them, staying in their house).	Buying lots of magazines, SAYING “YES” TO MANY SOLICITORS, AGREEING TO QUESTIONABLE BUSINESS ARRANGEMENTS (e.g., paying money in advance in a situation where this is not normally done).
		Interpretation Concerning for Frontotemporal Dementia (FTD), consider referral.

History of Motor Symptoms

History of Motor Symptoms

The presence of any unexplained/undiagnosed motor symptom listed below is an appropriate indication for referral. Alzheimer's disease is not associated with motor symptoms until the advanced stage of dementia.

Parkinsonism/resting tremor

PARKINSONISM AND RESTING TREMOR	Prompts:
Do have involuntary shaking in your hands, arms, legs or chin?	

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
		Defer to exam.
		Indications for referral (for Diagnostic Purposes)
		If present, refer to specialist. More concerning if at rest.

Rigidity

RIGIDITY	Prompts:
Do your limbs feel rigid or stiff?	Are you able to turn your head and neck easily?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
		Yes.
Interpretation	Interpretation	Interpretation
- Normal aging. - Do not consider normal joint stiffness due to arthritis.	Rigidity is not consistent with AD.	Defer to exam.
		Indications for referral (for Diagnostic Purposes)

Bradykinesia

BRADYKINESIA	Prompts:
Have your movements been slowing down?	Are you walking slower? Does it take you longer to button your shirt? Is your handwriting smaller?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
Interpretation - Mild slowing due to age is normal. - Do not consider changes explained by orthopedic conditions.	Interpretation Mild slowing may be normal, but there should be no motor changes with AD.	- Yes. Interpretation - Defer to exam-Bradykinesia is a feature of parkinsonism and may reflect a movement disorder. Indications for referral (for Diagnostic Purposes) - If symptoms are concerning or disabling, refer to a specialist if present.

Parkinsonian/Gait abnormality

PARKINSONIAN AND GAIT ABNORMALITY	Prompts
Have you had a change in your ability to walk?	Are you stooped over when walking? Do you drag your feet when you walk? Are your steps shorter? Do you get stuck when walking?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
		Symptoms present.
Interpretation	Interpretation	Interpretation
Mild stoop may be normal.	There should be no motor changes with AD.	Defer to physical exam.
Indications for referral (for Diagnostic Purposes)		Indications for referral (for Diagnostic Purposes)
Screen for other orthopedic issues.		If symptoms are concerning or disabling refer to a specialist.

Frequent falls

FREQUENT FALLS	Prompts:
Have you fallen down in the past couple of years?	How many times? What were the circumstances of the falls? (Tripping, weakness of legs, loss of consciousness, unsteadiness) Are you unsteady on your feet?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
Interpretation	Interpretation	Symptoms present. Interpretation
Changes in balance are common in aging, but falls should not be frequent.	Falls are not common early in AD.	Frequent falls are not common early in AD and may be due to neurologic, orthopedic, sensory or cardiac causes.
Indications for referral (for Diagnostic Purposes)		Indications for referral (for Diagnostic Purposes)
- No referral. - Use of cane or walker explained by an orthopedic or other problem are okay.		If present and not explained or due to prior diagnostic issue, refer to specialist.

Unilateral weakness

UNILATERAL WEAKNESS Are you weaker on one side of your body than the other?		Prompts: Have you had a stroke? Do you have trouble using one hand? Are you limping or dragging one foot?
NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
Interpretation Some reduced strength when aging is normal but should not be asymmetrical.	Interpretation Focal weakness is not consistent with AD.	- Symptoms present. Interpretation - Even subtle change may indicate prior ischemic stroke.
Indications for referral (for Diagnostic Purposes) - No referral. - May be due to known previously diagnosed and evaluated condition.	Indications for referral (for Diagnostic Purposes) Typical of AD/No referral (may be due to previously diagnosed condition).	Indications for referral (for Diagnostic Purposes) If present and not explained by previously diagnosed condition, refer.

Myoclonus

MYOCLONUS Do you have involuntary movements in your limbs, such as jerks or twitching?		Prompts:
NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
	Yes, it occurs when awake, but is relatively mild and came late in the illness (e.g., after problems with basic Activities of Daily Living (ADLS) developed)	- Yes, it was a very early problem. - Yes, it is very severe and interfering with normal movement.
	Interpretation	Interpretation
	The jerking upon falling asleep is normal.	Not common in the early stages of AD.
	Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)
	Typical of AD/No referral.	- Refer, could be consistent with Creutzfeldt-Jakob disease (CJD). - Or could require specialized management because of severity.

Motor Neuron Disease

MOTOR NEURON DISEASE Have you had changes to your muscles? Have you lost muscle mass? Are your muscles weaker?	Prompts: Have any of your muscles become smaller?
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NORMAL AGING NO REFERRAL		TYPICAL OF AD TYPE SYMPTOMS		REFERRAL INDICATED
Interpretation		Interpretation		Symptoms present.
Minor global changes in muscle mass are normal.		Focal motor changes are not consistent with AD.		Interpretation
				Defer to physical exam.
				Indications for referral (for Diagnostic Purposes)
				Refer for fasciculations or unexplained or focal muscular atrophy.

Alien Limb

ALIEN LIMB	Prompts:
Does one of your arms behave as if it doesn't belong to you?	Has your arm done something (e.g. unbuttoned your shirt/grabbed something) without your awareness or control?

NORMAL AGING NO REFERRAL		TYPICAL OF AD TYPE SYMPTOMS		REFERRAL INDICATED
				Symptom present.
				Interpretation
				Defer to physical exam.
				Indications for referral (for Diagnostic Purposes)
				If present, refer. This may be alien limb associated with Corticobasal Degeneration or Syndrome (CBD/CBS).

Dysarthria

DYSARTHRIA	Prompts:
Have you had slurring of your speech?	Does your speech sound as if you are drunk?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
		Symptom present.
		Interpretation
		Defer to physical exam.
		Indications for referral (for Diagnostic Purposes)
		If present, refer to specialist, unless explained by previous injury/disease.

Dysphagia

DYSPHAGIA	Prompts:
Have you had trouble swallowing?	Have you coughed or choked when eating or drinking? Have you had any other difficulty swallowing liquids or solid foods?

NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
	No.	Symptom present.
	Interpretation	Interpretation
	Not present in early stages of AD.	- Dysphagia may occur in end stage of all forms of dementia. - Early symptoms may reflect other neurodegenerative disease.
		Indications for referral (for Diagnostic Purposes)
		Refer to specialist.

Family history

FAMILY HISTORY Are there any members of your family with mental health problems, dementia, Parkinson's or other neurological problems?	Prompts: Dementia Alzheimer's disease Parkinson's disease schizophrenia bipolar depression
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NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS	REFERRAL INDICATED
One parent with dementia or Parkinson's, age of onset mid-60's or older.	One sibling with dementia or Parkinson's, age of onset before 65.	Two or more members of family (e.g., two siblings; one parent and one sibling) with dementia or Parkinson's AND age of onset for both before age 65.
Interpretation	Interpretation	Interpretation
- Consistent with normal aging. - Greatest risk of AD is age.	Common. However, if your patient has symptoms (i.e., the second person in same generation with symptoms), probe for symptoms in the other family member/s. Ask about atypical symptoms in other family members (e.g., had personality problems at presentation).	Person may be at risk even if they themselves do not have meaningful symptoms.
		Indications for referral (for Diagnostic Purposes) Consider referral for genetic counseling if patient is concerned about their family history.

Physical and Neurological Exam

General Appearance

Personal Hygiene and Dress

GENERAL APPEARANCE PERSONAL HYGIENE AND DRESS	
FINDING/INDETERMINATE	
• Soiled clothing • Malodorous (urine, feces)	
Interpretation	
• Typical of AD if significant functional impact (history indicates needs help with dressing and bathing). • Could be indicative of atypical dementia if very early.	

Signs of Trauma

GENERAL APPEARANCE SIGNS OF TRAUMA	
FINDING/INDETERMINATE	
• Bruising on face, torso	
Interpretation	
• Could indicate falls, if supported by history. • Could be sign of physical abuse.	
Indications for referral (for Diagnostic Purposes)	
• Physicians are mandatory reporters to Department of Public Health for elder abuse.	

Cranial Nerves

CRANIAL NERVES CRANIAL NERVES 3,4,6	
FINDING	
• Extraocular movements are impaired	
Interpretation	
• Not typical of AD. • Occurs in Progressive Supranuclear Palsy (PSP), and Wernicke's encephalopathy.	
Indications for referral (for Diagnostic Purposes)	
• Refer to neurology.	

Motor

Bulk

MOTOR BULK	
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FINDING
- Atrophy - Fasciculation's
Interpretation
- Not typical of AD. - May indicate amyotrophic lateral sclerosis (ALS).
Indications for referral (for Diagnostic Purposes)
Refer to neurology unless findings are previously documented and explained.

Tone

MOTOR TONE	
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FINDING		FINDING
Paratonia.		Cogwheel rigidity.
Interpretation		Interpretation
- Failure to relax during passive movement of the limbs – common in normal aging. - Also common in AD.		- Parkinsonian features only common in late-stage AD. - If early in the course of dementia could be (Lewy Body Dementia (LBD) or Parkinson's disease (PD).
Indications for referral (for Diagnostic Purposes)		Indications for referral (for Diagnostic Purposes)
No referral.		Refer to neurology if early in the course.

Power

MOTOR POWER	
FINDING	
Hemiparesis (facial asymmetry, unilateral weakness, pronator drift).	
Interpretation	
- Not typical in AD. - May indicate stroke.	
Indications for referral (for Diagnostic Purposes)	
Refer to neurology unless findings are previously documented and explained.	
FINDING	
Focal weakness in any muscles.	
Interpretation	
- Parkinsonian features only common in late-stage AD. - If early in the course of dementia could be Lewy Body Dementia (LBD), Parkinson's disease (PD).	
Indications for referral (for Diagnostic Purposes)	
Refer to neurology unless findings are previously documented and explained.	

Tremor

MOTOR TREMOR	
FINDING	FINDING/INDETERMINATE
Resting tremor, 4–8Hz, may be “pill-rolling.”	Postural or action tremor, 8–12Hz.
Interpretation	Interpretation
Parkinsonian tremor not typical in AD.	Not typical in AD, can be seen in other dementias, drug reactions, essential tremor (benign), and normal aging if very mild.
Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)
Refer.	Refer to neurology if severe and impairing function. Otherwise, referral not necessary

Other Parkinsonian Motor Features

MOTOR OTHER PARKINSONIAN MOTOR FEATURES	
FINDING	
- Masked facies - Hypophonia - Micrographia - Bradykinesia	
Interpretation	
- Not typical in AD. - Parkinsonian features occur in Parkinson disease (PD), Lewy Body Dementia (LBD), and in other dementias in late stage.	
Indications for referral (for Diagnostic Purposes)	
Refer – if early in the course of dementia or debilitating.	

Myoclonus

MOTOR MYOCLONUS	
FINDING	
Brief, shock-like, involuntary jerks.	
Interpretation	
May occur in late forms of AD.	
Indications for referral (for Diagnostic Purposes)	
Refer if early in course or debilitating.	

Deep Tendon Reflexes

REFLEXES DEEP TENDON REFLEXES	
FINDING	
Reflex asymmetry.	
Interpretation	
Not typical in AD.	
Indications for referral (for Diagnostic Purposes)	
Refer if unexplained or in combination with hemiparesis.	

Posture and Stance

STANCE POSTURE AND STANCE	
FINDING	FINDING/INDETERMINATE
Retropulsion (nearly falls if pulled back by shoulders from standing position).	Stooped posture.
Interpretation	Interpretation
Not typical in AD, can occur in aging.	Not typical in AD, can occur in aging.
Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)
Refer history of falls.	Refer if associated with other signs of parkinsonism.

Gait/Walking

GAIT WALKING	
FINDING	
- Reduced arm swing. - Shuffling gait.	
Interpretation	
Parkinsonian features not typical in AD until late stage.	
Indications for referral (for Diagnostic Purposes)	
Refer any gait abnormalities to neurology and physical therapy.	
FINDING	
- One leg stiff and foot does not come off ground well. - Shuffling gait.	
Interpretation	
Not typical of AD, hemiparetic gait.	
Indications for referral (for Diagnostic Purposes)	
Refer to neurology and physical therapy unless previously explained.	
FINDING	
Failure to lift feet off the ground.	
Interpretation	
Not typical of AD, called "magnetic gait," can be a sign of Normal Pressure Hydrocephalus (NPH).	
Indications for referral (for Diagnostic Purposes)	
Refer to Neurology.	

Standardized cognitive tests

Reference chart for standard cut-off scores

COMMONLY USED STANDARDIZED COGNITIVE TESTS

This toolkit makes limited use of cognitive testing. It assumes that the clinician will use a relatively short test that provides a single score representing overall cognitive function. The reference scores below assume that the patient has completed at least 6 years of education, and is being tested in their native language, with a version of the test that has been developed for use in that language.

The chart below provides cutoff scores for five commonly used tests. In each case, we provide a cutoff score for normal. A patient who scores at or above that number would be said to be performing normally on that test. We also provide a second cutoff, which denotes that maximum score that would be typically seen in a patient that has dementia due to Alzheimer's disease, i.e. most patients with dementia due to Alzheimer's disease should score below this cutoff.

The clinician should administer the test of their choice, and save the result for use in their final decision-making, as directed in the 'Decision Tree'

A BRIEF POWERPOINT IS AVAILABLE UPON REQUEST TO REVIEW BASIC CONCEPTS FOR THESE COGNITIVE TESTS. PDF VERSIONS OF THESE POWER POINTS CAN BE FOUND IN SECTION 3: PATIENT ASSESSMENT FORMS.

STANDARDIZED COGNITIVE TEST	Normal Performance Range	Typical Range for Patients with dementia due to AD
Montreal Cognitive Assessment (MoCA)	Greater than 26	Less than 22*
Mini-Mental Status Exam (MMSE)	Greater than 27	Less than 22*
Modified Mini-Mental Status Exam (3MSE)	Greater than 87	Less than 80*
Saint Louis University Mental Status (SLUMS)	Greater than 26	Less than 19
Rowland Universal Dementia Assessment Scale (RUDAS)	Greater than 26	Less than 22

***Standardized cognitive testing limitations:**

Testing results from patients with a low level of education, who speak English as a second language and/or are non-English speaking can be difficult to interpret and result in false positives. Cut-off scores above are for those patients with 6 years or more of education. For those who are not fluent in English and those with low levels of education, recommendations also include relying more on informant information or referring to a dementia specialist. See section below for additional guidance on testing in specific contexts

Low literacy and non-fluency in English: Cognitive tests for full assessment

The toolkit cannot currently recommend appropriate forms of cognitive testing for all of the wide varieties of cultural and language contexts encountered in practice. However, the toolkit has identified reasonable approaches for the common contexts in the table below. In these contexts, the identified test can be used in place of the tests recommended above for the full cognitive evaluation. The test should be delivered in the patient's native language by a medical provider who is a fluent speaker in that language, and not through an interpreter. If you must use an interpreter, they need to be professionally trained to do cognitive testing. When an interpreter is used, the data may be unreliable, and the evaluation should then rely on patient and informant history. For low levels of education, the cutoff score will be different from those with higher levels of education.

The Spanish version of the MoCA can be found here:

https://www.mocatest.org/pdf_files/test/MoCA-Test-Spanish.pdf and can be used for pts greater than 6 years of education. Limited data are available for people with less than 6 years of education. One test that has been investigated in low literacy Spanish people is the simplified version of the MMSE. The toolkit provides a version of the MMSE suitable for use in low literacy Spanish speaking individuals from South and Central America in the **Patient Assessment Forms section**. Cut-offs for normal and dementia are provided in the table below and are based on the work by Custodio, et al.-<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7232574>.

The RUDAS has been advocated as a cognitive testing tool that is usable in many languages and cultures. The toolkit developers are aware of data investigating its utility in Spanish speakers including high and low literacy. (Custodio, et al.-

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7232574/>.) Training information for the RUDAS can be found here: <https://www.dementia.org.au/resources/rowland-universal-dementia-assessment-scale-rudas>.

We have provided cut-offs for decision making in the table below.

There are several Chinese versions of MoCA. The toolkit provides versions of MoCA and MoCA basic in Chinese in the **Patient Assessment Forms section**.

CONTEXT	Recommended Test	Normal Performance Range	Typical Range for Patients with dementia due to AD
Spanish >6 yrs of education	Montreal Cognitive Assessment (MoCA)	Same as in English Greater than 26	Same as in English Less than 22
	RUDAS	Greater than 23	Less than 22
Spanish with 6 or fewer years of education	Mini Mental State Exam (MMSE)	Greater than 19	Less than 14
	RUDAS	Greater than 23	Less than 19
Chinese >6 yrs of education	Montreal Cognitive Assessment (MoCA)	Same as in English Greater than 26	Same as in English Less than 22
Chinese with 6 or fewer years of education	Montreal Cognitive Assessment-basic (MoCA basic)	Greater than 19	Less than 12

Imaging

IMAGING CT or MRI		
NORMAL AGING NO REFERRAL	TYPICAL OF AD TYPE SYMPTOMS, can be MILD COGNITIVE IMPAIRMENT, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
		Enlarged ventricles (disproportionate to atrophy), concerning for Normal Pressure Hydrocephalus (NPH).
		Interpretation
		If concern has been raised, should be directly assessed by neurologist.
Indications for referral (for Diagnostic Purposes)	Indications for referral (for Diagnostic Purposes)	
Reassure, no referral needed.		Refer to neurology.
		REFERRAL INDICATED
		Atrophy primarily in the frontal and/or temporal regions accompanied by clinical symptoms atypical for AD (apathy, personality changes, language dominant).
		Interpretation
		Could be behavior variant Frontotemporal Dementia (bvFTD) or atypical dementia.
		Indications for referral (for Diagnostic Purposes)
		Refer to dementia specialist
		REFERRAL INDICATED
		Severe white matter disease, strokes.
		Interpretation
		Could be co-pathology with AD but want to rule out vascular diseases.
		Indications for referral (for Diagnostic Purposes)
		Refer to dementia specialist.
INDETERMINATE		
Global volume loss, greater than expected for age.		
Interpretation		
Often read for AD, potentially consistent with any dementia, or aging.		
Indications for referral (for Diagnostic Purposes)		
Consider history. Refer if atypical for AD.		

Basic Lab work

LABS CBC, METABOLIC PANEL, TSH, B12	
NORMAL AGING NO REFERRAL - Should be normal or at baseline for patient considering other medical conditions. - If abnormal, typical cognitive symptoms persist after correction. Interpretation - Consistent with normal aging.	INDETERMINATE - Abnormal – symptoms resolve after correction. Interpretation - Continue to monitor but may be reversible deficit. Indications for referral (for Diagnostic Purposes) - Refer if cognitive symptoms persist after correction.
LABS RPR	
NORMAL AGING NO REFERRAL - Normal. Interpretation - Typical of normal aging, or AD.	REFERRAL INDICATED - Positive, Interpretation - May indicate acute or chronic infection. Indications for referral (for Diagnostic Purposes) - Requires referral to specialist.

AD biomarkers

Blood p-tau217 -or- Amyloid PET -or- CSF Abeta43, tau, p-tau	
NORMAL AGING NO REFERRAL	INDETERMINATE
- AD biomarkers should not be ordered in asymptomatic patients - If they are obtained they should be normal	Abnormal – (i.e. elevated biomarker for AD).
Interpretation	Interpretation
- Normal AD biomarkers are common and consistent with normal aging - If normal in the setting of AD symptoms, suggests AD is not the cause of symptoms - If strongly suspect AD, can consider additional biomarker studies (e.g., amyloid PET if current result is from blood)	- Indicates AD changes affecting the brain - Interpretation depends on symptoms - If symptoms are consistent with AD, then suggests that AD is the cause
	Indications for referral (for Diagnostic Purposes)
	- If abnormal in the setting of AD symptoms, referral depends on other considerations by the clinician - If abnormal in the setting of atypical symptoms, may be mixed etiology, referral is warranted

STEP THREE: DECISION SUPPORT

Interpretation of Full Assessment Outcomes

Outcome scenarios and referral recommendations

Based on the responses to the questions in the history, the examination (including cognitive testing), and lab testing, the full assessment can produce several outcomes, as detailed below. These outcomes and suggested management are also depicted in the **decision tree**:

1. **All responses fall into green categories**, indicating that the patient and informant perceive no functional changes, and no cognitive or behavioral changes beyond the types of symptoms that would be encountered with normal aging. The final decisions in this scenario are guided by the cognitive testing:
 - a. If performance on the **cognitive test is above the cutoff for normal**, the toolkit suggests that you reassure the patient and plan periodic reassessment every year or two to identify any worsening of symptoms or new symptoms. Referral is likely unnecessary.
 - b. If performance on the **cognitive test is below the cutoff for normal**, this indicates that the history or testing may be unreliable. The toolkit would recommend referral in this situation.
2. **Several responses fall into yellow categories**, indicating symptoms of the type seen in AD, and the **questions about activities of daily living (ADLs) indicate that they are NOT affected**, indicating **mild cognitive impairment**. The final decisions in this scenario can be guided by the cognitive testing and biomarker results:
 - a. If performance on **cognitive test is below the cutoff for dementia**, this indicates that the history or testing may be unreliable. The toolkit would recommend referral in this situation.
 - b. If performance on the **cognitive test is above the cutoff for dementia**, the clinician can pursue **AD biomarker testing**. If positive, then the conclusion is that the symptoms are likely due to AD. If negative, the symptoms are not likely to be due to AD. Referral decision depends on the clinician's goals for management.
3. **Several responses fall into yellow categories**, indicating symptoms of the type seen in AD, and the **questions about activities of daily living (ADLs) indicate that they ARE affected**, indicating **dementia**.
 - a. If performance on **cognitive test is above the cutoff for dementia**, this indicates that the history or testing may be unreliable. The toolkit would recommend referral in this situation.
 - b. If performance on the **cognitive test is below the cutoff for dementia**, the clinician can pursue **AD biomarker testing**. If positive, then the conclusion is that the symptoms are likely due to AD. If negative, the symptoms are not likely to be due to AD. Referral decision depends on the clinician's goals for management.
4. **Some of the responses fall into indeterminate categories**, indicating that there might be a non-neurodegenerative condition that may be affecting cognition, such as a psychiatric disorder, sleep disorder, or other problem. In this case, the problem should be managed, including referral as appropriate. Further decisions would depend on the outcome of that process:
 - a. If the condition is managed and the cognitive or behavioral symptoms resolve, reassure the patient and plan periodic reassessment every year or two using the detection questions.
 - b. If the **condition is managed but the symptoms persist, and the rest of the assessment indicates AD**, the clinician should proceed along the path for AD type of symptoms
 - c. If **one or more responses fall into red categories**, indicating symptoms that are not typical for AD referral to a dementia specialist is warranted.

Referral Considerations for AD-spectrum cases

The decision regarding referral to a dementia specialist for these cases depends on the clinical scenario

If the patient has AD-type symptoms, and:

1. **biomarkers have confirmed that AD** is a likely contributor to symptoms,
2. the patient has relatively a mild degree of impairment, either mild cognitive impairment or mild dementia,

then they may be eligible for anti-amyloid therapies that are currently only being administered in expert settings. In this case, the clinician must consider whether this is a possibility for this patient. A number of considerations may influence whether the clinician thinks this is appropriate for the patient, including:

1. The ability of the patient to receive frequent infusions at a specialized center and receive multiple MRIs for monitoring of adverse effects
2. The severity of impairment is relatively mild, usually at a level of cognitive changes without dementia or mild dementia. There is no universally accepted criterion for what constitutes a mild stage dementia, but many expert clinicians would say that if the disease has progressed to the point where a patient has stopped performing any instrumental activities of daily living cognitive changes and some changes in basic activities of daily living are apparent, this would not be considered mild.

In patients who have AD type symptoms and are **AD biomarker negative**, it is worth considering whether the biomarker could be a false negative. For example, if a patient has an insidiously progressive syndrome that has predominantly memory symptoms, and there are no other conditions to explain the symptoms, they otherwise might be eligible for anti-amyloid treatment, and a blood biomarker such as p-tau217 was used to assess for AD, then obtaining an amyloid PET scan or CSF Abeta and tau testing might be advisable before finalizing the assessment.

If a Referral to a Dementia Expert is Planned, it is Valuable to Provide the Following Information:

Goals for referral (include one or more)

- Second opinion about history and/or exam and findings
- Pursue further work up necessary
- Clarify diagnosis
- Offer treatment recommendations
- Patient and family requested the referral

What to include

- Brief summary of time course and prominent symptoms prompting referral
- Pertinent general medical records – summary of medical conditions and medications
- Results of any assessments of cognitive problems, including CD with scan images and copies of cognitive testing results if available

Some suggestions about how to develop a network to make referrals:

[State Alzheimer's Disease Centers](#) – ten academic sites that evaluate cognitive complaints

[Federal Alzheimer's Disease Research Centers](#)

[American Academy of Neurology](#) – find a neurologist near you

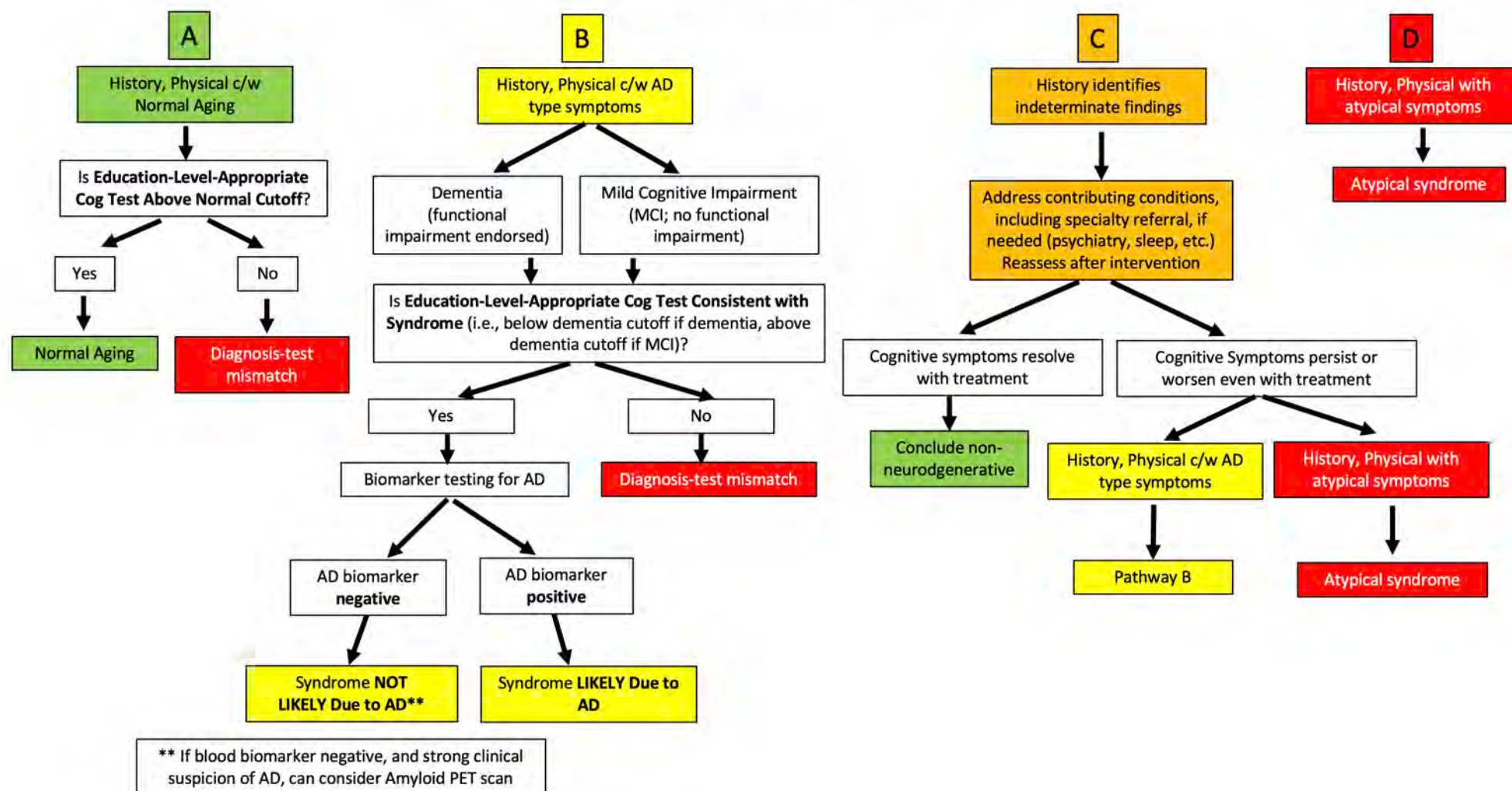
[Alzheimer's Association](#) – local chapters can often make referrals to MD with expertise

[Northern California Neuropsychology Forum](#) – find a neuropsychologist

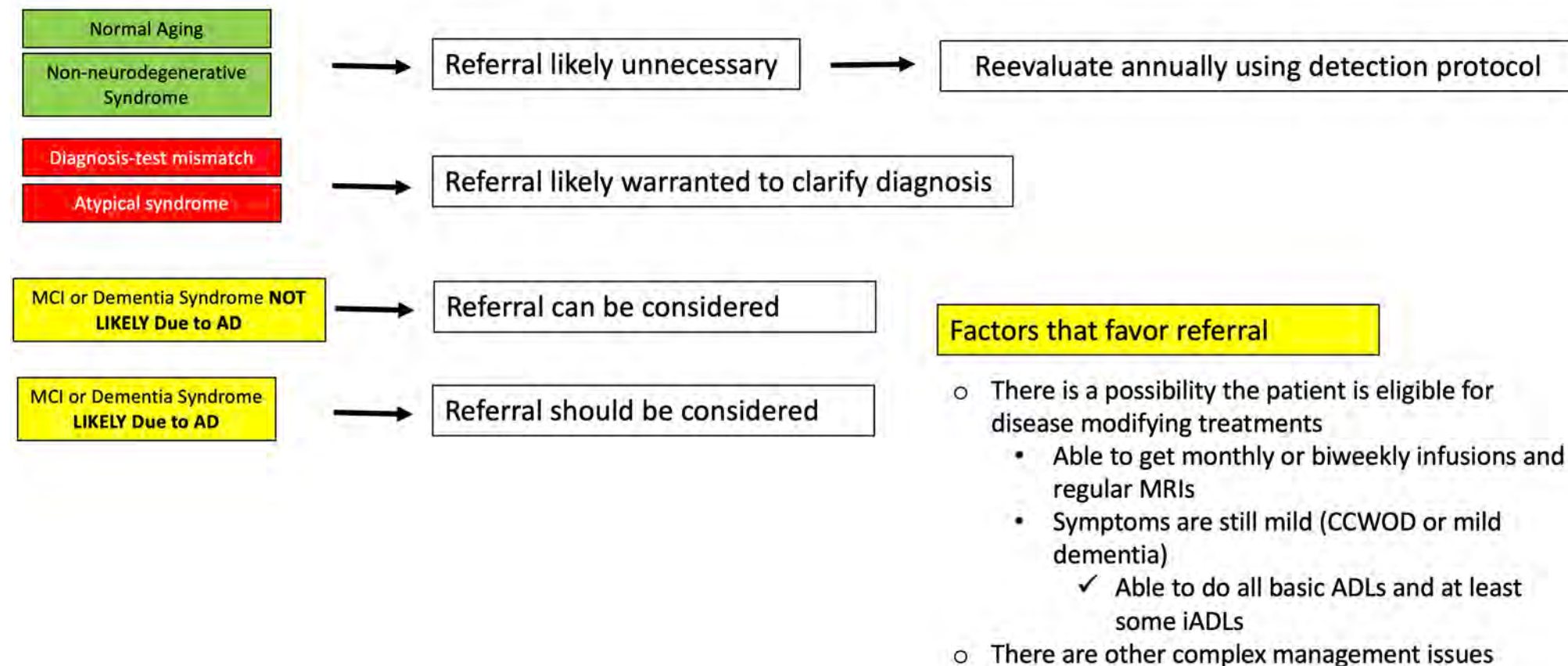
[American Academy of Clinical Neuropsychology](#) – search for clinical neuropsychologist

Diagnostic Decision Tree

Full Assessment **Diagnostic** Decision Tree (candidate)



Management and Referral Guidance (candidate)



STEP FOUR: DISCLOSURE AND SCRIPTS

Mild Cognitive Impairment

The script below assumes you have identified cognitive difficulties that seem in excess of normal aging, but not severe enough to be labeled as dementia. They may be due to a medical condition that might explain it (such as depression), or you *may not* have identified any medical conditions that may explain it, which may make neurodegenerative disease more likely. The script below addresses how to discuss the mild cognitive changes, your findings, and relevant plans for management and further assessment if you think this is appropriate.

The bullet points below identify key components of the discussion.

- Ask patient and family their impression of the cause of problem and goals of appointment
- Explain dementia syndrome, because most patients don't know what that is, and think that Alzheimer's and dementia are the same thing
- Explain components of work up/ruling out non-neurodegenerative causes
- Explain neurodegenerative disease, which helps patients understand what your workup can and can't say
- Describe and discuss clinical diagnosis and syndrome of Alzheimer's disease
- Discuss possible blood testing for Alzheimer's disease, if you feel it's warranted

Script to discuss mild cognitive impairment

"Thanks so much for your patience as we have collected all the information we need to assess your complaint. Now that we have gotten a full description of the problem and we have gotten results on the blood tests and brain imaging results [can refer to MRI or CT scan, as appropriate], this is a good time to review what we have found and discuss what is causing these problems.

Before I tell you what I think about the problems we've been discussing, I think it would be good for you to tell me what you are hoping for in this discussion. Do you have your own theories about what is causing the problem that you would like me to address? Are there specific diseases that you are worried about? Are there other specific questions that you would like me to answer if I can?"

This helps to establish whether the patient/family is expecting to hear about Alzheimer's disease, or whether they think this is all normal. It allows them to raise questions about the cause, and they may ask about toxins or genetics. Often, patients will raise questions about the future here, and about the role of certain treatments they read or heard about. They may ask questions like "do I have dementia or Alzheimer's disease".

"These are all great questions. I think our discussion will address some of them today, but we may talk about some of these questions during future visits. To start off, the answer to many of these questions starts with trying to establish the cause of the problem. First, it's helpful to talk about terminology. In medicine, we often use a term called dementia. The word dementia means that a person has had worsening problems with memory or thinking, and that the problem has gotten bad enough that it is preventing people from doing their normal daily functions, like working, or paying bills and similar tasks. The term dementia is important, because when a person has thinking problems that are bad enough to be called dementia, there is always some disease that is affecting the

brain's function and causing the problems. These include various types of medical problems in the body that also affect the brain, such as problems in body chemistry, vitamin deficiencies, and infections, and there could be various kinds of problems that happen in the brain specifically, like brain tumors and strokes, and also diseases that we call neurodegenerative diseases, such as Alzheimer's disease. Neurodegenerative diseases cause the nerve cells to shrink and not communicate well with each other, and because of these problems, the brain cannot do its job as well as before. The reason that this happens is that there are proteins that are building up in the brain and injuring the nerve cells. Proteins are chemicals, or building blocks, that normally do certain jobs in the brain, but in neurodegenerative disorders they change and instead of doing their normal jobs they start to injure the nerve cells. Alzheimer's is one kind of neurodegenerative disease that happens when certain proteins start to work badly. There are other neurodegenerative diseases, for example Parkinson's disease, that happen when other proteins start to work badly. Each of these diseases is caused by a different protein going bad. These changes cannot be seen by most kinds of testing, including most kinds of brain imaging, but we know they occur because researchers have looked at the brains of many people who had memory problems and then died and they have seen these neurodegenerative changes.

In your case, you do have some problems with your memory that seem to be a bit worse than we would usually see in someone your age, but it's not affecting your everyday abilities, and so it's not severe enough to be called dementia. BUT, it was still important to do a thorough assessment to see if there is any specific explanation of your complaints from a general medical problem that we might have found through blood testing or a brain scan."

If you identified any general medical issues you think may explain the cognitive problems that needs addressing, you can say the following.

"In your case, we identified XXXXXXXXXX, which can be associated with cognitive complaints. Hopefully, this is the main cause of your problems, and it is not a neurodegenerative disease. So, the first thing we should do is try to address this issue by XXXXXXXX (referring, treating as appropriate) and then seeing if your [memory or other thinking problems] improve."

If you did not identify any general medical issues that could explain the cognitive problems, you can say the following.

"We did not find any evidence for a specific general medical issue that can explain your complaints. This happens a lot. When someone has complaints that are not severe enough to be called dementia, it is difficult to be sure whether this is due to a neurodegenerative disease. Research shows that some patients with these types of cognitive changes that are not severe enough to be called dementia are already accumulating the proteins associated with neurodegenerative disease. In these cases, the memory does get worse over time and people do eventually develop dementia. On the other hand, normal aging does cause changes in thinking, and many patients with milder cognitive changes do not appear to have any neurodegenerative diseases and maintain the same thinking abilities for many years, and some even improve. It is very difficult to decide which patients might have these neurodegenerative proteins and to predict who might get worse over time. This means that we have to check in with you every few months to see if the memory or thinking problems are getting worse.

This might be a good time to **begin to address your management**

Whether you have a neurodegenerative disease or not, it's important to think about what you can do to prevent the problem from getting worse. Research shows that things that are bad for your heart, like smoking, high blood pressure, diabetes, and being overweight, are also bad for your brain. Most researchers believe that being careful

about avoiding these problems, and treating them if they are affecting you, can cut down the chances that your memory and thinking will get worse, even if you have proteins in your brain that cause neurodegenerative disease. Therefore, the most important thing we can do right now is to do everything we can to lower your risks to your heart and brain. In your case, I think it is particularly important to focus on XXXXXXXXXX [recommendations tailored to the individual regarding smoking, blood pressure, weight, diet, etc.].

If you are thinking about pursuing blood biomarker testing for Alzheimer's disease, you can continue in the following way. Language about an amyloid PET scan would be similar.

Another question we should talk about is whether you want to know more about whether you could have a neurodegenerative disease. We don't have a way of knowing the answer for every one of those diseases, but we do have tests that can tell us more about the possibility that you have Alzheimer's disease. There is now a blood test that tells us whether you have one of the proteins that causes Alzheimer's disease building up in the brain. This test can only tell us about Alzheimer's disease, and not any of the other neurodegenerative diseases. So if the test is abnormal, it says that Alzheimer's proteins are building up in the brain. If it's normal, there could still be other neurodegeneration proteins building up in the brain, but probably not Alzheimer's proteins.

If the test shows Alzheimer's proteins, that doesn't mean we know everything about your future. It does mean that we have to worry that your memory and thinking abilities may get worse in the future, but we can't know for sure if that will happen, or when it will happen if it does. Knowing that Alzheimer's disease proteins are building up in the brain might be helpful to make sure you and your family are prepared in case that does happen, and it can also help us think about special treatments that might be possible. If necessary, we can refer you to a specialist to think more about these treatments.

Cognitive changes with dementia

First, it's useful to start with an introduction and to assess the patient and family's goals and expectations. The bullet points below identify key components of the discussion.

- Ask patient and family their impression of the cause of problem and goals of appointment
- Explain dementia syndrome
- Explain components of work up/ruling out non-neurodegenerative causes
- Describe and discuss clinical diagnosis and syndrome of Alzheimer's disease
- Discuss possible blood testing for Alzheimer's disease

Script to discuss the diagnosis of dementia

"Thanks so much for your patience as we have collected all the information we need to assess your complaint. Now that we have gotten a full description of the problem, and we have gotten results on the blood tests and brain imaging results [can refer to MRI or CT scan, as appropriate], this is a good time to review what we have found and discuss what is causing these problems.

Before I tell you what I think about the problems we've been discussing, I think it would be good for you to tell me what you are hoping for in this discussion. Do you have own theories about what is causing the problem that you

would like me to address? Are there specific diseases that you are worried about? Are there other specific questions that you would like me to answer if I can?"

This helps to establish whether the patient/family is expecting to hear about Alzheimer's disease, or whether they think this is all normal. It allows them to raise questions about the cause, and they may ask about toxins or genetics. Often, patients will raise questions about the future here and about the role of certain treatments they read or heard about. They may ask questions like, "Do I have dementia or Alzheimer's disease?"

"These are all great questions. I think our discussion will address some of them today, but we may talk about some of these questions during future visits. To start off, the answer to many of these questions starts with trying to establish the cause of the problem. First, it's helpful to talk about terminology. In medicine, we often use a term called "dementia." This is not really a complete diagnosis but just a description of the problem. The word "dementia" means that a person has had worsening problems with memory or thinking and that the problem has now become severe enough that it's preventing people from attending to their normal daily functions, like working or paying bills and similar tasks. The term "dementia" is important because when a person's thinking problems get severe enough to be called "dementia," there is always some disease that is affecting the brain's function and causing the problems. The process that we went through was necessary to try to find this cause. There are many possible causes of dementia. These include various types of medical problems in the body that also affect the brain, such as problems in body chemistry, vitamin deficiencies, and infections, and there could be various kinds of problems that occur in the brain specifically, like brain tumors and strokes. As you know, we have done a thorough examination, blood tests, and a scan of your brain. We did not find evidence of any general medical problems in the body that could explain your memory complaints, and the scan did not show any strokes or brain tumors."

Many patients have systemic medical disorders such as diabetes, hypertension, or sleep apnea, which may increase the risk of dementia but would not be considered adequate explanations in themselves. The health provider might modify their discussion to acknowledge these problems and explain that they do not cause dementia by themselves.

"Once we have considered the kinds of problems that could show up on those tests and not found any evidence of those kinds of problems, we have to ask ourselves whether there are diseases that could cause the kind of trouble you are noticing but would not show up on any of those tests, and the answer is that there are diseases like that. We generally call them neurodegenerative diseases: "neuro," meaning it is affecting the nerve cells, and "degenerative," meaning that it is causing more and more trouble over time. Nerve cells are tiny structures in your brain that work together to take care of all of your thinking and movement. There are billions of them in the brain. Neurodegenerative diseases cause the nerve cells to shrink and not communicate well with each other, and some of the nerve cells even die, and because of these problems, the brain can't do its job as well as before. The reason that this happens is that there are proteins that are building up in the brain and injuring the nerve cells. Proteins are chemicals that normally do particular jobs in the brain, but in neurodegenerative disorders, they change and instead of doing their normal jobs they start to injure the nerve cells. These changes cannot be seen by most kinds of testing, including brain scans like a CAT scan or MRI, but we know they occur because researchers have looked at the brains of many people who had memory problems and then died. They have seen these neurodegenerative changes."

The most common neurodegenerative disease is Alzheimer's disease. This is caused by the accumulation of two proteins: one called a-beta and another called tau. Even though we cannot easily see these proteins, we can

know that they are there because of their effects on the brain. Researchers have shown that when these proteins that cause Alzheimer's disease begin to affect the brain, they do not affect the whole brain at once, but they tend to start by affecting the parts of the brain that have to do with memory. That's why the earliest changes in people with Alzheimer's disease are usually memory problems. As the disease spreads to other parts of the brain, it can cause other symptoms. In your (or your family member's) case, the problems you have told me about and the memory [or cognitive] tests tell us that there is a problem that began with memory difficulties, and it has slowly worsened over time. It is now affecting daily function, and therefore, it's severe enough to be called "dementia." When we see that kind of pattern, the cause is usually Alzheimer's disease, and so that is why this is the most likely thing to explain your problem as well.

Before we move on to talk about treatments, do you have any questions about the information I gave you? I know it's a lot, and it's very complicated, but if there was anything that didn't make sense to you, please go ahead and ask."

If you are thinking about pursuing blood biomarker testing for Alzheimer's disease, you can continue in the following way. Language about an amyloid PET scan would be similar.

If you want to know more about the possibility that Alzheimer's disease is causing the problems, we do have a blood test that tells us whether you have the proteins that cause Alzheimer's disease building up in the brain. This test can only tell us about Alzheimer's disease, and not any of the other neurodegenerative diseases. So, if the test is abnormal, it says that Alzheimer's proteins are building up in the brain, and that Alzheimer's disease is probably at least one of the problems that is causing your [memory or thinking] changes. If it's normal, there could still be other neurodegeneration proteins building up in the brain, but probably not Alzheimer's proteins.

Knowing if there are Alzheimer's disease proteins in the brain can help us be more prepared for what might happen in the future, and help us to decide what treatments we can use. If necessary, we can refer you to a specialist to think more about these treatments.

Medication treatment for dementia

This script (10 minutes) can be used to discuss treatment options that are available once the diagnosis of dementia has been made. It is important to bear in mind that some medications treat the symptoms but do not change the underlying disease process or prevent the dementia from progressing, while some treatments can remove causative proteins and slow decline. Side effects to be aware of with cholinesterase inhibitors are bradycardia and lowering of the seizure threshold, as well as the more commonly occurring GI effects. Memantine can also lower the seizure threshold and the dose needs to be lower in moderate to severe chronic kidney disease. Cholinesterase inhibitors are typically used in dementia due to Alzheimer's disease or Lewy body disease. Memantine is typically used in dementia due to Alzheimer's disease.

Disease modifying treatments include anti-amyloid infusions, which can slow decline in cognition and function, and have potential adverse effects including ARIA (see section in background on these treatments)

Bullets to consider discussing include:

- Discussion that commonly used medications are symptomatic treatment, not disease modifying

- Discussion about cholinesterase inhibitors – efficacy, side effects
- Discussion about memantine – efficacy, side effects
- Discussion about disease modifying treatments, if these are being contemplated
- Non-medication options – exercise, social engagement, brain exercises
- Review of advice about diet and supplements

Script to discuss medication treatment for dementia

“Let’s talk about treatment options. There are medications available that can help with symptoms of dementia. While these medications help with the symptoms, it is important to realize that they do not slow down the damage that is happening to the nerve cells. They just adjust the chemistry of the brain to help the brain work better.

There are two types of these medications which target different chemicals (neurotransmitters) in the brain. You can take one type or the other or both, but it is important to start one first, see how you react to it and whether you will stay on it, and then later decide on the second type of medication. Each of these medications will require you to start slowly and build up to a final dose. If side effects prevent you from continuing to take the medication at any point, you may not be able to take them, but often side effects are relatively mild and go away once your body gets used to the medicine. I will discuss common side effects before prescribing any of the medications. It is important to know that you can stop the medications suddenly at any time (without tapering) if you need to because of a side effect, especially an allergic reaction.

Most people start with a type of medication called a cholinesterase inhibitor. The ones we use most commonly are donepezil (Aricept), galantamine (Razadyne), or rivastigmine (Exelon). All of these medicines work by boosting the level of a chemical in the brain called acetylcholine, and this helps the brain cells work a bit better. These drugs don’t usually stop memory loss or make memory better, but they can slow down the worsening of your memory. This means that when you are taking the drug, you have to know what to expect. Because they don’t make your memory better, but it is hard to know if these drugs are helping you because you wouldn’t know how your memory would have been a few months from now if you were not taking the drug. You just have to take the drug based on confidence in the research that showed that the average patient with Alzheimer’s disease is better off on the drug than if they were not on it. Even if you are not noticing any improvement, as long as the drug doesn’t cause side effects, we recommend staying on it. Unfortunately, we have been using these drugs for many years now, and we know that even though it keeps patients a little better than not being on the drug, people still decline over time and these drugs can’t stop that. This is why we continue to do research to find even better drugs. We can talk about that in a few minutes.

The most common side effects include nausea and diarrhea; sometimes people get over this after a week or so, but other people do not. Sometimes different versions of the drug like patches on the skin are better tolerated than others but not always. Sometimes we can stop the medication and restart on a smaller dose and work you up to a full dose more slowly as your body gets used to it. These medicines can also cause slowing of the heart rate which can cause dizziness, shortness of breath, or even chest pain – if you develop any of these, please stop the medication until you contact me. Because they can cause nightmares, we recommend that you take them in the morning (though your pharmacist may put a label on it to take at night – that is because some people have mild nausea and prefer to sleep through it).

The other type of medication is called memantine (Namenda). This works in a different way and can be taken with the medications I just described, although they should be started one-by-one so that the effect of each one can be judged individually. Memantine is generally well tolerated, and side effects tend to vary from patient to patient. This is taken either twice daily (generic) or in a sustained release format once a day (brand name). Usually,

memantine is added later when the symptoms are a bit more severe, so it makes sense to concentrate on the cholinesterase inhibitors now and think about memantine in the future.

If you are considering disease modifying therapies, you talk about them in the following way. Or, if you do not consider the patient eligible, but they ask about them, some of the wording below can be useful. The wording below is appropriate for currently available treatments as of the date of this revision (see last revision date at the beginning of the document). This discussion assumes you've told the patient about neurodegenerative diseases, and how they are caused by abnormal proteins.

There are also drugs can remove some of the abnormal proteins that build up in the brain with Alzheimer's disease. They can't be used to treat any other neurodegenerative disease. These drugs have to be given into your vein at a special center at least once a month for at least several months. You have to be carefully monitored, and get MRIs every few weeks. Even these drugs don't completely stop the disease, but they do slow it down, so that your memory would probably be better after a few months of taking the drug than it would have been if you had not been taking the drug. These treatments can have serious side effect that can even be life-threatening, but most patients taking the drug don't have these serious side effects. Because of these side effects, the drug is not considered safe for all patients. I can give you some information about these drugs so you can read about them if you are interested. If you are, then we can send you to a specialist that would give you more information, and do decide if these drugs would be reasonably safe for you, and if they think it is, they can potentially start you on that kind of treatment.

If a patients asks about the new/recently approved drugs for Alzheimer's disease, but you do not think they are appropriate, you can say the following.

There are also drugs can remove some of the abnormal proteins that build up in the brain with Alzheimer's disease. These drugs have to be started early in the disease to have a change of working, and they can also have very serious side effects, including causing brain swelling and bleeding. In your case, I do not think you are a good candidate for these drugs because [your reason here, could be "the problem with your memory has been going on for a while and is too severe to be helped with these drugs", or "your other medical problems would make it very risky for you to be on these drugs", or other appropriate reasons].

People may ask about treatment trials. Patients can find their own trials through the websites below or may be referred to a tertiary referral center.

Many people are interested in clinical trials. It can be a good way to advance research. Some studies are drug (medication) trials and others are non-drug studies. Two good resources for clinical trials are clinicaltrials.gov and the Alzheimer's Association. You can see which trials you might qualify for. Please let me know if you have any questions.

Many people will ask if there are specific things that could be done, like mental exercise, to help patients.

That is a very good question. While there is no specific research indicating that specific brain exercises can improve dementia, it does make sense that using the brain helps keep it functioning. It is recommended that patients stay as active mentally as they can. Particularly in early dementia (and mild cognitive changes), mental activity is useful. This should not feel punishing (that is, it should not be some thing that you fail at each time you try) and should be something that you enjoy and look forward to. This can include games, puzzles, word searches, as well as discussions with friends and family or computer games.

Physical exercise is also useful not only for physical health but for mental health – brain function and mood both can get better with physical exercise. Once again, aim for something that is pleasant and brings joy. Possibilities include Silver Sneakers, dancing, aquatic aerobics (good for those with arthritis), walks with family or friends, chair aerobics, yoga.

Lastly, and most importantly, is socialization. Many patients tend to withdraw as the disease gets worse. It is important to keep contact with family and friends. This can significantly improve your mood and ability to interact with people. The mental and physical exercise above can easily be done with friends and family, which would make it even more helpful to the brain.

Many people will ask if there are specific vitamins or supplements that people with dementia should be taking.

That is a very good question. There is evidence that a healthy diet, particularly a Mediterranean diet, lessens the chance of developing Alzheimer's disease and is healthy for the heart as well, so it makes sense to follow that diet if possible. Supplements are more complicated. We have checked to see if you are low in specific vitamins (such as B12) and have recommended supplementation if needed. As far as other supplements go, none is currently recommended or clearly proven to be helpful. Some supplements can be harmful, and some can interfere with your medications. The best way to learn about the latest information is to visit a reliable website because these recommendations can change. Two good sources are The Mayo Clinic (<https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/diagnosis-treatment>) and The Alzheimer's Association (<https://www.alz.org/alzheimers-dementia/treatments/medications-for-memory>) It is important to let both your pharmacist and me know what supplements you are taking if you decide to take some."

Dementia Related Behavioral Symptoms

This is a script (10 minutes) to begin to introduce or explain the occurrence of dementia related behavioral symptoms. These can range from annoying to unsafe and occur among all etiologies and stages of dementia. The history should have identified the presence of them but even if they aren't present now, a brief introduction will be helpful when/if they do emerge.

Bullets to include are:

- Behavioral symptoms are a result of changes in the brain and are not intentional.
- Behavioral symptoms can range from being annoying to being unsafe.
- Non-drug approaches are often more successful and have fewer risk of side effects.
- Medication can sometimes reduce the frequency and intensity but often requires frequent adjustments in dosages and changes.
- There are classes and organizations to assist in supporting caregivers to learn to manage these behaviors.

Script to discuss dementia related behavioral symptoms

"I wanted to review some of the symptoms that often accompany the memory and thinking symptoms we are most familiar with when we think of dementia. These are changes that tend to affect how someone behaves rather than how they think or remember. They don't occur in everyone, but I want to mention them, so you are prepared if you observe them and aren't surprised. Have you heard about these or noticed any of these?"

You can target your response to specific behaviors or generically let them know that they may observe them going forward and you will be available to help them or refer them to someone who can

It is important to recognize that these changes are due to the same brain disease that causes memory problems and are not being done intentionally by the person with dementia. In fact, it often reflects their discomfort and anxiety with interpreting the confusing environment around them. This frustration and confusion are often expressed with an increase in irritability, anger, or lack of cooperation. The severity of these symptoms can range from being annoying to being unsafe – for example, repeating stories is annoying, but it isn't a risky behavior. However, we want you to be sure to tell us about any symptoms causing you to worry about your safety or the safety of your loved one since they may require immediate attention. We can help you figure out what interventions might improve the problem and how urgent they are. Please be sure to let us know if you notice them.

If these kinds of problems are happening, there are a few approaches we can try. Many people would think first about medications. You should know that this may not be the most useful way to deal with these problems. A lot of research has been done to look for specific medications that can help with these behavioral problems without causing a lot of side effects, and the research hasn't identified specific medications that are very good for this. The best thing is usually to start with other ways to deal with the problem, instead of medication, and these can be quite helpful.

Often, we can look for things we can change in the place where they are staying, or ways that we can change how we deal with them, instead of expecting them to change. For example, learning new communication techniques that are calm or simple can be helpful. Simplifying the environment so it is not as busy and distracting can be helpful – like reducing background noise or clutter, and providing less complicated schedules. It is best to avoid

confronting what may seem like false beliefs or misinterpretation as this can often only make the person more stubborn about the issue. Changing the subject or distracting the person with a different activity may be more successful. These solutions are not always obvious or easy to learn; sometimes they are actually the opposite of what you might think. There are classes and reading materials by experts that you might find helpful. I'd be happy to share some places for you to begin if you would find it helpful.

In general, we cannot expect anything that we try for these behavioral problems to eliminate or completely fix the problems. If we get a 25 to 50 percent improvement, that would usually be considered pretty good, so it's important to think about that when trying to deal with these problems. We often try the non-medication things first, because they are often successful and have no risks or side effects. However, if the behaviors are causing a big problem, or endangering someone, we may consider medications or other treatments. If we have to try medications, it may take a couple of trials of different medications until we find one that works, and it is often hard to find one that quiets the problem without a lot of side effects, but we can often find something that at least allows better care for the patient and maintains safety."

Providing contact information for the Alzheimer's Association <https://www.alz.org/alzheimers-dementia/treatments/treatments-for-behavior> and Caregiver Resource Center of California <https://www.caregivercalifornia.org/> can be an invaluable resource for caregivers

Discussing driving safety

DRIVING SCRIPTS

During the evaluation, before a diagnosis is made:

This script (5 minutes) can be used to ensure safety during the work-up especially if the patient and/or informant express concerns about driving or cognitive testing is significantly impaired but reporting is not yet a requirement:

“As a healthcare provider, my job is to keep my patients healthy and safe. I also have a public health duty to keep others in our community safe. I don’t want to see you get hurt or hurt anyone else. At this time, based on what you and your family tell me and/or today’s evaluation, I have to advise you that I do not think you should be driving, and I am going to ask you not to drive until the evaluation of your memory and thinking is completed and we know more.”

OR

“I suggest you have an evaluation that shows you are safe to drive. I can refer you to a driver evaluation program, run by an Occupational Therapist who specializes in assessing driving skills and providing adaptations and other assistance to help people continue to drive safely.

I know that this is a very difficult change to even consider, and I appreciate the challenges that it may present. However, your safety and that of others have to be my primary concern. We will definitely discuss this again. Do you have any questions?”

People may ask more about the process, and you may want to prepare them that reporting will be required if a diagnosis of dementia is made in the future. It may be good to let them know that the occupational therapist is a mandated reporter to DMV if they assess the individual is not safe. This article can be helpful from the Family Caregiver Alliance: (<https://www.caregiver.org/resource/dementia-driving-and-california-state-law/>)

BILLING

Evaluating a Concern

This table provides guidance on how to plan for and bill for the time required to make a diagnosis. It covers the process of collecting the information to identify that there is a concern, to thoroughly evaluate the concern, and to convey the outcome to the patient and family. An additional table below provides information on billing for continued management once the problem is diagnosed. The gray rows highlight interactions that would cover three dedicated meetings to identify, evaluate, and disclose a diagnosis.

Type of Visit	Length of Visit	Frequency of Visit	Codes and National Reimbursement Rates	Reference
ANNUAL WELLNESS VISIT Use for - Brief questions to assess whether there is a cognitive complaint - Questions can be administered by trained clinical staff (other than billing provider) Toolkit sections - Questions for patient and informant - If no informant then do Mini-Cog	Not specified Can be billed with problem-focused E/M visit, same-day, separate note (99211-99215 depending on length of visit or complexity of medical decision making)	Initial, then every 12 months	Initial G0438 (\$173.70–\$189.77) Annual G0439 (\$117.71–\$128.60)	www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AWV_Chart_ICN905706.pdf
IDENTIFICATION OF SIGNIFICANCE OF UNANTICIPATED COGNITIVE COMPLAINT Use for - When cognitive complaints (or health provider concerns) arise during a visit that was scheduled for other purposes - This means extra time had to be added to the planned visit Toolkit sections - Questions for patient and informant - If no informant then do Mini-Cog after	30 min beyond regular visit	Must be billed with another E/M code (cannot be used with AWV) Cannot be added to wellness visit	Add-on Code: 99354 (\$131.35–\$143.50)	Prolonged Service with Direct Face-to-Face Patient Contact www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/downloads/mm5972.pdf

Type of Visit	Length of Visit	Frequency of Visit	Codes and National Reimbursement Rates	Reference
SCHEDULED VISIT TO IDENTIFY SIGNIFICANCE OF COGNITIVE COMPLAINT Use for - When a cognitive complaint came up briefly on a prior visit or by phone or other communication Toolkit sections - Questions for patient and informant - If no informant then do Mini-Cog	25-min visit	Not specified	Established patient 99214 (\$108.74–\$118.80) Can “bill for time” spent counseling patient or for complexity of medical decision making	Evaluation and Management Services www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/eval-mgmt-serv-guide-ICN006764.pdf
EVALUATION (FULL HX/WORK-UP) Use for - When a significant cognitive complaint has been identified and now a full assessment is needed Toolkit sections - Full hx with patient and informant (if available) - Neurologic exam - MoCA - Labs and imaging	New patient: 60 min Est. patient: 40 min	Not specified	New patient 99205 (\$209.23–\$228.58) Established 99215 (\$146.43–\$159.97) Can add prolonged services code if needed Can “bill for time” or complexity of medical decision making	Evaluation and Management Services www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/eval-mgmt-serv-guide-ICN006764.pdf
DIAGNOSIS AND COUNSELING Use for - Disclosing diagnosis with patient and informant (if available) - Education and support - Discuss driving if necessary - Prescribe reading or video - Brief treatment recommendations Toolkit sections - Sample scripts	25–40 min	Not specified	99214, 25 min (\$108.74–\$118.80) 99215, 40 min (\$146.43–\$159.97) Can add prolonged services code if needed Can “bill for time” spent counseling patient or for complexity of medical decision making	Detailed and Comprehensive E/M codes www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/eval-mgmt-serv-guide-ICN006764.pdf

PHONE FOLLOW-UP & REFERRAL FOR UNCLEAR DIAGNOSIS Use for • Explain need to patient and family about need for additional assessment or need for referral Toolkit sections • Recommended wording for referrals	unknown	Not specified	99358 (\$113.41–\$123.90)	Prolonged Services without Face-to-Face Patient Contact www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/Downloads/MM9905.pdf
IN PERSON FOLLOW- UP & REFERRAL FOR UNCLEAR DIAGNOSIS Use for • Explain need to patient and family about need for additional assessment or need for referral • Additional history-taking or assessment to help clarify diagnosis Toolkit sections • Recommended wording for referrals	25 – 40 min	Not specified	99214, 25min (\$108.74 – \$118.80) 99215, 40min (\$146.43 – \$159.97) Can add prolonged services code if needed Can “bill for time” spent counseling patient or for complexity of medical decision making	Detailed and Comprehensive E/M codes www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/eval-mgmt-serv-guide-ICN006764.pdf

After Diagnosis

This table provides guidance on how to bill for additional visits required to continue to plan management and manage patients *after diagnosis has been established*.

Type of Visit	Length of Visit	Frequency of	Codes and National	Reference
COGNITIVE EVALUATION AND CARE PLANNING VISIT Use for - Collecting additional information needed for care planning - Documenting needs (or lack of need) in all important aspects of care (specified in reference) - Discussion/Instruction with patient and family on care plan Toolkit sections - N/A	50–90 min	Not specified	99483 (formerly G0505) (\$238.30–\$260.34)	www.alz.org/careplanning/downloads/cms-consensus.pdf Care plan must include: - Cog/fxn/stg, DM Capacity, Mood/bhvr, Safety, Meds, Caregiver, ACP - Must demonstrate moderate to highly complex medical decision making in documentation
FOLLOW-UP VISITS Use for - Collecting additional information - Following up on outcomes of specific intervention Toolkit sections - N/A	25–40 min	Not specified	99214, 25 min (\$108.74–\$118.80) 99215, 40 min (\$146.43–\$159.97) Can add prolonged services code if needed Can “bill for time” spent counseling patient or for complexity of medical decision making	Detailed and Comprehensive E/M codes www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/eval-mgmt-serv-guide-ICN006764.pdf
PALLIATIVE CARE/ACP VISIT Use for - Explanation and discussion of Advance Directives - May include completion of forms Toolkit sections - N/A	30 min, plus additional time as needed	Not specified, can be added on to AWV	99497 (first 30 min) 99498 (each additional 30 min) National reimbursement rates: 99497 = \$82.90–\$90.57 99498 = \$72.50–\$79.20	www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf

COMPLEX CHRONIC CARE MANAGEMENT Use for - Monthly follow-up with clinical staff (RN, SW, trained MA) under general supervision of billing provider - Facilitate implementation of care plan (education, support, safety monitoring, care coordination, linkages to community services) Toolkit sections - N/A	20+ minutes of clinical staff time per month plus a minimum of 15 min of provider time for general supervision	Cumulative time spent providing non-face-to-face care management on monthly basis	99490, 20 min clinical staff time per month (assumes 15 min provider time per month) 99487, 60 min clinical staff time per month (assumes at least 15 min provider time per month) Add-on code: 99489, for every 30 min of additional clinical staff time (use with 99487)	Chronic Care Management Services: www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf Must have an initiating in-person visit with provider (i.e., E&M, AWW, 99483) Health system must provide 24/7 telephone access to clinical staff Medicare beneficiaries will pay 20% co-pay out-of-pocket if they don't have supplementary insurance or Medicaid Patient/caregiver must be informed about the service and co-pay and their acceptance of service must be documented in record Must maintain comprehensive care plan in EMR that includes: Problem list, prognosis, treatment goals, Symptom management, Planned interventions, Medication management, Community/ social services ordered, coordination with outside agencies
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Type of Visit	Length of Visit	Frequency of Visit	Codes and National Reimbursement Rates	Reference
TRANSITIONAL CARE MANAGEMENT Use for 30-day period of post-discharge care management initiated upon discharge from hospital, skilled nursing, or nursing home facility - Includes medication review and reconciliation	Time not specified	Only within 30 days post-discharge from hospital, SNF, or NH	99496: \$216.44 –\$303.30 High-complexity Face-to-face visit within 7 days of discharge (provider only) 99495: \$152.86 –\$213.76 Moderate-complexity face-to-face visit within 14 days of discharge (provider only)	www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Transitional-Care-Management-Services-Fact-Sheet-ICN908628.pdf Face-to-face visit with provider, must demonstrate moderate to high complexity of medical decision-making. Non face-to-face care coordination may be provided by clinical staff under supervision.

SECTION 3: PATIENT ASSESSMENT FORMS



Assessment of Cognitive Complaints Toolkit

For Alzheimer's Disease

Patient Assessment Forms

PRODUCED BY THE
CALIFORNIA
ALZHEIMER'S DISEASE
CENTERS AND FUNDED
BY THE CALIFORNIA
DEPARTMENT OF PUBLIC
HEALTH, ALZHEIMER'S
DISEASE PROGRAM

The following Patient Assessment forms are available in this section:

- Detecting Cognitive Concerns
- Pre-Visit Questionnaire for patients
- Pre-Visit Questionnaire for informants
- Pre-Visit Questionnaire for support staff to administer to patient and informants
- Full Cognitive Evaluation for primary care provider

The following Patient Assessment forms are available upon request:

- Mini-Cog brief test
- Mini-Mental State Examination (MMSE)
- Montreal Cognitive Assessment (MoCA)-English
- Montreal Cognitive Assessment (MoCA)- English Blind
- Rowland Universal Dementia Assessment Scale (RUDAS)
- Montreal Cognitive Assessment (MoCA)-Spanish
- Montreal Cognitive Assessment (MoCA)-Basic Chinese
- Montreal Cognitive Assessment (MoCA)-Hong Kong Cantonese Chinese
- Montreal Cognitive Assessment (MoCA)-Beijing Simplified Chinese
- Montreal Cognitive Assessment (MoCA)-Taiwan Traditional Chinese
- Brain Health Test-English

Cognitive testing tutorials:

We have created brief PowerPoint tutorials for the following cognitive tests, as well as one for best practices. This interim version of the toolkit includes PDF versions of these PowerPoints for review and informational purposes in the following section. The PowerPoint tutorials are available upon request.

- Cognitive testing for Primary Care Practices
- Mini-Cog
- MMSE-Mini-Mental State Exam
- MoCA- Montreal Cognitive Assessment
- SLUMS-St. Louis University Mental Status exam
- 3MS- Modified Mini-Mental State

As noted in our MoCA tutorial, the MoCA developers recommend training and certification through their website:

<https://www.mocatest.org/about>.

Specific training for the RUDAS is available through this link: <https://www.dementia.org.au/resources/rowland-universal-dementia-assessment-scale-rudas>.

Name:
Date of birth:
Date:

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease (ACCT-AD)
DETECTING COGNITIVE CONCERNS

MEMORY, LANGUAGE AND PERSONALITY CHANGES		
PATIENT COMPONENT-Part 1	Yes	Please provide additional comments if necessary
MEMORY		
Do you think your memory has changed in the last 5–10 years? For example: - Do you have any trouble remembering recent events, like a family event, dinner, movie or a book? - Do you have any trouble remembering recent conversations?		

LANGUAGE		
Have you noticed changes in your language? For example: Do you have any trouble finding words or understanding conversations?		

PERSONALITY		
Have you noticed changes in your personality? For example: - Are you more irritable or do you anger more easily? - Do you have any trouble getting along with people?		

- If there are indications of impairment (yes responses), continue to patient component- part 2.
- If there are no indications, skip to informant component-part 1 to confirm patient's responses.
- If there are no indications and no informant is available, perform mini-cog. If score is normal, end assessment, reassure patient and repeat in one year.
- If the patient has any errors on the mini-cog, proceed to a full cognitive evaluation.

PATIENT COMPONENT- Part 2	Yes	Please provide additional comments if necessary
MEMORY		
Do you think your memory changes are worse than your peers?		
Have you stopped doing anything because of memory changes?		
Has anybody commented to you about changes in your memory?		

LANGUAGE		
Do you think your language changes are worse than your peers?		
Have you stopped doing anything because of these language changes?		
Has anybody commented to you about these changes in your language?		

PERSONALITY		
Do you think your personality changes are worse than those of your peers?		
Have you stopped doing anything because of these personality changes?		
Has anyone commented on these personality changes to you?		

- If there are indications (yes responses), do a full cognitive evaluation.
- If there are no indications, proceed to informant component-part 1 to confirm patient responses.
- If there are no indications and no informant is available, perform mini-cog. If mini-cog score is normal, reassure patient and repeat in one year.
- If the patient has any errors on the mini-cog, proceed to a full cognitive evaluation.

MEMORY, LANGUAGE AND PERSONALITY CHANGES		
INFORMANT COMPONENT-Part 1 (spouse, family member, caregiver or friend)	Yes	Please provide additional comments if necessary
MEMORY		
Do you think the patient's memory has changed in the last 5–10 years? For example: - Does the patient have any trouble remembering recent events, like a family event, dinner, movie or a book? - Does the patient have any trouble remembering recent conversations?		

LANGUAGE		
Have you noticed changes in the patient's language? For example: Have you noticed that the patient has any trouble finding words or understanding conversations?		

PERSONALITY		
Have you noticed changes in the patient's personality? For example: - Have you noticed that the patient is more irritable or that they anger more easily? - Have you noticed if the patient is having any trouble getting along with people?		

- If there are indications (yes responses), proceed to informant component-part 2.
- If there are no indications, end detection questions here, reassure patient and repeat in one year.

INFORMANT COMPONENT-Part 2 (Spouse, family member, caregiver or friend).	Yes	Please provide additional comments if necessary
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MEMORY		
Do you think the patient's memory changes are worse than their peers?		
Has the patient stopped doing anything because of memory changes?		
Has anybody commented to you about the patient's changes in their memory?		

LANGUAGE		
Do you think the patient's language changes are worse than their peers?		
Has the patient stopped doing anything because of language changes?		
Have you noticed changes in the patient's language?		

PERSONALITY		
Do you think the patient's personality changes are worse than those of their peers?		
Has the patient stopped doing anything because of these personality changes?		
Has anyone commented to you about the patient's personality changes?		

- If there are indications (yes responses), do a full cognitive evaluation.
- If there are no indications, reassure patient and repeat in one year

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit patient questionnaire-
v.25

PATIENT NAME:		
DATE OF BIRTH:		
DATE:		
RACE:	PRIMARY LANGUAGE:	YEARS OF EDUCATION:
This questionnaire will assist the medical team in completing your evaluation. Please: ➤ Answer these questions honestly and to the best of your ability. ➤ Be specific. For example, "Last Tuesday, I (my loved one) got lost on the way home from the store. It was scary." In addition to the questions below your medical provider may also ask you details about: ➤ Past and current medical problems and surgical history ➤ Family medical history ➤ Your social history ➤ All medications that you are currently taking including: prescription medications, over-the-counter vitamins, aspirin, etc. herbal supplements, ➤ Past or present use of alcohol, marijuana (CBD/THC) or other social drugs such as stimulants, narcotics, or sedatives.		
Question: (check all that apply)	YES	Please provide additional comments if necessary:
Do you have any problems with memory?		
Do you misplace items often (e.g., phone, keys)?		
Do you rely more on notes?		
Do you have trouble with recent memory (conversations, recent events) compared to remote memory?		
Do you ask repetitive questions?		
Do you have difficulty expressing words, difficulty understanding words or conversations?		
Do you have difficulty finding the word or name you want to use?		
Do you have difficulty understanding what people are saying to you?		
Do you have any difficulty pronouncing words that were easy for you to pronounce in the past?		
Do you have difficulty planning, starting, or finishing complicated tasks at home or at work?		
Do you have difficulty keeping your home or office as neat and organized/clean as it used to?		
Do you have problems finishing a task because you get distracted easily?		
Do you get lost while walking or driving?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit patient questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Do you have difficulty driving to familiar places (walking or driving) i.e., grocery store, post office, friend's house, etc?		
Do you get lost in a familiar store or restaurant?		
Do you have difficulty seeing things properly or judging distances properly?		
Does your motor vehicle show evidence of damage?		
Do you have difficulty figuring out how to position yourself/themselves to sit in a chair?		
Do you complain of difficulty seeing while reading?		
Do you complain that your eyes don't work?		
Do you have trouble seeing things that are right in front of you?		
Do you have difficulty recognizing people?		
Has your mood changed?		
Do you cry a lot?		
Do you feel hopeless about life or about the future?		
Do you feel worthless or bad about yourself?		
Have you lost motivation or energy to do things you used to enjoy?		
Do you have decreased interest in social activities?		
Do you have decreased interest in church or community groups?		
Do you have decreased interest in hobbies?		
Do you become angry more easily?		
Do you get angry about things that would not have bothered you in the past?		
Sometimes we have patients who seem to forget how to behave in public. Has this been an issue for you?		
Have you done anything that may have been embarrassing to the family? e.g., calling people fat in public when they might hear?		
Have you ever told dirty jokes in inappropriate situations?		
Have you ever told personal things about yourself or family to strangers?		
Have you ever eaten off other people's plates at restaurants?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit patient questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Have there been any problems with beliefs that are unusual or not realistic?		
Do you feel like someone is out to get you?		
Do you feel like you might have special powers or special relationships with famous or powerful people?		
Have you been seeing or hearing anything that might not be there (or others can't see or hear)?		
Have you become fixated on certain ideas that you can't get out of your head or have developed any specific rituals?		
Do you have any obsessions with certain political or religious ideas?		
Do you have any obsessions about timing or routine being adhered to precisely?		
Do you have any obsessions with specific games, movies, or specific forms of entertainment?		
Have you had any changes in sleep?		
Do you wake up a lot in the middle of the night?		
Do you have problems falling sleep?		
Has your partner reported that you may have problems acting out dreams (yelling, screaming, hitting)?		
Do you snore?		
Has your partner ever reported that you may have breathing stoppages while you sleep?		
Are you sleepy during the day?		
Have there been changes in your eating habits?		
Have you been eating more or less than usual?		
Have you had any unintentional weight gain?		
Have you had any unintentional weight loss?		
Do you want to eat specific foods all the time?		
Do you want to eat sweets or carbohydrates more than you used to?		
Do you seem less concerned about others' needs, problems?		
Do you feel you are not reacting appropriately in an emergency or when someone needs help?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit patient questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Do you feel you are not reacting emotionally when someone has a particularly sad or happy event (e.g., a loss or major achievement)?		
Do you seem to be more open to scams or solicitations?		
Have you been buying lots of magazines or online offers?		
Have you ever been fooled by a suspicious business arrangement?		
Do you have involuntary shaking in your hands, arms, legs, or chin?		
Do your limbs feel rigid or stiff?		
Are you able to turn your head and neck easily?		
Have your movements been slowing down?		
Are you walking slower?		
Does it take you longer to button your shirt?		
Is your handwriting smaller?		
Have you had changes in your ability to walk?		
Are you stooped over when walking?		
Do you drag your feet when you walk?		
Are your steps shorter or do you get stuck when walking?		
Have you fallen in the past couple of years?		
If yes, how many times have you fallen?		
What were the circumstances of the falls? (Tripping, weakness of legs, loss of consciousness, unsteadiness)		
Do you feel unsteady on your feet?		
Are you weaker on one side of your body than the other?		
Have you had a stroke?		
Do you have trouble using one hand?		
Are you limping or dragging one foot?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit patient questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Do you have involuntary movement of your limbs, such as jerking or twitching?		
Have you had changes to your muscles?		
Have you lost muscle mass?		
Are your muscles weaker?		
Have any of your muscles become smaller?		
Does one of your arms behave as if it doesn't belong to you?		
Has your arm (unbuttoned your shirt/grabbed something) without your awareness or control?		
Have you had slurring of your speech?		
Does your speech sound as if you are drunk?		
Have you had trouble swallowing?		
Have you coughed or choked when eating or drinking?		
Have you had any other difficulty swallowing liquids or solid foods?		
Are there any members of your family with "mental health problems, dementia, Parkinson's or other neurological problems"? For example: Alzheimer's disease, Parkinson's, schizophrenia, bipolar, depression		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit patient questionnaire-
v.25

Please check the box if any of the following are true:	YES	Please provide additional comments if necessary:
Have you had any changes in your ability to manage basic activities of daily living due to changes in memory or thinking?		
I need assistance with bathing.		
I need assistance to dress.		
I need assistance to manage my bladder and bowels without accidents		
Has there been a change in your ability to manage your household due to problems with memory or thinking?		
I need assistance to manage my own shopping.		
I need assistance to pay my bills on time.		
I need assistance to complete household chores or projects.		
I have left the stove on.		
I need assistance to follow recipes.		
I do not drive.		
I have trouble completing tasks at work.		
I lost my job because I was unable to complete tasks at work.		
I need assistance to manage my own medications.		
I have difficulty answering the phone.		
I am unable to do my own laundry.		
I am unable to manage forms of transportation (Example: taking the bus, call for a cab, etc.)		
I am unable to manage my finances (Example: checking account, retirement account, banking)		
Thank you for completing the cognitive complaints patient questionnaire. Your input is very valuable for a thorough evaluation. Please feel free to provide your physician further information below if necessary.		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit informant questionnaire-
v.25

PATIENT NAME:		
DATE OF BIRTH:		
DATE:		
RACE:	PRIMARY LANGUAGE:	YEARS OF EDUCATION:
NAME OF PERSON COMPLETING QUESTIONNAIRE: (If other than patient. Please respond to questions on behalf of patient above.) _____		
RELATIONSHIP TO PATIENT: _____		
How often do you spend time with patient: Daily ☐ Weekly ☐ Monthly ☐ Every 3 month ☐ Every 6 month ☐ Yearly ☐		
This questionnaire will assist the medical team in completing the patient's evaluation. Please: ➤ Answer these questions honestly and to the best of your ability. ➤ Be specific. For example, "Last Tuesday, my loved one got lost on the way home from the store. It was scary." In addition to the questions below the medical provider may also ask details about: ➤ Past and current medical problems and surgical history ➤ Family medical history ➤ The patient's social history ➤ All medications that the patient is currently taking including: prescription medications, over-the-counter vitamins, aspirin, etc. herbal supplements, ➤ Past or present use of: alcohol, marijuana (CBD/THC) or other social drugs such as stimulants, narcotics, or sedatives.		
Question: (check all that apply)	YES	Please provide additional comments if necessary:
Does the patient have any problems with memory?		
Does the patient misplace items often (e.g., phone, keys)?		
Does the patient rely more on notes?		
Does the patient have trouble with recent memory (conversations, recent events) compared to remote memory?		
Does the patient ask repetitive questions?		
Does the patient have difficulty expressing words, difficulty understanding words or conversations?		
Does the patient have difficulty finding the word or name they want to use?		
Does the patient have difficulty understanding what people are saying to them?		
Does the patient have any difficulty pronouncing words that were easy for them to pronounce in the past?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit informant questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Does the patient have difficulty planning, starting, or finishing complicated tasks at home or at work?		
Does the patient have difficulty keeping their home or office as neat and organized/clean as it used to?		
Does the patient have problems finishing a task because they get distracted easily?		
Does the patient get lost while walking or driving?		
Does the patient have difficulty driving to familiar places (walking or driving) i.e., grocery store, post office, friend's house, etc?		
Does the patient get lost in a familiar store or restaurant?		
Does the patient have difficulty seeing things properly or judging distances properly?		
Does the patient's motor vehicle show evidence of damage?		
Does the patient have difficulty figuring out how to position themselves to sit in a chair?		
Does the patient complain of difficulty seeing while reading?		
Does the patient complain that their eyes do not work?		
Does the patient have trouble seeing things that are right in front of them?		
Does the patient have difficulty recognizing people?		
Has the patient's mood changed?		
Does the patient cry a lot?		
Does the patient feel hopeless about life or about the future?		
Does the patient feel worthless or bad about themselves?		
Has the patient lost motivation or energy to do things they used to enjoy?		
Does the patient have decreased interest in social activities?		
Does the patient have decreased interest in church or community groups?		
Does the patient have decreased interest in hobbies?		
Does the patient become angry more easily?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit informant questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Does the patient get angry about things that would not have bothered them in the past?		
Sometimes we have patients who seem to forget how to behave in public. Has this been an issue for the patient?		
Has the patient done anything that may have been embarrassing to the family? e.g., calling people fat in public when they might hear?		
Has the patient ever told dirty jokes in inappropriate situations?		
Has the patient ever told personal things about themselves or family to strangers?		
Has the patient ever eaten from other people's plates at restaurants?		
Has the patient had any problems with beliefs that are unusual or not realistic?		
Does the patient feel like someone is out to get them?		
Does the patient feel like they might have special powers or special relationships with famous or powerful people		
Has the patient been seeing or hearing anything that might not be there (or others can't see or hear)?		
Has the patient become fixated on certain ideas that they can't get out of their head or have developed any specific rituals?		
Does the patient have any obsessions with certain political or religious ideas?		
Does the patient have any obsessions about timing or routine being adhered to precisely?		
Does the patient have any obsessions with specific games, movies or specific forms of entertainment?		
Does the patient have any changes in sleep?		
Does the patient wake up a lot in the middle of the night?		
Does the patient have problems falling sleep?		
Has the patient's partner reported that the patient may have problems acting out dreams (yelling, screaming, hitting)?		
Does the patient snore?		
Has the patient's partner ever reported that the patient may have breathing stoppages while they sleep?		
Is the patient sleepy during the day?		
Have there been changes in the patients eating habits?		
Has the patient been eating more or less than usual?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit informant questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Has the patient had any unintentional weight gain?		
Has the patient had any unintentional weight loss?		
Does the patient want to eat specific foods all the time?		
Does the patient want to eat sweets or carbohydrates more than they used to?		
Does the patient seem less concerned about others' needs, problems?		
Do you feel the patient does not react appropriately in an emergency or when someone needs help?		
Do you feel the patient does not react emotionally when someone has a particularly sad or happy event (e.g., a loss or major achievement)?		
Does the patient seem to be more open to scams or solicitations?		
Has the patient been buying lots of magazines or online offers?		
Has the patient ever been fooled by a suspicious business arrangement?		
Does the patient have involuntary shaking in their hands, arms, legs, or chin?		
Does the patient's limbs feel rigid or stiff?		
Is the patient able to turn their head and neck easily?		
Have the patient's movements been slowing down?		
Is the patient walking slower?		
Does it take the patient longer to button their shirt?		
Is the patient's handwriting smaller?		
Has the patient had changes in their ability to walk?		
Is the patient stooped over when walking?		
Does the patient drag their feet when they walk?		
Is the patient's steps shorter or do they get stuck when walking?		
Has the patient fallen in the past couple of years?		
If yes, how many times has the patient fallen?		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit informant questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
What were the circumstances of the patient's falls? (Tripping, weakness of legs, loss of consciousness, unsteadiness)		
Does the patient feel unsteady on their feet?		
Is the patient weaker on one side of their body than the other?		
Has the patient had a stroke?		
Does the patient have trouble using one hand?		
Does the patient limp or drag one foot?		
Does the patient have involuntary movement of your limbs, such as jerking or twitching?		
Has the patient had changes to their muscles?		
Has the patient lost muscle mass?		
Are the patient's muscles weaker?		
Has any of the patient's muscles become smaller?		
Does one of the patient's arms behave as if it does not belong to them?		
Has the patients arm unbuttoned their shirt or grabbed something without their awareness or control?		
Does the patient have slurring of their speech?		
Does the patient's speech sound as if they are drunk?		
Does the patient have trouble swallowing?		
Does the patient cough or choke when eating or drinking?		
Has the patient had any other difficulty swallowing liquids or solid foods?		
Are there any members of the patient's family with "mental health problems, dementia, Parkinson's or other neurological problems"? For example: Alzheimer's disease, Parkinson's, schizophrenia, bipolar, depression.		

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease: pre-visit informant questionnaire-
v.25

Question: (check all that apply)	YES	Please provide additional comments if necessary:
Has the patient had any changes in their ability to manage basic activities of daily living due to changes in memory or thinking?		
The patient requires help to bathe.		
The patient requires help to dress.		
The patient is not able to manage their bladder and bowels without accidents		
Has there been a change in the patient's ability to manage their household due to problems with memory or thinking?		
The patient requires help to manage their own shopping.		
The patient requires help to pay their bills on time.		
Is the patient requiring help to complete household chores or projects		
The patient has left the stove on.		
The patient requires help to follow recipes.		
The patient is not able to drive.		
The patient is having trouble completing tasks at work.		
The patient has lost their job because of trouble completing tasks at work.		
The patient has difficulty answering the phone		
The patient is unable to do their laundry		
The patient is unable to manage their transportation (Example: taking the bus, calling a cab, etc.)		
The patient cannot manage their finances (Example: checking account, retirement account, banking)		
Thank you for completing the cognitive complaints patient questionnaire. Your input is very valuable for a thorough evaluation. Please feel free to provide the patient's physician further information below if necessary.		

Patient name:	Date:	
MR#:	Date of birth:	
Name of person completing questionnaire:	Informant's name and relationship:	
Patient's race:	Patient's ethnicity: (circle one) Hispanic/Latino or Non-Hispanic/Latino	
Patient's primary language:	Patient's level of education:	
Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease (ACCT-AD) <i>Pre-visit questionnaire to be completed by support staff prior to visit</i>		
HISTORY OF PRESENT ILLNESS (HPI)		
	PATIENT If patient unreliable, obtain history from informant.	INFORMANT If Informant does not agree with pt or informant has additional details describe below.
CHIEF COMPLAINT		
Can you give me a brief overview of the main complaints you have about your memory or cognition?		
DURATION/EARLY SYMPTOMS		
To have a good understanding of what's going on, it helps to start at the beginning. What were the first symptoms you noticed, and how long ago was that?		
EVOLUTION		
For any symptoms that the patient brings up, make sure that general terms like "I forget things" are clarified, usually it's necessary to get examples. You might say, "Can you give me an example of the kinds of [things, words, events, whatever the person said] forget?" Or, if they describe it in terms of problems with certain tasks, like, "I can't get things done at work." You might say, "OK, when you are trying to do [whatever task they said they have trouble with], what happens?"		
Have the symptoms worsened or changed over time? If they say yes, ask: What makes you say things are worse? Have any new symptoms developed that weren't there at the beginning?		

POTENTIAL NON-NEURODEGENERATIVE CAUSES			
Are there any particular events that were associated with the onset or worsening of the symptoms, like medical illness, accidents or major life stresses?			
FULL COGNITIVE EVALUATION			
	PATIENT	INFORMANT	
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.	
MEMORY			
	YES		YES
Does the patient have any problems with memory or thinking?			
Does the patient misplace items often (e.g., phone, keys)?			
Does the patient rely more on notes?			
Does the patient have trouble with recent memory (conversations, recent events) compared to remote memory?			
Does the patient ask repetitive questions?			
LANGUAGE			
Does the patient have difficulty expressing words, difficulty understanding words or conversations?			
Does the patient have difficulty finding the word or name they want to use?			
Does the patient have difficulty understanding what people are saying to them?			
Does the patient have any difficulty pronouncing words that were easy for them to pronounce in the past?			
EXECUTIVE FUNCTIONS			
Does the patient have difficulty planning, starting, or finishing complicated tasks at home or at work?			
Does the patient have difficulty keeping their home or office as neat and organized/clean as it used to?			
Does the patient have problems finishing a task because they get distracted easily?			
VISUAL-SPATIAL			
Does the patient get lost while walking or driving?			
Does the patient have difficulty finding familiar places (walking or driving) i.e., grocery store, post office, friend's house, etc.?			
Does the patient get lost in a familiar store or restaurant?			
Does the patient have difficulty seeing things properly or judging distances properly?			

Question:(check all that apply)	PATIENT		INFORMANT	
	YES	Please provide additional comments if necessary:	YES	Please provide additional comments if necessary:
Does the patient's motor vehicle show evidence of damage?				
Does the patient have difficulty figuring out how to position themselves to sit in a chair?				
Does the patient complain of difficulty seeing while reading?				
Does the patient complain that their eyes do not work?				
Does the patient have trouble seeing things that are right in front of them?				
Does the patient have difficulty recognizing people?				
DEPRESSION				
Has the patient's mood changed?				
Does the patient cry a lot?				
Does the patient feel hopeless about life or about the future?				
Does the patient feel worthless or bad about themselves?				
APATHY				
Has the patient lost motivation or energy to do things they used to enjoy?				
Does the patient have decreased interest in social activities?				
Does the patient have decreased interest in church or community groups?				
Does the patient have decreased interest in hobbies?				
IRRITABILITY/ANGER				
Does the patient become angry more easily?				
Does the patient get angry about things that would not have bothered them in the past?				
DISINHIBITION				
Sometimes we have patients who seem to forget how to behave in public. Has this been an issue for the patient?				
Has the patient done anything that may have been embarrassing to the family? e.g., calling people fat in public when they might hear				
Has the patient ever told dirty jokes in inappropriate situations?				
Has the patient ever told personal things about themselves or family to strangers?				
Has the patient ever eaten from other people's plates at restaurants?				

Question:(check all that apply)	PATIENT		INFORMANT	
	YES	Please provide additional comments if necessary:	YES	Please provide additional comments if necessary:
DELUSIONS				
Has the patient had any problems with beliefs that are unusual or not realistic?				
Does the patient feel like someone is out to get them?				
Does the patient feel like they might have special powers or special relationships with famous or powerful people?				
HALLUCINATIONS				
Has the patient been seeing or hearing anything that might not be there (or others can't see or hear)?				
OBSESSIONS/COMPULSIONS				
Has the patient become fixated on certain ideas that they can't get out of their head or have developed any specific rituals?				
Does the patient have any obsessions with certain political or religious ideas?				
Does the patient have any obsessions about timing or routine being adhered to precisely?				
Does the patient have any obsessions with specific games, movies, or specific forms of entertainment?				
SLEEP				
Does the patient have any changes in sleep?				
Does the patient wake up a lot in the middle of the night?				
Does the patient have problems falling sleep?				
Has the patient's partner reported that the patient may have problems acting out dreams (yelling, screaming, hitting)?				
Does the patient snore?				
Has the patient's partner ever reported that the patient may have breathing stoppages while they sleep?				
Is the patient sleepy during the day?				
EATING BEHAVIORS				
Have there been changes in the patients eating habits?				
Has the patient been eating more or less than usual?				
Has the patient had any unintentional weight gain?				
Has the patient had any unintentional weight loss?				

Question:(check all that apply)	PATIENT		INFORMANT	
	YES	Please provide additional comments if necessary:	YES	Please provide additional comments if necessary:
Does the patient want to eat specific foods all the time?				
Does the patient want to eat sweets or carbohydrates more than they used to?				
LOSS OF EMPATHY				
Does the patient seem less concerned about others' needs, problems?				
Does the patient not react appropriately in an emergency or when someone needs help?				
Does the patient not react emotionally when someone has a particularly sad or happy event (e.g., a loss or major achievement)?				
JUDGMENT/GULLIBILITY				
Does the patient seem to be more open to scams or solicitations?				
Has the patient been buying lots of magazines or online offers?				
Has the patient ever been fooled by a suspicious business arrangement?				
PARKINSONISM AND RESTING TREMOR				
Does the patient have involuntary shaking in their hands, arms, legs, or chin?				
RIGIDITY				
Do the patient's limbs feel rigid or stiff?				
Does the patient have difficulty turning their head and neck easily?				
BRADYKINESIA				
Have the patients' movements been slowing down?				
Is the patient walking slower?				
Does it take the patient longer to button their shirt?				
Is the patient's handwriting smaller?				
PARKINSONIAN AND GAIT ABNORMALITY				
Has the patient had changes in their ability to walk?				
Is the patient stooped over when walking?				
Does the patient drag their feet when they walk?				
Are the patient's steps shorter or do they get stuck when walking?				

Question:(check all that apply)	PATIENT		INFORMANT	
	YES	Please provide additional comments if necessary:	YES	Please provide additional comments if necessary:
FREQUENT FALLS				
Has the patient fallen in the past couple of years?				
If yes, how many times has the patient fallen?				
What were the circumstances of the patient's falls? (tripping, weakness of legs, loss of consciousness, unsteadiness)				
Does the patient feel unsteady on their feet?				
UNILATERAL WEAKNESS				
Is the patient weaker on one side of their body more than the other?				
Has the patient had a stroke?				
Does the patient have trouble using one hand?				
Does the patient limp or drag one foot?				
MYOCLONUS				
Does the patient have involuntary movement of their limbs, such as jerking or twitching?				
MOTOR NEURON DISEASE				
Has the patient had changes in their muscles?				
Has the patient lost muscle mass?				
Are the patient's muscles weaker?				
Has any of the patient's muscles become smaller?				
ALIEN LIMB				
Does one of the patient's arms behave as if it does not belong to them?				
Has the patients arm unbuttoned their shirt or grabbed something without their awareness or control?				
DYSARTHRIA				
Does the patient have slurring of their speech?				
Does the patient's speech sound as if they are drunk?				
DYSPHAGIA				
Does the patient have trouble swallowing?				

Question:(check all that apply)	PATIENT		INFORMANT	
	YES	Please provide additional comments if necessary:		YES
Does the patient cough or choke when eating or drinking?				
Has the patient had any other difficulty swallowing liquids or solid foods?				
FAMILY HISTORY				
Are there any members of the patient's family with "mental health problems, dementia, Parkinson's or other neurological problems"? For example: Alzheimer's disease, Parkinson's, schizophrenia, bipolar, depression				
BASIC ACTIVITES OF DAILY LIVING (BADLS)				
Has the patient had any changes in their ability to manage basic activities of daily living due to changes in memory or thinking?				
Does the patient require help to bathe?				
Does the patient require help to dress?				
Is the patient unable to manage their bladder and bowels without accidents?				
Does the patient need help with toileting? Are they unable to use the bathroom without help?				
Does the patient need assistance with transferring? (Example: can they move from a bed, chair, or wheelchair and back again.)				
Does the patient require assistance to eat?				
INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLS)				
Has there been a change in the patient's ability to manage their household due to problems with memory or thinking?				
Does the patient require help to manage their own shopping?				
Does the patient require help to pay their bills on time?				
Does the patient require help to complete household chores, housekeeping or projects?				
Has the patient left the stove on?				
Does the patient require help to follow recipes or cook?				
Has the patient stopped driving?				
Is the patient having trouble completing tasks at work?				

Question:(check all that apply)	PATIENT		INFORMANT	
	YES	Please provide additional comments if necessary:		YES
Has the patient lost their job because of trouble completing tasks at work?				
Is the patient unable to manage their own medications?				
Is the patient unable to do their laundry?				
Is the patient unable to use the telephone?				
Is the patient unable to manage their finances? (Example: checking account, retirement funds, banking needs)				
Is the patient unable to manage transportation? (Example: using a bus or calling a taxi)				
Please provide any further details that you feel may be important to share with the patient's primary care provider:				

PHYSICAL AND NEUROLOGICAL EXAMINATION <i>To be completed by Primary Care provider</i>	
GENERAL APPEARANCE Personal hygiene and dress Signs of trauma?	normal/abnormal Notes:
CRANIAL NERVES Cranial nerves 3,4,6	normal/abnormal Notes:
MOTOR Bulk Tone Power Tremor Other Parkinsonian Motor Features Myoclonus	normal/abnormal Notes:
REFLEXES Deep tendon reflexes	normal/abnormal Notes:
STANCE Posture and Stance	normal/abnormal Notes:
GAIT Walking	normal/abnormal Notes:
COGNITION Standardized Cognitive Test score (MoCA /MMSE/SLUMS/3MS/RUDAS) *See interpretation manual for guidelines regarding need for administration of standardized cognitive test, scores and potential need for referral to dementia specialist.	Notes:
IMAGING CT or MRI	Notes:
LAB WORK CBC, METABOLIC PANEL, TSH, B12 RPR	Notes:

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease Diagnostic Tables
To be completed by Primary Care provider

Based on the patient/informant responses to the ACCT-AD evaluation what is the severity of the problem?	
No significant cognitive changes	
Mild cognitive impairment (MCI) (cognitive and behavioral changes that do not affect the ability to function independently close to the prior level)	
Dementia (cognitive and behavioral changes impairing daily function)	

What is the suspected underlying cause of the syndrome at this point in time?	
Not enough specific symptoms to choose a possible cause	
Typical AD	
Atypical neurodegeneration (LBD, FTD, atypical AD, EOAD)	
Indeterminate (Only check this box if any of the following conditions may be the main reason for the cognitive impairment: sleep apnea, depression, other psychiatric issues, etc.)	

The symptoms below may be a neurodegenerative disease process but are atypical for Alzheimer's disease. Were any of these symptoms or confounders present during your assessment that might have justified an expert dementia referral? (check all that apply)	
Early age of onset	
RPD (Condition developed sub-acutely over weeks to months, or rarely acutely over days, in contrast to most dementing conditions that take years to progress)	
Cognitive testing results that are inconsistent with clinical severity	
Red Flag behavioral or neuropsychiatric symptom/s (i.e., Toolkit manual pages 45-46, 48, 52, 56-63)	
Movement disorder (see Toolkit manual 'History of Motor Symptoms' pages 64-72)	
History of TBI with known impact on cognitive function	
None	

The clinical features below make assessment for neurodegenerative disease difficult and may not be reliable in primary care settings. Were any of these features present that might have justified an expert dementia referral? (check all that apply)	
Low education and/or language constraints that can't be addressed in my clinic	
Reliable informant not available/poor historian/insufficient information	
Long standing psychiatric illness with significant impact on daily function (i.e. schizophrenia or bipolar disorder now unable to keep a job)	
History of remote TBI with known impact on cognitive function	
Other, please describe:	
None	

Did you identify any of the symptoms or features below that could affect cognition and may justify other additional assessment?	
Sleep apnea	
Depression	
Psychiatric issue	
Sensory impairment (i.e. hearing or vision)	
Cerebrovascular injury, including stroke	
Intracranial tumor that may be affecting cognition	
Abnormal labs, briefly describe:	
Other abnormal imaging findings (i.e., other than atrophy or white matter ischemic type changes)	
Other, briefly describe:	
None	

Patient name:	Date: ACCT-AD full cognitive evaluation-v.25
MR#	Patient's date of birth:
Name of person completing questionnaire:	Informants name and relationship:
Patient's race:	Patient's ethnicity: (circle one) Hispanic/Latino or Non-Hispanic/Latino
Patient's preferred language:	Patient's years of education:
Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease (ACCT-AD) FULL COGNITIVE EVALUATION	

HISTORY OF PRESENT ILLNESS (HPI)		
	PATIENT	INFORMANT
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.
CHIEF COMPLAINT		
We'll talk in more detail, but can you give me a brief overview of the main things that brought you here?		
DURATION/EARLY SYMPTOMS		
To have a good understanding of what's going on, it helps to start at the beginning.		
What were the first symptoms you noticed, and how long ago was that?		
CLARIFICATION		
For any symptoms that the patient brings up, make sure that general terms like "I forget things" are clarified, usually it's necessary to get examples.		
You might say, "Can you give me an example of the kinds of [things, words, events, whatever the person said] forget?"		
Or, if they describe it in terms of problems with certain tasks, like, "I can't get things done at work."		
You might say, "OK, when you are trying to do [whatever task they said they have trouble with], what happens?"		
EVOLUTION		
Have the symptoms worsened or changed over time?		
If they say yes, ask: What makes you say things are worse?		
Have any new symptoms developed that weren't there at the beginning?		
POTENTIAL NON-NEURODEGENERATIVE CAUSES		
Are there any particular events that were associated with the onset or worsening of the symptoms, like medical illness, accidents or major life stresses?		

EVALUATION		
	PATIENT	INFORMANT
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.
MEMORY		
Do you have any problems with your memory?	Yes ☐	Yes ☐
Prompts - Do you misplace items often (e.g., phone, keys)? - Do you rely more on notes? - Do you have more trouble with recent memory (conversations, recent events) compared to remote memory? - Do you ask repetitive questions?	Notes:	Notes:
LANGUAGE		
Do you have difficulty expressing words, difficulty understanding words or conversations?	Yes ☐	Yes ☐
Prompts - Do you have trouble finding the word or name you want to use? - Do you have any difficulty understanding what people are saying to you? - Do you have difficulty pronouncing words that were easy for you to pronounce in the past?	Notes:	Notes:
EXECUTIVE FUNCTIONS		
Do you have difficulty planning, starting or finishing complicated tasks at home or at work?	Yes ☐	Yes ☐
Prompts - Is your home or office as neat and organized/clean as it used to? - Do you have problems finishing a task because you get distracted easily?	Notes:	Notes:
VISUAL-SPATIAL		
Do you get lost while walking or driving?	Yes ☐	Yes ☐
Prompts - Can you drive to familiar places? i.e. grocery store, post office, friend's house, etc. - Do you get lost in a familiar store or restaurant? - Do you have difficulty seeing things properly or judging distances properly? - Does your motor vehicle show evidence of damage? - Do you have difficulty figuring out how to position yourself to sit in a chair? - Do you complain of difficulty seeing while reading? - Do you complain that your eyes don't work? - Do you have trouble seeing things that are right in front of you? - Do you have difficulty recognizing people?	Notes:	Notes:

	PATIENT	INFORMANT
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.
DEPRESSION		
Has your mood changed?	Yes ☐	Yes ☐
Prompts - Do you cry a lot? - Do you feel hopeless about life or about the future? - Do you feel worthless or bad about yourself?		
APATHY		
Have you lost motivation or energy to do things you used to enjoy?	Yes ☐	Yes ☐
Prompts - Do you have decreased interest in social activities? - Do you have decreased interest in church or community groups? - Do you have decreased interest in hobbies?	Notes:	Notes:
IRRITABILITY/ANGER		
Do you become angry more easily?	Yes ☐	Yes ☐
Prompts Do you get angry about things that would not have bothered you in the past?	Notes:	Notes:
DISINHIBITION		
Sometimes we have patients who seem to forget how to behave in public. Has this been an issue for you?	Yes ☐	Yes ☐
Prompts - Have you done anything that may have been embarrassing to the family? e.g., calling people fat in public when they might hear? - Have you ever told dirty jokes in inappropriate situations? - Have you ever told personal things about yourself or family to strangers? - Have you ever eaten off of other people's plates at restaurants?	Notes:	Notes:
DELUSIONS		
Have there been any problems with beliefs that are unusual or not realistic?	Yes ☐	Yes ☐
Prompts - Do you feel like someone is out to get you? - Do you feel like you might have special powers or special relationships with famous or powerful people?	Notes:	Notes:

	PATIENT	INFORMANT
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.
HALLUCINATIONS		
Have you been seeing or hearing anything that might not be there (or others can't see or hear)?	Yes ☐	Yes ☐
	Notes:	Notes:
OBSESSIONS/COMPULSIONS		
Have you become fixated on certain ideas that you can't get out of your head or have developed any specific rituals?	Yes ☐	Yes ☐
Prompts - Do you have any obsessions with certain political or religious ideas? - Do you have any obsessions about timing or routine being adhered to precisely? - Do you have any obsessions with specific games, movies or specific forms of entertainment?	Notes:	Notes:
SLEEP		
Have you had any changes in sleep?	Yes ☐	Yes ☐
Prompts - Do you wake up a lot in the middle of the night? - Do you have problems falling sleep? - Has your partner reported that you may have problems acting out dreams (yelling, screaming, hitting)? - Do you snore? - Has your partner ever reported that you may have breathing stoppages while you sleep? - Do you sleep during the day?	Notes:	Notes:
EATING BEHAVIORS		
Have there been changes in your eating habits?	Yes ☐	Yes ☐
Prompts - Have you been eating more or less than usual? - Have you had unintentional weight gain? - If yes, how much weight have you gained? - Have you had unintentional weight loss? - If yes, have much weight have you lost? - Do you want to eat specific foods all the time? - Do you want to eat sweets or carbohydrates more than you used to?	Notes:	Notes:
LOSS OF EMPATHY		
Do you seem less concerned about others' needs or problems?	Yes ☐	Yes ☐
Prompts - Do you feel you are not reacting appropriately in an emergency or when someone needs help? - Do you feel you are not reacting emotionally when someone has a particularly sad or happy event (e.g., a loss or major achievement)?	Notes:	Notes:

	PATIENT If patient unreliable, obtain history from informant.	INFORMANT If Informant does not agree with pt or informant has additional details describe below.
JUDGMENT/GULLIBILITY		
Do you seem to be more open to scams or solicitations?	Yes ☐	Yes ☐
Prompts - Have you been buying lots of magazines or online offers? - Have you ever been fooled by a suspicious business arrangement?	Notes:	Notes:

MOTOR SYMPTOMS		
	PATIENT If patient unreliable, obtain history from informant.	INFORMANT If Informant does not agree with pt or informant has additional details describe below.
PARKINSONISM AND RESTING TREMOR		
Do you have involuntary shaking in your hands, arms, legs or chin?	Yes ☐	Yes ☐
	Notes:	Notes:
RIGIDITY		
Do your limbs feel rigid or stiff?	Yes ☐	Yes ☐
Prompts Do you turn your head and neck easily?	Notes:	Notes:
MOTOR NEURON DISEASE		
Do you have twitching of your muscles?	Yes ☐	Yes ☐
Prompts Have you lost muscle mass?	Notes:	Notes:
BRADYKINESIA		
Have your movements been slowing down?	Yes ☐	Yes ☐
Prompts - Do you walk slower? - Does it take you longer to button your shirt? - Is your handwriting smaller?	Notes:	Notes:
PARKINSONIAN AND GAIT ABNORMALITY		
Have you had changes in your ability to walk?	Yes ☐	Yes ☐
Prompts - Are you stooped over when walking? - Do you drag your feet when you walk? - Do you get stuck when walking or are your steps shorter?	Notes:	Notes:

	PATIENT	INFORMANT
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.
FREQUENT FALLS		
Have you fallen in the last couple of years?	Yes ☐	Yes ☐
Prompts - If yes, how many times have you fallen? - What were the circumstances of the falls? (tripping, weakness of legs, loss of consciousness, unsteadiness) - Do you feel unsteady on your feet?	Notes:	Notes:
UNILATERAL WEAKNESS		
Do you feel weaker on one side of your body than the other?	Yes ☐	Yes ☐
Prompts - Have you had a stroke? If yes, when was your stroke? - Do you have trouble using one hand? - Do you limp or drag one foot?	Notes:	Notes:
MYOCLONUS		
Do you have involuntary movements of your limbs, such as jerking or twitching?	Yes ☐	Yes ☐
Prompts - Do you have loss of muscle mass? - Do you have weaker muscles? - Have any of your muscles become smaller?	Notes:	Notes:
ALIEN LIMB		
Does one of your arms behave as if it doesn't belong to you?	Yes ☐	Yes ☐
Prompts Has your arm (unbuttoned your shirt/grabbed something) without your awareness or control?	Notes:	Notes:
DYSARTHRIA		
Have you had slurring of your speech?	Yes ☐	Yes ☐
Prompts Does your speech sound as if you are drunk?	Notes:	Notes:
DYSPHAGIA		
Have you had trouble swallowing?	Yes ☐	Yes ☐
Prompts - Do you cough or choke when eating or drinking? - Do you have any other difficulty swallowing liquids or solid foods?	Notes:	Notes:

FAMILY HISTORY AND FUNCTION		
	PATIENT	INFORMANT
	If patient unreliable, obtain history from informant.	If Informant does not agree with pt or informant has additional details describe below.
FAMILY HISTORY		
Are there any members of your family with “mental health problems, dementia, Parkinson’s or other neurological problems”? For example: Alzheimer’s disease, Parkinson’s, schizophrenia, bipolar, depression	Yes ☐	Yes ☐
	Notes:	Notes:
BASIC ACTIVITIES OF DAILY LIVING (BADLs)		
Have you had any changes in your ability to manage basic activities of daily living due to changes in memory or thinking?	Yes ☐	Yes ☐
Prompts - Do you need assistance to bathe? - Do you need assistance to dress? - Are you unable to manage your bladder and bowels without accidents?	Notes:	Notes:
INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs)		
Has there been a change in your ability to manage your household due to problems with memory or thinking?	Yes ☐	Yes ☐
Prompts - Are you unable to manage your shopping? - Are you unable to pay your bills on time? - Are you unable to complete household chores or projects? - Do you ever leave the stove on? - Are you unable to follow recipes? - Are you unable to drive? - Do you have trouble completing tasks at work? - Have you lost your job because of trouble completing tasks at work? - Are you unable to manage your own medications? - Is the patient unable to do their laundry? - Is the patient unable to use the telephone? - Is the patient unable to manage their finances? (Example: checking account, retirement funds, banking needs) - Is the patient unable to manage transportation? (Example: using a bus or calling a taxi)	Notes:	Notes:

PHYSICAL AND NEUROLOGICAL EXAMINATION	
GENERAL APPEARANCE Personal hygiene and dress Signs of trauma?	normal/abnormal Notes:
CRANIAL NERVES Cranial nerves 3,4,6	normal/abnormal Notes:
MOTOR Bulk Tone Power Tremor Other Parkinsonian Motor Features Myoclonus	normal/abnormal Notes:
REFLEXES Deep tendon reflexes	normal/abnormal Notes:
STANCE Posture and Stance	normal/abnormal Notes:
GAIT Walking	normal/abnormal Notes:
COGNITION Standardized Cognitive Test score (MoCA /MMSE/SLUMS/3MS/RUDAS) *See interpretation manual for guidelines regarding need for administration of standardized cognitive test, scores and potential need for referral to dementia specialist.	Notes:
IMAGING CT or MRI	Notes:
LAB WORK CBC, METABOLIC PANEL, TSH, B12 RPR	Notes:

Assessment of Cognitive Complaints Toolkit for Alzheimer's Disease Diagnostic Tables

Based on the patient/informant responses to the ACCT-AD evaluation what is the severity of the problem?

No significant cognitive changes

Mild cognitive impairment (MCI) (cognitive and behavioral changes that do not affect the ability to function independently close to the prior level)

Dementia (cognitive and behavioral changes impairing daily function)

What is the suspected underlying cause of the syndrome at this point in time?

Not enough specific symptoms to choose a possible cause

Typical AD

Atypical neurodegeneration (LBD, FTD, atypical AD, EOAD)

Indeterminate (Only check this box if any of the following conditions may be the main reason for the cognitive impairment: sleep apnea, depression, other psychiatric issues, etc.)

The symptoms below may be a neurodegenerative disease process but are atypical for Alzheimer's disease. Were any of these symptoms or confounders present during your assessment that might have justified an expert dementia referral?

(check all that apply)

Early age of onset

RPD (Condition developed sub-acutely over weeks to months, or rarely acutely over days, in contrast to most dementing conditions that take years to progress)

Cognitive testing results that are inconsistent with clinical severity

Red Flag behavioral or neuropsychiatric symptom/s (i.e., Toolkit manual pages 45-46, 48, 52, 56-63)

Movement disorder (see Toolkit manual 'History of Motor Symptoms' pages 64-72)

History of TBI with known impact on cognitive function

None

The clinical features below make assessment for neurodegenerative disease difficult and may not be reliable in primary care settings.

Were any of these features present that might have justified an expert dementia referral?

(check all that apply)

Low education and/or language constraints that can't be addressed in my clinic

Reliable informant not available/poor historian/insufficient information

Long standing psychiatric illness with significant impact on daily function (i.e. schizophrenia or bipolar disorder now unable to keep a job)

History of remote TBI with known impact on cognitive function

Other, please describe:

None

Did you identify any of the symptoms or features below that could affect cognition and may justify other additional assessment?

Sleep apnea

Depression

Psychiatric issue

Sensory impairment (i.e. hearing or vision)

Cerebrovascular injury, including stroke

Intracranial tumor that may be affecting cognition

Abnormal labs, briefly describe:

Other abnormal imaging findings (i.e., other than atrophy or white matter ischemic type changes)

Other, briefly describe:

None