SECTION 1: INSTRUCTION MANUAL

Assessment of Cognitive Complaints Toolkit

For Alzheimer's Disease

Instruction Manual

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

CONTENTS

PLEASE READ THIS SECTION BEFORE USING THE TOOLKIT

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 section

This **instruction manual** contains essential background information about the goals of this toolkit and how to use it. It also includes information on the various causes of dementia, how we can recognize them, the terms used to classify patients according to how severe their problem is, the guidelines and reasons to diagnose cognitive impairment, and the strengths and limitations of this toolkit. It also contains resources for patients and families. To have the best understanding of how and why to use this toolkit, 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)**.

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.

Detection versus diagnosis

Practitioners can have different goals regarding cognitive complaints. First, they may wish to ensure that they identify patients in their practice with significant cognitive or behavioral complaints or follow up on a concern raised by staff or a question from a patient or family member. This can be accomplished in a few minutes by asking a few simple questions and, if necessary, using brief cognitive tests. The toolkit refers to this process as **detection**. This is not the same as a **diagnosis**, which 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 in the opinion of the toolkit developers, it is necessary to pursue the full assessment to establish a diagnosis in every patient in whom a significant cognitive or behavioral complaint has been detected. This can be done within the primary care setting for many patients or through a referral to an expert.

Goals of the toolkit

The goal of this toolkit is to guide clinicians in the **detection and full assessment of cognitive and behavioral changes** in their patients. Although specialty physicians are often relied on to provide work-up and diagnosis, the number of these specialists is insufficient to evaluate all patients who need assessment. Therefore, this toolkit provides guidance on detecting cognitive and behavioral concerns and proceeding to fully evaluate these concerns without necessarily needing to refer patients. The toolkit provides instructions on how to elicit the patient's history, how to collect and interpret the physical examination, and how to conduct and interpret limited cognitive testing. This toolkit focuses on the diagnosis of mild cognitive changes or dementia due to typical Alzheimer's disease (AD). It also helps clinicians identify clinical features that suggest that a patient's cognitive changes may not be due to AD and should prompt referral for atypical dementias or other conditions. In most settings where specialty expertise (neurology, psychiatry, or geriatrics) is available, referral of patients with atypical symptoms is appropriate.

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, thorough 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, ordering and interpreting basic lab tests and imaging, 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
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.

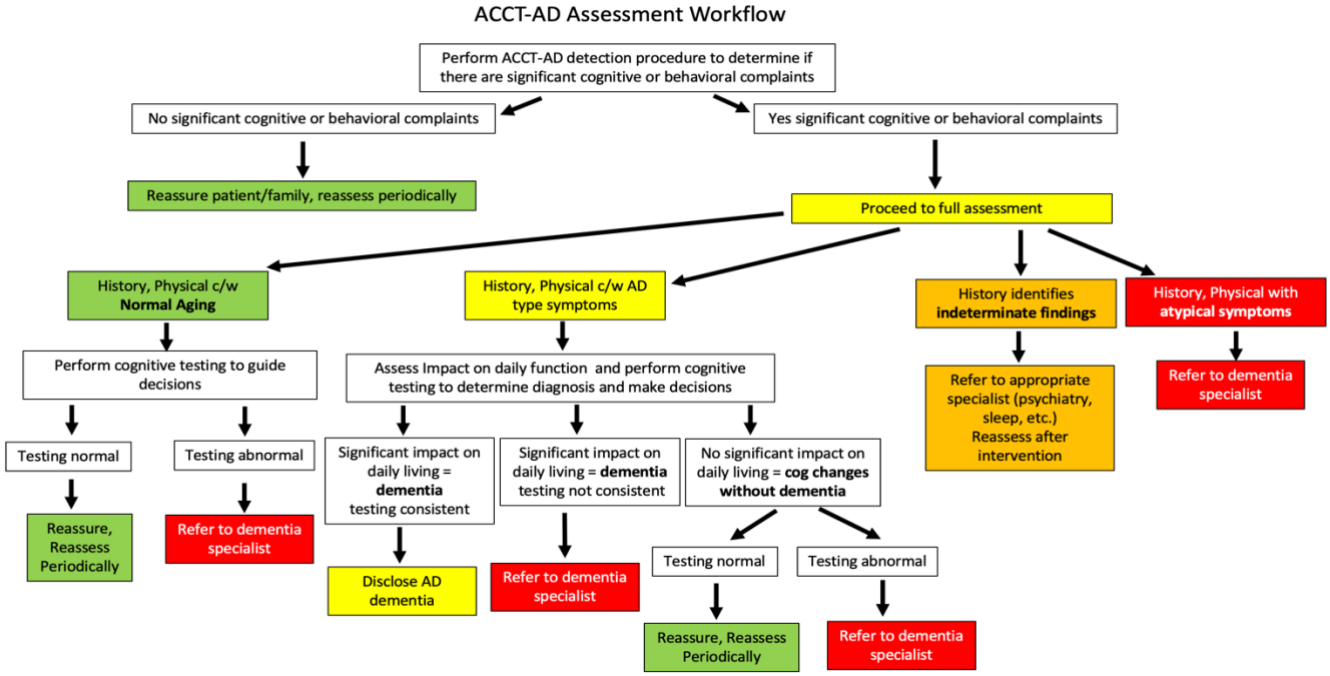
Approach to Assessment

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 but do not affect daily function and thus are not severe enough to be called dementia. Such symptoms are referred to in this toolkit as **cognitive changes without dementia**. Depending on the patient's performance on limited cognitive testing and the preference of the clinician and patient, referral to a specialist may be indicated. **It is strongly advised to read the section below in this instruction manual on mild cognitive changes versus dementia.** The cause of these mild cognitive changes could be:
    a. Non-specific and due to a number of causes, including normal aging, cerebrovascular disease, mood disorders, or other issues
    b. Early signs of a neurodegenerative disease, including AD or another disease
3. The complaints are severe enough to be diagnosed as dementia but are typical of AD and, therefore, do not necessarily need to be referred to a specialist.
4. The complaints potentially indicate another neurological, or in some cases, a non-neurological cause, and suggest that referral to a specialist is appropriate.



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 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.

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 cognitive changes without dementia 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.

LANGUAGE **Are you having difficulty expressing yourself or difficulty understanding words or conversation?**	Prompts: 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.

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.

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. **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 Manua**l, 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 Manua**l, 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

INFORMATION REGARDING TOOLKIT BACKGROUND AND DEMENTIA

Why was this toolkit developed?

The Alzheimer's Association reported in 2018 that there were over 650,000 Californians 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, and identify other cognitive problems requiring specialty 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.

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.

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://bhw.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 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	May be 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: +/− memory	Executive: +/− 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:

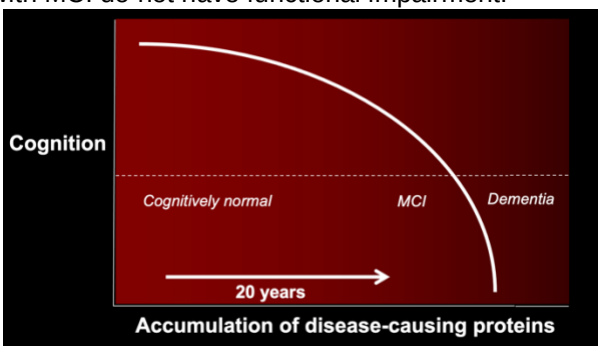
- MCI is cognitive impairment with little or no functional impairment.
- MCI is often caused by neurodegenerative disease, but not always.
- It is important to diagnose MCI because it can help providers follow patients more carefully and can help prepare patients and families for the future.
- MCI can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

Traditionally, a patient was only considered to have a possible neurodegenerative disease if they had a diagnosis of dementia. This term 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 it is not acceptable for normal aging to cause severe enough cognitive change to cause 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 such as blood testing or imaging.

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.

Beginning in about the early 2000's dementia researchers began to recognize that 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 has revealed that many of these patients go on to develop dementia. The term "Mild Cognitive Impairment" (MCI) has been 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.

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. In addition, the evaluation for cognitive impairment at this mild level of severity should include the same assessment that is done for dementia, including history, physical examination, blood testing and imaging. 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 honest 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 amnestic MCI for those with primarily memory complaints, and non-amnestic 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 some authors insist that terms like MCI cannot be used based on subjective complaints alone. In order to avoid controversial use of technical terms, and because we do not expect comprehensive neuropsychological testing to be done in the primary care setting, we have adopted the term '**Cognitive Changes Without Dementia'** as a generic term for this entity.

Role of other medical 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, 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 Cognitive Impairment Without Dementia diagnosis, such non-neurological medical conditions have a higher likelihood of accounting for the complaints.

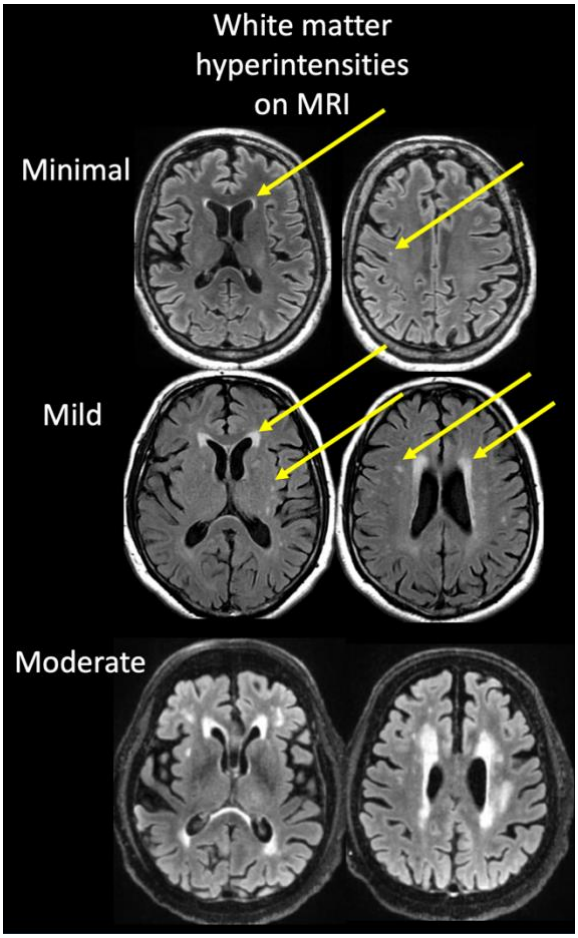
Vascular disease affecting the brain is a special case to consider. If a patient has a history of sudden onset of neurological complaints, including cognitive complaints, this may represent a stroke or other non-neurodegenerative condition, and immediate referral to a neurologist is recommended. On the 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. Such changes can be seen on MRI scans and to some degree on CT scans, but the presence of these changes does not rule out the presence of neurodegenerative disease. Autopsy studies indicate that the majority of patients who develop dementia do have evidence of neurodegenerative disease proteins, even if they have cerebrovascular disease. Most patients with dementia due to cerebrovascular disease have symptoms that are very similar to those in Alzheimer's disease, and it is very difficult to clinically differentiate those with a dementia due to cerebrovascular disease from those due to Alzheimer's disease that also have cerebrovascular disease. Thus, the toolkit does not provide any specific guidance on diagnosis of vascular dementia. Rather, if the history suggests a diagnosis of dementia due to Alzheimer's disease, the clinician should disclose that diagnosis. If brain imaging suggests significant changes from small vessel cerebrovascular disease, the clinician can acknowledge that this may be making a contribution, which can provide additional motivation for addressing cardiovascular risk factors.

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 (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 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 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 can be obtained from PET scanning, CSF analysis or blood testing
- Biomarkers can be abnormal in asymptomatic patients, and their significance in that setting is not always clear
- Biomarkers should only be obtained and interpreted in the context of a full diagnostic assessment for a cognitive or behavioral complaint that could represent neurodegenerative disease

Neurodegenerative diseases are thought to be caused by accumulation of toxic proteins, with each disease being associated with a different type of protein disorder (pages 12-13 above). Continuing progress is being made in developing tests to detect and quantify the specific biological changes underlying each disorder (biomarkers). Although more biomarkers are becoming available, their interpretation and implications for prognosis and treatment **must be considered in light of the clinical presentation, and therefore they should only be obtained in the context of a thorough clinical assessment**. Because of this complexity, the current version of the toolkit (v.20.8) recommends that biomarker testing should only be obtained in the setting of an expert consultation. However, these tests are becoming increasingly available, and in some cases can be obtained by a patient directly from a commercial laboratory. We therefore provide some basic information about their use.

Alzheimer's disease: Biomarkers for AD can now be obtained from **PET scanning, cerebrospinal fluid (CSF) analysis, or blood testing**. FDA-approved F18-labelled radiopharmaceuticals for PET scanning are available to detect of amyloid plaques and tau tangles, the diagnostic pathological features of AD. CLIA-approved assays are also available for quantification of Abeta-42 (the main constituent of amyloid plaques), total tau and phosphorylated tau in the CSF, where reduced Abeta-42 combined with elevated tau and phospho-tau levels are also strongly predictive of Alzheimer's pathology in the brain. Extensive research has shown that these biological changes are detectable for ten to twenty years before a patient develops symptoms. A substantial portion of elders with normal cognitive function will show abnormalities on these tests, depending on their age. Asymptomatic patients showing biological changes suggesting Alzheimer's disease do have an increased risk of cognitive decline to dementia, but many patients do not develop symptoms, and autopsy studies commonly identify patients with substantial Alzheimer's pathology who were asymptomatic in life. Blood tests for various forms of Abeta proteins and phosphorylated tau have recently become available. Research has shown that several of these tests also strongly predict the presence of Alzheimer's pathology in the brain. The CLIA approved versions of these tests have had very limited use in clinical practice thus far.

The significance of PET, CSF, or blood findings suggesting Alzheimer's disease must be interpreted in light of the clinical presentation. It is currently not recommended to obtain these tests in patients who are asymptomatic, because precise prognostication is not possible. If asymptomatic patients do obtain results suggesting Alzheimer's disease, they should be counseled that although these findings do suggest that the biology of Alzheimer's disease is affecting them, it does not mean that they will suffer symptoms from this. A program for regular follow-up should be established. Conversely, in patients with dementia, the presence of these markers strongly suggests that Alzheimer's disease is contributing to their symptoms, although it does not rule out other contributors, and mixed pathology with Alzheimer's and other neurodegenerative proteins is common. In patients with mild cognitive changes, the interpretation is more complex. For those patients with a clear history of insidiously progressive decline who currently show abnormal performance on cognitive testing, these markers indicate that Alzheimer's disease is likely contributing, and their risk of progressing to dementia over the next few years is substantial, although how quickly this happens still varies widely. For patients with subjective concerns that have not worsened much over time, the interpretation is not necessarily clear at present.

Lewy body dementia: Tests to detect pathological synuclein protein, the main constituent of Lewy bodies, in the CSF have recently become available. Although research suggests high sensitivity and specificity, additional interpretation beyond confirming the presence of Lewy bodies as a probable pathology in the brain has not been established.

Neurofilament Light Chain (NfL): NfL is another protein that can be measured in the CSF or blood, and blood NfL assays are also commercially available. 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. Precise ranges for normal and abnormal levels of NfL have not yet been established. 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, including autosomal dominant mutations, can cause neurodegenerative disease, including Alzheimer's disease
- Neurodegenerative diseases caused by mutations are usually atypical in some way, as indicated by age of onset or other clinical features, which should prompt referral
- APOE-e4 is a genetic risk factor for Alzheimer's disease, but is not considered useful for diagnosis and or precise prognosis. It can be helpful for planning treatment with anti-amyloid monoclonal antibodies
- Any genetic testing should be preceded by 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 mutations, including several autosomal dominant mutations. For some diseases, like Huntington's disease, autosomal dominant mutations are the main causes. For others, such mutations account for a portion of the cases. In Alzheimer's disease, autosomal dominant mutations account for only about one percent of all cases. In these families, the mutations are highly penetrant, and so should affect about 50% of family members, on average, and 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 around 20 to 30%. Genetic testing for neurodegenerative disease should be driven by clinical suspicion, and any features suggesting genetic causes of neurodegenerative disease are marked as "red flags" in this toolkit. Genetic testing should usually be done as part of an expert assessment, and should be preceded by genetic counseling to review the implications for the patient and their family.

Apolipoprotein E (APOE): The APOE gene can code for several variants, labelled APOE-e2, APOE-e3, and APOE-e4. APOE-e4 is the least common, but carrying an APOE-e4 allele increases the risk of developing Alzheimer's disease at an earlier age (e.g. late 50s, early 60s), and carrying two APOE-e4 alleles further increases that risk. However, carrying APOE-e4 is not considered a cause of Alzheimer's disease, and many patients, even some with two APOE-e4 alleles, do not develop Alzheimer's disease. Therefore, APOE-e4 has limited value for diagnosis or prognosis, and so APOE-e4 is not recommended for these purposes.

However, carriage of an APOE-e4 allele has been associated with an increased risk of Amyloid Related Imaging Abnormalities (ARIA), including cerebral edema and hemorrhages, in the setting of monoclonal antibody treatments to remove Alzheimer's disease related amyloid. Therefore, APOE testing is recommend if patients are being considered for such treatments in order to inform the patient about the risk of adverse effects. Such testing and counseling should be done in the context of an expert assessment, to include genetic counseling.

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 framework for HRA 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.

Specific diagnosis of neurodegenerative disease has value for several reasons:

- 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.

- The specific diagnosis determines currently available treatment and can guide polypharmacy decisions. There are specifically approved therapies for AD, but not for most other forms of dementia due to neurodegenerative disease. 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.

- It has specific 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 patients with DLB and particularly PSP are at very high risk of falls. There are many other similar prognostic implications.

- It has specific implications for future treatments. Many treatments that are currently being developed are targeted at the specific proteins that cause each of the neurodegenerative syndromes. Once these treatments are developed, it will be critical to make a specific diagnosis to guide therapy.

- It has specific implications for participating in 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.

Why should a specific diagnosis be pursued in a primary care setting?

- Failure to identify the specific cause of cognitive or behavioral changes can delay appropriate treatment and lead to avoidable adverse health outcomes. Waiting lists for dementia specialty consultations are typically long, and specialty care can be very difficult to access in some settings, such as rural practice settings. While a specific diagnosis for the cause of cognitive or behavioral changes can be complex and require such expertise, this is not always the case. With proper assessment, a reliable diagnosis can be achieved in any setting, particularly for more common etiologies such as AD.

- If patients with common problems (e.g. cognitive complaints that are typical for aging or dementia likely due to AD) are identified and accurately diagnosed in a primary care setting, this will allow for more efficient use of specialty referrals.

- 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 and control of symptoms and treatments by the primary care practice.

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). 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. 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 high school) will sometimes have achieved reasonable literacy skills, for example through work experiences. In this situation, the full cognitive evaluation can be considered valid, but the patient should ideally 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). If referral 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).

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 of 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 not 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 a "mouthpiece" 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 respected, scores will not be valid. Thus, the clinician must ensure that the person being the "mouthpiece" 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 "cut point" 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/

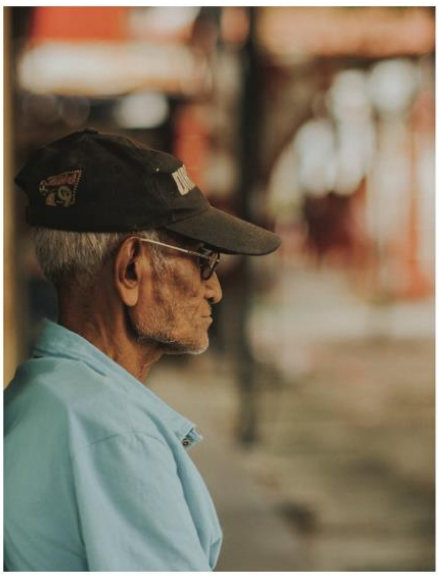
Activities

- 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.ssww.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
- 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

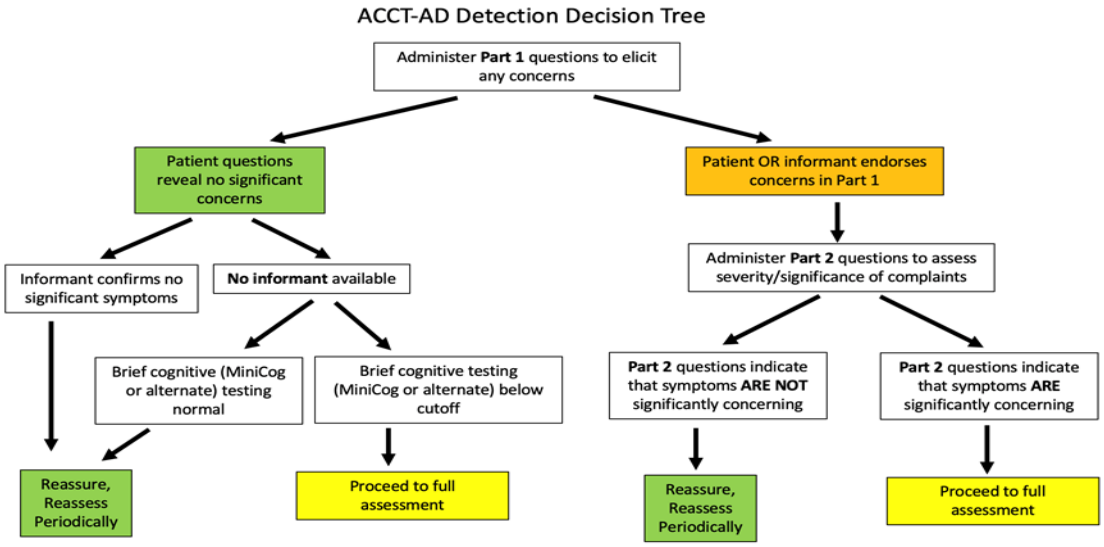
STEP ONE: DETECTING COGNITIVE CONCERNS

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**	**ANSWER-YES** **BRING BACK FOR FULL ASSESSMENT**
All my friends complain about the same thing. Actually, I think my memory is still better than my peers.	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	**Interpretation**
Normal aging	Concerning for cognitive impairment.

MEMORY **Have you stopped doing anything because of these changes?**	Prompts:

ANSWER **GO TO NEXT QUESTION**	**ANSWER-YES** **BRING BACK FOR FULL ASSESSMENT**
I might rely on my phone or calendar more.	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	**Interpretation**
Normal aging	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**	**ANSWER-YES** **BRING BACK FOR FULL ASSESSMENT**
My children occasionally say I repeat a story.	My wife tells me that I am always asking her what the schedule is. My friends comment that I often miss appointments.
Interpretation	**Interpretation**
Normal aging	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	**ANSWER-YES BRING BACK FOR FULL ASSESSMENT**
All my friends complain about the same thing. Actually, I think my vocabulary is more limited.	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	**Interpretation**
Normal aging	Concerning for cognitive impairment.

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

ANSWER-NO GO TO NEXT QUESTION	**ANSWER-YES BRING BACK FOR FULL ASSESSMENT**
My life is very busy.	I stopped participating in my book club. I still go but speak less at social occasions.
Interpretation	**Interpretation**
Normal aging if confirmed with informant or negative mini cognitive testing	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	**ANSWER-YES BRING BACK FOR FULL ASSESSMENT**
No.	My wife says I use words like "thingy" more than I used to.
Interpretation	**Interpretation**
Normal aging	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**	**ANSWER-YES** **BRING IN FOR FULL ASSESSMENT**
We are all just getting crabby. We all are doing less than we used to.	I seem to be much less patient than my friends. I'm much less interested in doing things than my friends.
Interpretation	**Interpretation**
Normal aging	Concerning for cognitive impairment

PERSONALITY **Have you stopped doing anything because of these personality changes?**	Prompts:

ANSWER-NO **GO TO NEXT QUESTION**	**ANSWER-YES** **BRING IN FOR FULL ASSESSMENT**
I'm busier than ever.	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	**Interpretation**
Normal aging	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**	**ANSWER-YES** **BRING IN FOR FULL ASSESSMENT**
	My friends think that I tend to get angry more easily.
Interpretation	**Interpretation**
Normal aging	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**	**ANSWER-YES** **REQUIRES FOLLOW-UP IN PART 2**
Yes, they often go into a room and forget why they're there. They have more difficulty remembering names.	Yes, any other complaint
Interpretation	**Interpretation**
Normal aging if confirmed with informant or negative mini-cognitive testing	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**	**ANSWER-YES** **REQUIRES FOLLOW-UP IN PART 2.**
They have occasional problems coming up with a word.	Yes. I think that it's harder for them to get their point across.
Interpretation	**Interpretation**
Normal aging if confirmed with informant or negative mini-cognitive testing	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**	**ANSWER-YES** **REQUIRES FOLLOW-UP IN PART 2**
No.	They might be a little less patient. Our family thinks they're more difficult to get along with.
Interpretation	**Interpretation**
Normal aging if confirmed with informant or negative mini cognitive testing	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**	**ANSWER-YES** **BRING IN FOR FULL ASSESSMENT**
All their friends complain about the same thing. Actually, I think their memory is still better than our peers.	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	**Interpretation**
Normal aging if confirmed with informant or negative mini cognitive testing	Concerning for cognitive impairment.

MEMORY **Have they stopped doing anything because of these memory changes**?	Prompts:

ANSWER-NO **GO TO NEXT QUESTION**	**ANSWER-YES** **BRING IN FOR FULL ASSESSMENT**
They might rely on phone or calendar more.	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	**Interpretation**
Normal aging	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**	**ANSWER-YES** **BRING IN FOR FULL ASSESSMENT**
Their children occasionally say they will repeat a story.	They are always asking me what the schedule is. I notice that they often miss appointments.
Interpretation	**Interpretation**
Normal aging	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 **Do you think their personality changes are worse than those of their 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**
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 **Have they stopped doing anything because of these personality changes?**	Prompts:

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 **Has anyone commented on these personality changes to you**?	Prompts:

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 task. With the clock drawing task, the maximum score is 12; without 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

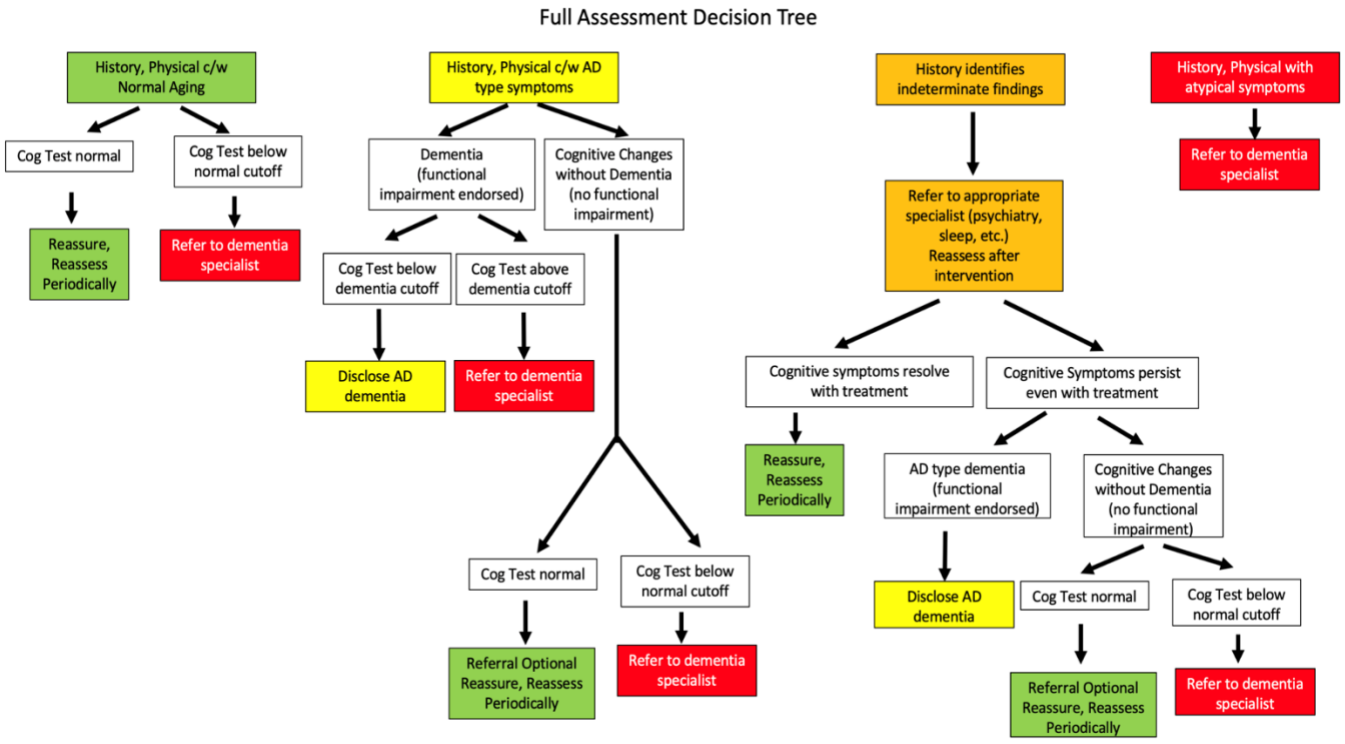
B. Pursue full cognitive evaluation, using **form provided in Patient Evaluation Forms section**
   a. Patient and informant attend appointment for accurate history and evaluation
   b. Go through all questions, even those not endorsed in pre-visit questionnaire
   c. Refer to **Reference and Interpretation Manual as needed** for interpretation of patient/informant responses

C. Complete **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. Move on to Step 3, Interpretation, using **Decision Tree** to finalize diagnosis and establish plan. The decision tree is copied below.



INTERPRETATION TABLES: Full Cognitive Evaluation

History of Present Illness

Chief Complaint

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

NORMAL AGING OR COGNITIVE CHANGES WITHOUT DEMENTIA, depending on answers to rest of questions	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **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?**	Comments: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, depending on answers to rest of questions	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED**
	• Started to notice **FORGETTING MINOR THINGS** a few years ago, misplacing things, forgetting a conversation. • Symptoms were already present, seemed to get worse at a particular time (e.g., hospitalization), recovered but not all the way.	• 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	Comments:
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?"	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.

Evolution –changes in symptoms

History of Present Illness **EVOLUTION**	Comments:
Have these symptoms worsened or changed over time? If yes, ask, "What makes you say things are worse?"	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.

NORMAL AGING **NO REFERRAL**	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED** **NO**
	• Used to **FORGET** once in a while, now forgets **MORE FREQUENTLY;** memory recall seems shorter (e.g., repeating questions after a short time)	

Evolution-new symptoms

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

NORMAL AGING NO REFERRAL	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED NO**
	• 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 NO REFERRAL	
	• 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 NO REFERRAL	
	• 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.	

Non –Neurodegenerative cause

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?**	Prompts: 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.

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?

NORMAL AGING OR COGNITIVE CHANGES WITHOUT DEMENTIA, depending on answers to rest of questions	**TYPICAL OF AD TYPE DEMENTIA NO REFERRAL**	**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 **Have there been changes in ability to manage basic activities of daily living due to changes in memory or thinking?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, depending on answers to rest of questions	**TYPICAL OF DEMENTIA DUE TO AD TYPE SYMPTOMS NO REFERRAL**	**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 ability, 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?

NORMAL AGING NO REFERRAL	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Are you having difficulty expressing yourself or difficulty understanding words or conversation?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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. **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 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 **Do you have difficulty planning, starting or finishing complicated tasks at home or at work?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Do you get lost while walking or driving?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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?

NORMAL AGING NO REFERRAL		**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Do you have difficulty recognizing people?**	Prompts:

NORMAL AGING NO REFERRAL	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Has your mood changed?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Have you lost motivation or energy to do things you used to enjoy?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**		**REFERRAL INDICATED** **See indeterminate below**

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

NORMAL AGING **NO REFERRAL**	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Sometimes we have patients who seem to forget how to behave in public. Has this been an issue?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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	**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.	• 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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	**Interpretation**
	• Common in moderate AD.	• Unusual in AD. Typical of non-degenerative psychiatric syndromes. Literature not clear on which dementias this goes with.

Hallucinations

HALLUCINATIONS **Have you been seeing or hearing anything that might not be there (or others can't see or hear)?**	Prompts:

NORMAL AGING NO REFERRAL	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED**
	• **HEARING VOICES**, name called, sounds in house.	• **SEEING PEOPLE, SEEING LITTLE PEOPLE, ANIMALS.** • **SEEING SHAPES AND PATTERNS** on uniform surfaces (e.g., wall looks wavy or has patterns).
	Interpretation	**Interpretation**
	• Significance unclear. Follow over time for changes, as this would not dissuade from AD diagnosis.	• Unusual in AD. Suggestive of Lewy Body Dementia (LBD). Often occurs at night, when in bed.

Obsessions/Compulsions

OBSESSIONS/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?

NORMAL AGING **NO REFERRAL**	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED**
	• Frequently **OPENS AND CLOSES DRAWERS**, looks for things a lot. • **VERY FIXATED** on upcoming events, worried about being prepared hours in advance.	• 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 **Any changes in sleep?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Any problems acting out dreams (yelling, screaming, hitting)?**	Prompts:

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

NORMAL AGING **NO REFERRAL**	**TYPICAL OF AD TYPE SYMPTOMS**	**REFERRAL INDICATED** **See indeterminate below**

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 **Have there been changes in your eating habits?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, 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).

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

NORMAL AGING **NO REFERRAL**	**TYPICAL OF AD TYPE SYMPTOMS, can be COGNITIVE CHANGES WITHOUT DEMENTIA, 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 **Do have involuntary shaking in your hands, arms, legs or chin?**	Prompts:

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 **Do your limbs feel rigid or stiff?**	Prompts: 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 **Have your movements been slowing down?**	Prompts: 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 COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED**
		• Yes.
Interpretation	**Interpretation**	**Interpretation**
• Mild slowing due to age is normal. • Do not consider changes explained by orthopedic conditions.	• Mild slowing may be normal, but there should be no motor changes with AD.	• 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 **Have you had a change in your ability to walk?**	Prompts 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 **Have you fallen down in the past couple of years?**	Prompts: 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**
		• Symptoms present.
Interpretation	**Interpretation**	**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 COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED**
		• Symptoms present.
Interpretation	**Interpretation**	**Interpretation**
• Some reduced strength when aging is normal but should not be asymmetrical.	• Focal weakness is not consistent with AD.	• Even subtle change may indicate prior ischemic stroke.
Indications for referral (for Diagnostic Purposes)	**Indications for referral (for Diagnostic Purposes)**	**Indications for referral (for Diagnostic Purposes)**
• No referral. • May be due to known previously diagnosed and evaluated condition.	• Typical of AD/No referral (may be due to previously diagnosed condition).	• 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 COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE**	**REFERRAL INDICATED**
• Yes, I have jerks like that when falling asleep.	• 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**	**Interpretation**
• The jerking upon falling asleep is normal.	• Myoclonus is common in the late stages of AD.	• 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?

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 **Does one of your arms behave as if it doesn't belong to you?**	Prompts: 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 **Have you had slurring of your speech?**	Prompts: 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 **Have you had trouble swallowing?**	Prompts: 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

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	

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	

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 COGNITIVE CHANGES WITHOUT DEMENTIA, or DEMENTIA, depending on functional impact, REFERRAL PER DECISION TREE	REFERRAL INDICATED
• No mass, hemorrhage or infection. Mild global volume loss consistent with age. • Mild white matter changes.	• Global volume loss, perhaps more notable in parietal lobes. Small hippocampus. Mild white matter changes.	• Some enlarged ventricles, concerning for Normal Pressure Hydrocephalus (NPH).
Interpretation	**Interpretation**	**Interpretation**
• Normal aging.	• Consistent with AD.	• 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
		• Significant 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.

Lab work

LABS **CBC, METABOLIC PANEL, TSH, B12**	

NORMAL AGING **NO REFERRAL**		**INDETERMINATE**
• Should be normal or at baseline for patient considering other medical conditions. • If abnormal, typical cognitive symptoms persist after correction.		• Abnormal – symptoms resolve after correction.
Interpretation		**Interpretation**
• Consistent with normal aging.		• 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**		**REFERRAL INDICATED**
• Normal.		• Positive,
Interpretation		**Interpretation**
• Typical of normal aging, or AD.		• May indicate acute or chronic infection.
		Indications for referral (for Diagnostic Purposes)
		• Requires referral to specialist.

STEP THREE: DECISION SUPPORT

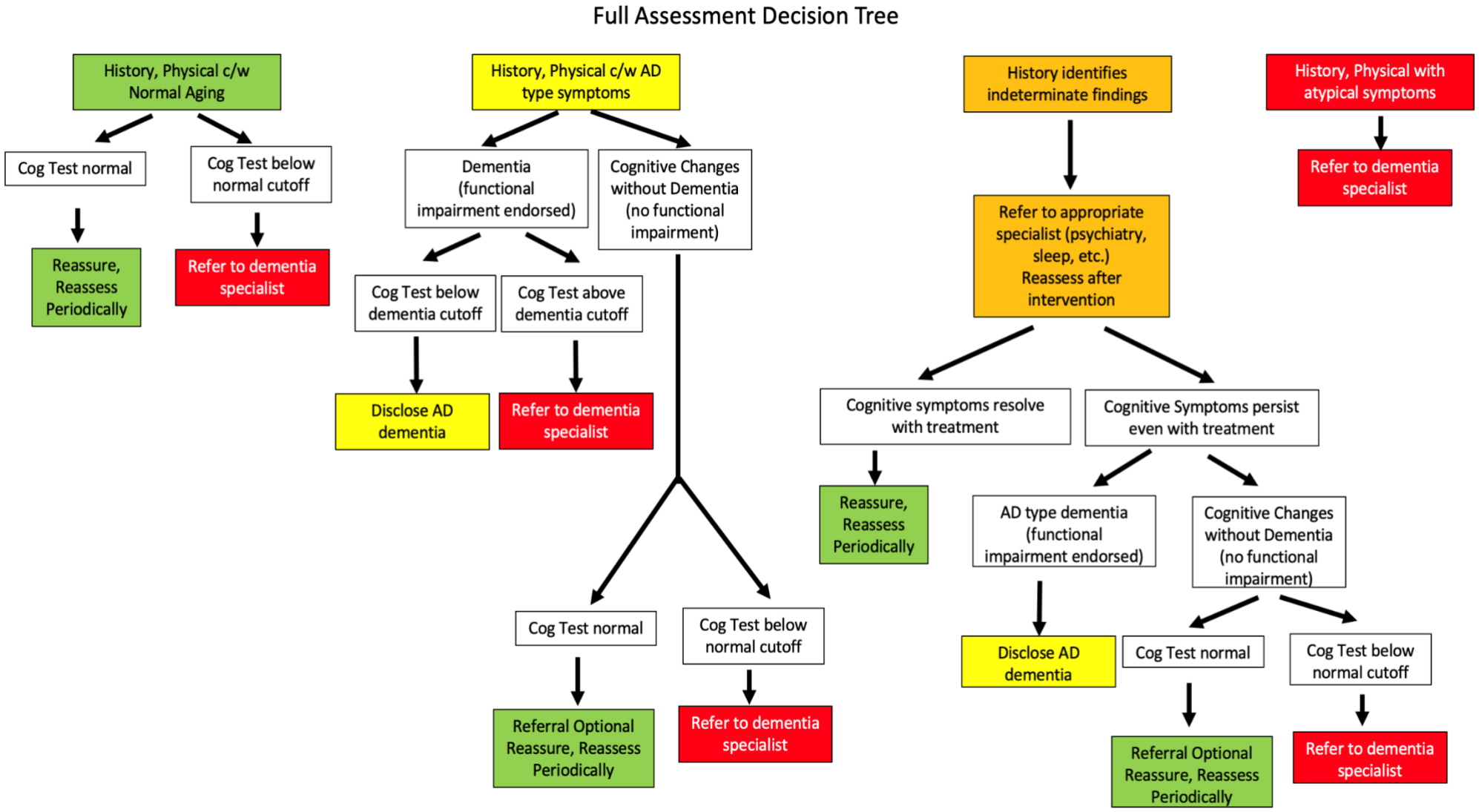
Interpretation of Full Assessment Outcomes

Outcome scenarios and recommendations

Based on the responses to the questions in the history, the physical exam, 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**, reassure the patient and plan periodic reassessment every year or two to identify any worsening of symptoms or new symptoms.
   - **b.** If performance on the **cognitive test is below the cutoff for normal**, this indicates that the history may be unreliable or there is another discrepancy. 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 **cognitive changes without dementia**. 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 clinician can disclose cognitive changes without dementia and plan periodic reassessment every year to identify any worsening of symptoms or new symptoms, unless the patient wants further assessment or wants to participate in research (see **cognitive changes without dementia disclosure script**).
   - **b.** If performance on **cognitive test is below the cutoff for normal,** this indicates that the likelihood of a neurodegenerative cause in this patient is increased. The toolkit would recommend referral in this situation.
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**. In this case, the clinician should disclose a diagnosis of dementia due to AD.
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 patient should be referred for assessment and management of that problem. 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 dementia due to AD, the clinician should disclose the diagnosis of dementia due to AD.
   - **c.** If the condition is managed but the symptoms persist, and the rest of the assessment indicates symptoms that are typical of AD but not affecting ADLs, consistent with **cognitive changes without dementia,** the patient should be managed according to item 2 above.
5. **One or more responses fall into red categories**, indicating symptoms that are not typical for AD and thus potentially representing an atypical form of AD or a non-AD neurodegenerative disease. Such patients should be referred to a dementia specialist regardless of the severity of the problem.

Decision Tree



STEP FOUR: DISCLOSURE AND SCRIPTS

Cognitive changes without dementia (i.e., Mild Cognitive Impairment)

The script below assumes you have identified cognitive difficulties that seem in excess of normal aging, and that your assessment did not identify any medical conditions that may explain it. Thus, you have taken the assessment as far as you can take it. This script assumes that at this point the differential rests between normal aging and early neurodegenerative disease. It contains two slightly different alternatives depending on the outcome of limited cognitive testing in your office. First, it is useful to start with an introduction and to assess the patient and family's goals and expectations (this part is the same as the script for dementia):

Script to discuss cognitive changes without 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 give you my impression, 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 now become severe enough that it is 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 is 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. These include various types of general medical problems in the body that also affect the brain, such as abnormalities 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, 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 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. We do not really understand what makes them change, but it is something that can happen,

particularly as we get older. These changes are microscopic, and they are too small for us to see 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 bothering you more than is typical for your age, but it's not affecting your everyday function, and so it's not severe enough to be called dementia. Because your complaints are significant, 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 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. The first thing we should do is try to address this issue by XXXXXXX (referring, treating as appropriate) and then seeing if your complaints improve."

If you did not identify any issues you think may 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 is not uncommon, and many people have similar issues. When someone has complaints such as yours 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 cognitive function 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. The general course of action in this case is to keep a close eye on things and monitor to see if things are getting worse.

Unfortunately, if the proteins associated with neurodegenerative disease are accumulating, there is currently no way to completely stop that from happening. There are no specific medications or other approved treatments for this type of memory impairment. Researchers are working very hard to develop new medications. On the other hand, there are things we can do that might decrease the chance that things will get worse. Research shows that risk factors for heart disease, like smoking, high blood pressure, diabetes, and being overweight, are also associated with an increased risk of dementia. Most researchers believe that being very attentive to these risk factors might slow the progression of 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.]. As we work on this, we will plan on checking in with you regularly about your memory complaints, roughly every few months. Let's take this opportunity to do everything we can to protect your brain."

At this point, it's important to talk more about the possibility of referral and how it might benefit the patient. To introduce the idea, you can say the following.

"At this point, it's important to talk more about the possibility of referral and how it might benefit you (or the patient). While our assessment here has been very thorough and complete, it's important now to talk about the possibility of referring you to a specialist and how this might benefit you. While it's true that we cannot know for sure whether the problems you are having will get worse over time, there is more that a specialist can do to try to figure that out. For instance, there is more in-depth cognitive testing, and there are specific kinds of brain imaging that are not commonly used in general practice, and also certain kinds of tests such as a lumbar puncture, which is also referred to as a spinal tap, that might be able to show whether you have the proteins that cause neurodegenerative diseases such as Alzheimer's disease already accumulating in the brain. A specialist would use that information to try to give you a better idea of how you might change in the future. It's important to recognize that even if they find evidence of those proteins, there is nothing they can do to get rid of them, and really nothing they could do to change what the future holds beyond what we have already discussed. A specialist evaluation would accomplish two things beyond what we have done today: 1) It would give you some more knowledge about the chances that your problems will get worse over time, and 2) It will give you a chance to enroll in clinical trials of new treatments for these kinds of conditions. Many specialty centers are involved in this type of research, and many of the research projects would first try to figure out whether you have neurodegenerative proteins as the cause of your problem."

If performance on limited cognitive testing (e.g. with MoCA, 3MSE, SLUMS or a similar test) is normal, then you can say the following.

"If you would like to be referred to a specialist to have an even more detailed assessment, I would be happy to refer you to one. If you do not want to do that, I will keep track of this problem with you, including repeating some of the assessments we did today at future visits, and if things seem to be getting worse, we can definitely revisit the idea of a referral to a specialist."

However, The ACCT-AD toolkit recommends that if a person with cognitive change without dementia scores below specific cutoffs for significant cognitive impairment (see interpretation manual), or if a "red flag" type symptom is noted, that such a person be referred for further assessment that would include more detailed cognitive testing. Therefore, if this patient scores below a cutoff on cognitive testing, or a "red flag" symptom is detected, we recommend saying something like the following

"In your case, it's important to point out that you had some trouble with the cognitive test that we did today. While that's not proof that any diseases are occurring in the brain, it is a bit more worrisome than if you had scored well. The current expert guidelines recommend in this case that you be referred for more detailed cognitive testing, and therefore I think it is a good idea that I refer you to an expert center. Unless you object to this, I'm going to go ahead and do that."

-Or-

"In addition to your memory complaints, I also noted that you have some symptoms that include XXXXXXX. In this situation, the current expert guidelines recommend that you be referred for more detailed cognitive testing, and therefore I think it is a good idea that I refer you to an expert center. Unless you object to this, I'm going to go ahead and do that."

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

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 give you my impression, 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 general medical problems in the body that also affect the brain, such as abnormalities 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 carry out all 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. We do not really understand what makes them change, but it is something that can happen, particularly as we get older. These changes are microscopic, and they are too small for us to see by most kinds of testing, including brain imaging, 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 form of neurodegenerative disease is Alzheimer's disease. This is a form of neurodegenerative disease that 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 complaints. As the disease spreads to other parts of the brain, it can affect other brain systems and cause other symptoms. In your (or your family member's) case, the history and the memory [or cognitive] tests strongly suggest 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."

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 make clear that medications that are currently available treat the symptoms but do not change the underlying disease process or prevent the dementia from progressing. Side effects to be aware of with cholinesterase inhibitors are bradycardia and lowering of the seizure threshold, as well as the more commonly known GI effects. Memantine can also lower the seizure threshold and the dose needs to be lower in moderate to severe chronic kidney disease. Bullets to be sure to include are:

- Discussion that medications are symptomatic treatment, not disease modifying
- Discussion about cholinesterase inhibitors – efficacy, side effects
- Discussion about memantine – efficacy, side effects
- 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, including memory loss and mild language difficulties. While these medications help with the symptoms, it is important to realize that they do not slow down the progression of the disease.

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. You might have heard of donepezil (Aricept), galantamine (Razadyne), or rivastigmine (Exelon). All of these medicines work by boost- ing the level of a chemical in the brain called acetylcholine, and this helps the brain cells work a bit better. These drugs were approved by the FDA after studies where they compared patients taking the drug to other patients taking a fake drug (placebo). This is how most drugs are tested. When they did this with the cholinesterase inhibitors, they would start these drugs (or placebo) and then follow patients over time to see how they would do while continuing treatment. They found that those on the fake drug (or placebo) showed a decline in thinking abilities on testing and in everyday function over a few months. The ones taking the real drug showed less decline. This means that when you are taking the drug, you have to know what to expect. The drug didn't make anyone better, it just kept people better than they would have been without the drug. So, if you were taking the drug, it would be hard to know if it was helping you because you wouldn't know how you would have been a few months from now if you were not taking the drug.

You just have to take the drug based on faith 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. Each of the drugs I mentioned has been studied separately, and they all had the effect that I described, so it's pretty reliable. 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 formulations like patches called acetylcholine 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 night- mares, it is preferable to 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, though 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.

People may ask about disease-modifying therapies. There are currently no disease-modifying therapies. 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 clinical trials.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 impairment), mental activity is useful. This should not feel punishing to the patient (i.e., it should not be some- thing that they fail at each time they try, something that they once did but are now obviously no longer capable of doing) and should be something that they 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 respond to 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. Patients tend to withdraw as they progress. Helping them to maintain social contact is extremely important and can significantly improve their mood and ability to inter- act. The mental and physical exercise above can easily be done with friends and family to allow as much socialization as possible.

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 which tend to affect how someone behaves rather than how they think or remember. They don't occur in every case, 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 report 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 assess what interventions might improve the symptoms 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 productive approach. A lot of research has been done to identify specific medications that can help with these behavioral symptoms without causing a lot of side effects, and the research hasn't identified specific medications that have a very good track record. Because any medicine can cause side effects, and the research so far hasn't provided very good guidance on which medicines to use, the best option is usually to start with other approaches to the problem, rather than medication, and these can be quite helpful.

Often, we can identify and adapt strategies that may help them adjust. For example, learning new communication techniques that are calm or simpler can be helpful. Simplifying the environment so it is not overwhelming can reduce frustration – reducing background noise or clutter, 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 individual more

emphatic about the issue. Changing the subject or distracting the individual 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 any intervention 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 strategies I described first as they are often successful and have no risks or side effects. However, if the behaviors are particularly distressing 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. You can share this article from Family Caregiver Alliance: 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, AWV, 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

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 upon request:

- Detecting Cognitive Concerns
- Full Cognitive Evaluation
- Pre-Visit Questionnaire
- 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.