Assessment of Cognitive Complaints Toolkit

for Alzheimer's Disease

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

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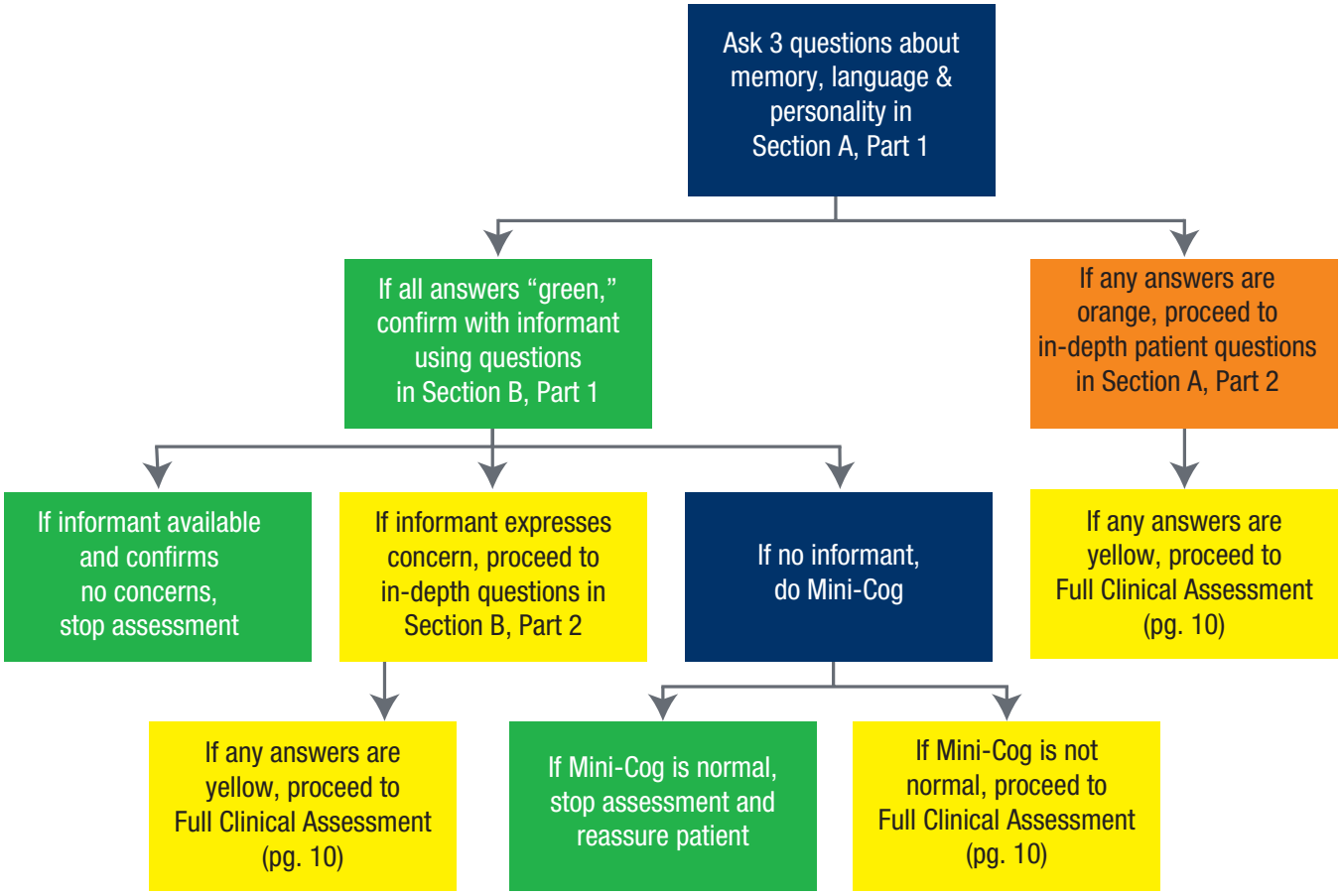
WELLNESS VISIT INTERVIEW



Subdomain: MEMORY
Question: Do you think your 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	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. Yes, I often go into a room and forget why I'm there. I have more difficulty remembering names.	Normal aging if confirmed with informant or negative min-cog.	No referral.	✓
Yes, any other complaint.	Could be cognitive impairment.	Requires follow-up questions below in Part 2.	?

Subdomain: LANGUAGE
Question: Have you noticed changes in your language?
Prompts: Trouble finding words or understanding conversations

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. I have occasional problems coming up with a word.	Normal aging if confirmed with informant or negative Mini-Cog.	No referral.	✓
Yes. I think that it's harder for me to get my point across.	Could be cognitive impairment.	Requires follow-up questions below in Part 2.	?

Subdomain: PERSONALITY
Question: Have you noticed changes in your personality?
Prompts: More irritable/anger more easily
Trouble getting along with people?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No.	Normal aging if confirmed with informant or negative Mini-Cog.	No referral.	✓
Yes. I might be a little less patient. My family thinks I'm more difficult to get along with.	Could be cognitive impairment.	Requires follow-up questions below in Part 2.	?

IF THERE ARE ANY INDICATIONS OF IMPAIRMENT, CONTINUE TO THE IN-DEPTH PATIENT QUESTIONS IN THE NEXT PART OF THIS SECTION.
IF THERE ARE NO INDICATIONS, SKIP TO THE NEXT SECTION TO CONFIRM ANSWERS WITH THE INFORMANT.

Subdomain: MEMORY (ASK *ALL* THREE QUESTIONS)

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. All my friends complain about the same thing. Actually, I think my memory is still better than my peers.	Normal aging.	Confirm with informant, negative Mini-Cog.	✓
Yes. 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.	Concerning for cognitive impairment.	Bring back for full assessment.	?

Question: Have you stopped doing anything because of these changes?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. I might rely on my phone or calendar more.	Normal aging.	No referral.	✓
Yes. 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.	Concerning for cognitive impairment.	Bring back for full assessment.	?

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. My children occasionally say I repeat a story.	Normal aging.	No referral.	✓
Yes. My wife tells me that I am always asking her what the schedule is. My friends comment that I often miss appointments.	Concerning for cognitive impairment.	Bring back for full assessment.	?

Subdomain: LANGUAGE (ASK *ALL* THREE QUESTIONS)

Question: Do you think your language changes are worse than your peers?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. All my friends complain about the same thing. Actually, I think my vocabulary is more limited.	Normal aging.	No referral.
Yes. 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).	Concerning for cognitive impairment.	Bring back for full assessment.

Question: Have you stopped doing anything because of these language changes?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. My life is very busy.	Normal aging.	Confirm with informant, negative Mini-Cog.
Yes. I stopped participating in my book club. I still go but speak less at social occasions.	Concerning for cognitive impairment.	Bring back for full assessment.

Question: Has anybody commented to you to you about these changes in your language?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
Yes. My wife says I use words like "thingy" more than I used to.	Concerning for cognitive impairment.	Bring back for full assessment.

Subdomain: PERSONALITY (ASK *ALL* THREE QUESTIONS)

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. We are all just getting crabby. We all are doing less than we used to.	Normal aging.	No referral.
Yes. I seem to be much less patient than my friends. I'm much less interested in doing things than my friends.	Concerning for cognitive impairment.	Bring back for full assessment.

Question: Have you stopped doing anything because of these personality changes?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. I'm busier than ever.	Normal aging.	No referral.
Yes. 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.	Concerning for cognitive impairment.	Bring back for full assessment.

Question: Has anyone commented on these personality changes to you?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
Yes. My friends think that I tend to get angry more easily.	Concerning for cognitive impairment.	Bring back for full assessment.

IF THERE ARE ANY INDICATIONS, DO A FULL ASSESSMENT.
IF THERE ARE NO INDICATIONS, PROCEED TO THE NEXT SECTION TO CONFIRM ANSWERS WITH THE INFORMANT.
IF THERE ARE NO INDICATIONS AND NO INFORMANT IS AVAILABLE, PERFORM MINI-COG. IF SCORE IS NORMAL, END ASSESSMENT AND REPEAT IN ONE YEAR.
IF THE PATIENT HAS ANY ERRORS ON THE MINI-COG, PROCEED TO A FULL ASSESSMENT.

Subdomain: MEMORY
Question: 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	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. Yes, they often go into a room and forget why they're there. They have more difficulty remembering names.	Normal aging if confirmed with negative min-cog.	No referral.
Yes, any other complaint.	Could be cognitive impairment.	Requires follow-up questions below in Part 2.

Subdomain: LANGUAGE
Question: Have you noticed changes in their language?
Prompts: Trouble finding words
Trouble understanding conversations

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. They have occasional problems coming up with a word.	Normal aging if confirmed with negative Mini-Cog.	No referral.
Yes. I think that it's harder for them to get their point across.	Could be cognitive impairment.	Requires follow-up questions below in Part 2.

Subdomain: PERSONALITY
Question: Have you noticed changes in their personality?
Prompts: More irritable/anger more easily
Trouble getting along with people?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging if confirmed with negative Mini-Cog.	No referral.
Yes. They might be a little less patient. Our family thinks they're more difficult to get along with.	Could be cognitive impairment.	Requires follow-up questions below in Part 2.

IF THERE ARE ANY INDICATIONS, FINISH THIS SECTION. IF THERE ARE NO INDICATIONS, END THE ASSESSMENT HERE AND REPEAT IN ONE YEAR.

Subdomain: MEMORY (ASK *ALL* THREE QUESTIONS)

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. All their friends complain about the same thing. Actually, I think their memory is still better than their peers.	Normal aging.	Confirm with negative Mini-Cog.
Yes. 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.	Concerning for cognitive impairment.	Bring in for full assessment.

Question: Have they stopped doing anything because of these changes?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. They might rely on my phone or calendar more.	Normal aging.	No referral.
Yes. 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.	Concerning for cognitive impairment.	Bring in for full assessment.

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. Their children occasionally say they will repeat a story.	Normal aging.	No referral.
Yes. They are always asking me what the schedule is. I notice that they often miss appointments.	Concerning for cognitive impairment.	Bring in for full assessment.

Subdomain: LANGUAGE (ASK *ALL* THREE QUESTIONS)

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. All their friends complain about the same thing. Actually, I think their vocabulary is more limited.	Normal aging.	No referral.	✓
Yes. They don't speak as easily as in the past. They don't seem to be able to participate in discussions as well as in the past. They are hesitant to talk on the phone because of their speech (or comprehension).	Concerning for cognitive impairment.	Bring in for full assessment.	?

Question: Have they stopped doing anything because of these language changes?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No. Their life is very busy.	Normal aging.	Confirm with negative Mini-Cog.	✓
Yes. They stopped participating in their book club. They still go but speak less at social occasions.	Concerning for cognitive impairment.	Bring in for full assessment.	?

Question: Have you noticed any changes in their language?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No.	Normal aging.	No referral.	✓
Yes. They use words like "thingy" more than they used to.	Concerning for cognitive impairment.	Bring in for full assessment.	?

Subdomain: PERSONALITY (ASK *ALL* THREE QUESTIONS)

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. We are all just getting crabby. We all are doing less than we used to.	Normal aging.	No referral.
Yes. They seem to be much less patient than their friends. They are much less interested in doing things than their friends.	Concerning for cognitive impairment.	Bring in for full assessment.

Question: Have they stopped doing anything because of these personality changes?

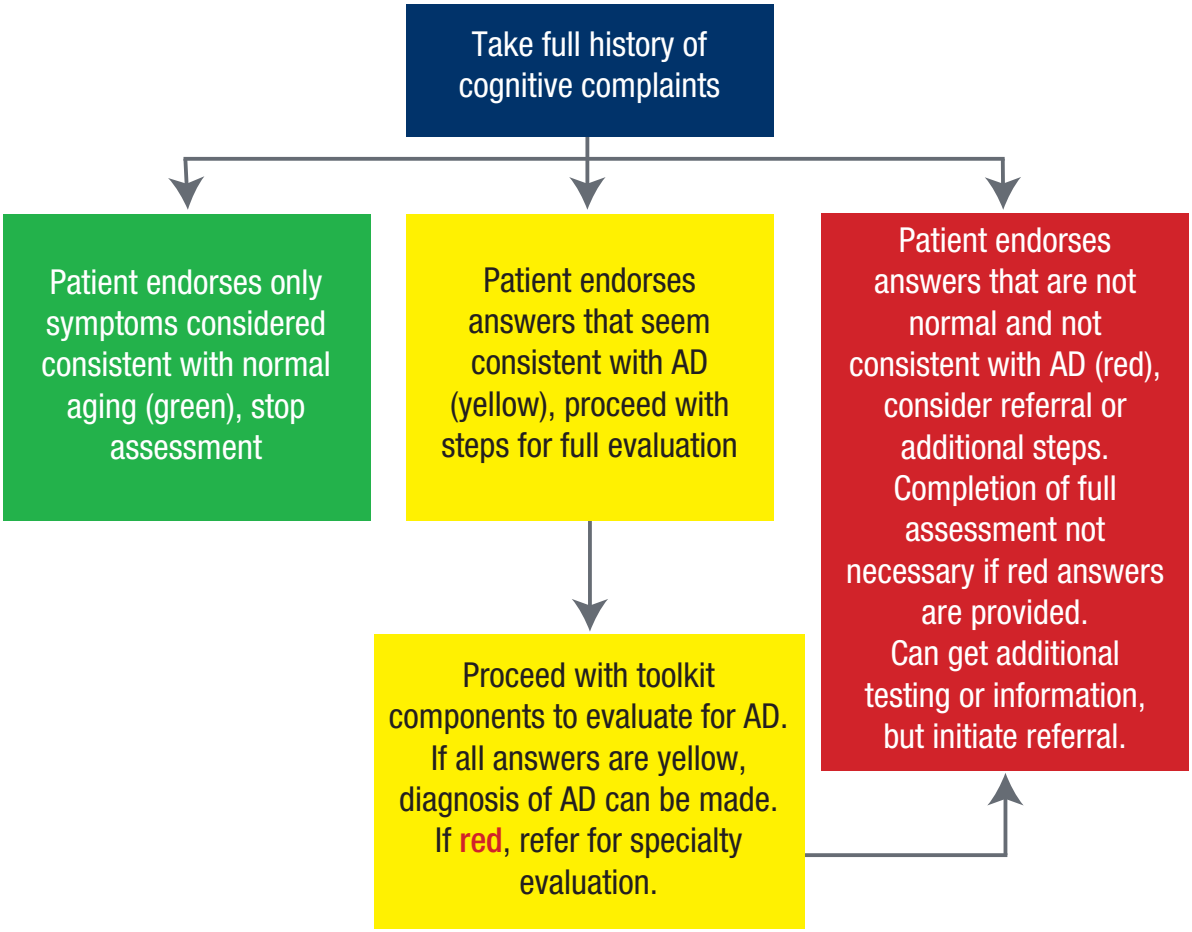
Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No. They are busier than ever.	Normal aging.	No referral.
Yes. I don't like to go out to dinner with them anymore. They are just not interested in hobbies like they used to be.	Concerning for cognitive impairment.	Bring in for full assessment.

Question: Has anyone commented on these personality changes to you?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
Yes. Their friends think that they tend to get angry more easily.	Concerning for cognitive impairment.	Bring in for full assessment.

IF THERE ARE ANY INDICATIONS, DO A FULL ASSESSMENT.
IF THERE ARE NO INDICATIONS, END ASSESSMENT AND REPEAT IN ONE YEAR.

FULL CLINICAL ASSESSMENT



Open Questioning and History of Present Illness

Subdomain: CHIEF COMPLAINT

Question: 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.)

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Having trouble with memory.	Typical of AD or normal aging.	No referral.	?
I'm having trouble speaking, getting my words out.	Word finding trouble could be typical of AD but is not usually chief complaint. Could be progressive aphasia. After HPI, first questions probing domains should be about language.	If language is indeed main problem, should refer as possible progressive aphasia.	?
Personality has changed.	Uncommon chief complaint in AD; could be FTD. After HPI, first questions probing domains should be about socioemotional behavior.	If behavior is indeed main problem, should refer as possible FTD or atypical dementia.	!

Subdomain: HPI, DURATION, EARLY SYMPTOMS

Question: OK, 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 give indication of what neurological systems involved first, each disease characteristically involves specific systems early, and progresses to involve other systems over time

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Started to notice forgetting minor things a few years ago, misplacing things, forgetting a conversation.	Typical in AD.	No referral.	?
Symptoms were already present, seemed to get worse at a particular time (e.g., hospitalization), recovered but not all the way.	This is not uncommon in AD.	Would not prompt referral in and of itself.	?
Non-episodic memory problems emerge as early symptoms.	If early symptoms are not memory, this could signify atypical AD or non-AD. Domain questions should first probe whatever is earliest symptom.	Referral appropriate if early symptoms were not memory.	?
Symptoms just noticed a few months ago or less, and now has significant impairment (e.g., out of work, not doing activities at home).	Concerning for rapidly progressive dementia or other encephalopathy.	Immediate referral to neurology for workup that would include imaging, EEG, LP, and comprehensive lab assessment, possible body scanning. Cancer/ paraneoplastic, auto-immune and infectious are top concerns.	!
Symptoms waxing and waning over a few months, also with sleepiness.	Concerning for delirium or possibly Lewy body dementia.	Begin metabolic assessment for delirium, if unrevealing, refer immediately.	!

Subdomain: HPI, CLARIFICATION

Question: For any symptoms that the patient brings up, make sure that general terms like "I forget things" are clarified, usually it's necessary to get examples. Might say, "Can you give me an example of the kinds of [things, words, events, whatever the person said] forget?" Or, if they describe it in terms of problems with certain tasks, like, "I can't get things done at work." Might say, "OK, when you are trying to do [whatever task they said they have trouble with], what happens?"
Comments: People use terms like *memory* differently. For instance someone who complains of memory problems might mean word retrieval, forgetting what you are doing after a few seconds, or forgetting events after minutes/days/hours. All these have different brain anatomy. This is to further ensure that when they say "memory" they mean forgetting recent events.

Subdomain: HPI, EVOLUTION

Question: "Have the symptoms worsened or changed over time?" If they say yes, clarify, "What makes you say things are worse?"
Prompts: Avoid asking, "Why do you think they are worse?". This often results in theories about etiology, like "Because I think my brain is deteriorating" or "because I'm stressed."

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Used to be forgetting once in a while, now happens more frequently, and memory seems to be shorter (e.g., repeating questions after a short time.	Typical of AD.	Typical of AD/No referral

Question: "Have any new symptoms developed that weren't there at the beginning?"
Prompts: As new parts of the brain are involved, new symptoms emerge.

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Used to be just forgetting, now seeing other things, like trouble finding words, finding way around familiar places like their neighborhood, having more trouble organizing, remembering steps to things.	Typical of AD, Indicates spread of disease to temporal, parietal and frontal regions.	Typical of AD/No referral.
Starting to change behavior, getting irritable, mild delusional thought (e.g., thinks people might be stealing), lower motivation.	Typical behavioral features in AD.	Typical of AD/No referral.
Developing profound problem with language and communication.	When emerge later, can still be AD, but sometimes indicates atypical syndrome or mixed pathology.	Probe area of problem in language section, and if any "red" symptoms, refer.
Developing more unusual behavior, such bizarre delusions (thinks they are someone else, thinks someone is not who they are), hallucinations, abnormal social interactions with strangers.	When emerge later, can still be AD, but sometimes indicates atypical syndrome, or mixed pathology.	Probe area of problem in behavior section, and if any "red" symptoms, refer.

Subdomain: HPI, POTENTIAL NON-NEURODEGENERATIVE CAUSES

Question: “Are there any particular events that were associated with the onset or worsening of the symptoms, like medical illness, accidents or major life stresses?”

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
If onset clearly relates to surgery, accident, etc., should consider referral.		If onset clearly relates to surgery, accident, etc., should consider referral.

Subdomain: MEMORY

Question: Do you have any problems with your memory or thinking?
Prompts: Trouble keeping track of schedule?
Misplacing items often (e.g., phone, keys)?
Relying more on notes?
Having more trouble with recent memory (conversations, recent events) compared to remote memory?
Having trouble remembering how to get to familiar places or how to do familiar tasks?
Repetitive questions?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Occasionally misplace an item or forget a word but it is not disruptive. Occasionally walk into a room and forget 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.	Normal aging.	No referral.	✓
Never forget important events, but loss of details (e.g., remembered going making an appointment but forgot what day).	Typical of AD. This would be very early, concerning in terms of the type of memory loss but sounds very mild and can also be seen with normal aging.	Typical of AD/No referral.	?
Relying on notes, calendar, assistance on others to remember information they used to manage on own. Recent information/events lost compared to relatively intact information/events from long ago. Misplacing items is a regular occurrence, disruptive to daily schedule. Repetitive questions or story telling. Symptoms are gradually and progressively worsening.	Typical of AD.	Typical of AD/No referral.	?

Subdomain: LANGUAGE

Question: 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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
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.	Normal aging.	No referral.	✓
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. These symptoms are not the presenting symptom but are occurring in the context of progressive memory and/or other cognitive difficulties.	Typical of AD.	Typical of AD/No referral.	?
Word finding is the primary and first presenting symptom, which compromises ability to communicate. May be described as a "memory problem" (but 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.	Concerning for a primary progressive aphasia caused by FTD, PSP, atypical AD, or other etiologies.	Referral indicated.	!
The primary and first presenting symptom is difficulty understanding single words or phrases, can't remember what some words mean.	Concerning for FTD, semantic variant, and other temporal lobe disorders.	Referral indicated.	!

Subdomain: EXECUTIVE FUNCTIONS

Question: Do they have difficulty planning/executing?
Prompts: Planning and accomplishing a series of errands?
Paying the bills/ organizing paperwork?
Are they keeping their home as neat/organized/clean as they used to?
No longer preparing holiday meals for the family?
Completing projects for their hobbies or minor home repairs?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Papers in office are now scattered, disorganized. They used to be very able to fix anything/do complicated crafts but now get confused or the end result is not as good as would have been previously. Don't do things in an organized way, for instance can't figure out how to pack correct clothing for a trip, can plan a gathering or trip. Gets confused about steps in cooking a recipe. Gets easily distracted, doesn't finish tasks.	Common in AD.	Typical of AD/No referral.
Yes, they come home with items not on their shopping list or they went to wrong place or they forgot to go to a location. They have made many late payments/ missed payments/paid twice. Utility notices for cutoff.	Common in AD, could be indicative of memory problems.	Typical of AD/No referral.

Question: Difficulty completing tasks at work?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No longer takes on tasks, no longer able to complete assignments.	This can be seen in AD but if this is the most prominent complaint in a relatively younger individual. Could be mood related or related to apathy/socioemotional function.	Consider other causes and consider referral.

Subdomain: VISUAL-SPATIAL

Question: Do they get lost?
Prompts: Driving to familiar places?
Have they ever called you because they didn't know how to get home or were lost?
Did they ever drive to the wrong place?
Have they ever taken much longer than expected to arrive at destination or at home?
Do they have difficulty finding their car in a parking lot?
Do they get lost in a familiar store or restaurant?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Yes, we visited DC and he had difficulty navigating. Not familiar with DC, never been there.	Not necessarily related to dementia/AD.	No referral.	✓
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.	Common in AD, could represent memory problems rather than visuospatial, but common in early AD.	Typical of AD/No referral.	?
Would not be able to go to store in car to get something.	Common in AD, could represent memory problems rather than visuospatial, but common in early AD.	Typical of AD/No referral.	?
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.	Common in AD.	Typical of AD/No referral.	?
Could not find their way to the restroom at the restaurant where eat regularly.	Common in AD.	Typical of AD/No referral.	?

Question: Do they have difficulty seeing things properly or judging distances properly?
Prompts: Does their motor vehicle show evidence of damage?
Do they have difficulty figuring out how to position themselves to sit in a chair?
Do they complain of difficulty seeing while reading?
Do they complain that their eyes don't work?
Do they have trouble seeing things that are right in front of time?
Do they complain of vision difficulty despite having their glasses checked?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Minor scrapes and body damage, patient unaware/ did not report.	Common in AD.	Typical of AD/No referral.
Yes to any of the prompts.	This may indicate predominant parietal deficits.	Consider referral for less common forms of dementia/AD.
Yes, they complain that they can't read because they have trouble seeing. 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.	AD patients may have difficulty following a storyline and remembering what they read, but eye problems are not a common symptom. This can be seen in other types of dementia including PSP and posterior cortical atrophy.	If eye problems are a prominent complaint, consider referral especially if already worked up by ophthalmology or optometry.

Question: Do they have difficulty recognizing people?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
They have difficulty remembering the names of people at church but recognize the faces.	Normal aging, does not indicate facial recognition problems.	No referral.
They have difficulty remembering the names of people at church.	Consistent with AD. If prominent and progressive, may be a form of word-finding trouble consistent with AD.	Typical of AD/No referral.
They think that I (their spouse) am someone else.	Common in late AD. If this is an early and prominent symptom, may indicate another diagnosis, such as DLB.	Referral if early and prominent symptom.

Subdomain: DEPRESSION

Question: How has your (their) mood been?
Prompts: Crying a lot?
Hopeless about life or about the future?
Feeling worthless or bad about yourself?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Cry sometimes when I get frustrated because I forget something or make a mistake.	Not indicative of depression per se. Common complaint in early AD.	Typical of AD/No referral.
I get irritable, angry more easily than before. I feel down a lot. Cry a lot because I feel sad, hopeless. Often think I'd like to be dead (or having more active suicidal thoughts).	Not indicative of depression per se. Common in AD and many other dementias. Consistent with depression. May co-occur with AD or other dementias.	Typical of AD/No referral.
Don't want to do anything, making excuses not to do activities.	Indicates *apathy*, common in AD and many other dementias. May be consistent with depression, but need other indicators of low mood.	If apathy is the earliest and predominant symptom, consider referral depending on other symptoms.

Subdomain: APATHY

Question: Have you (they) 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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Don't want to do anything, making excuses not to do activities.	Indicates *apathy*, common in AD and many other dementias. May be consistent with depression, but need other indicators of low mood.	If apathy is the earliest and predominant symptom, consider referral depending on other symptoms.

Subdomain: IRRITABILITY/ANGER

Question: Do you (they) become angry more easily?
Prompts: Get angry about things that would not have bothered them in the past?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Gets angry and might yell, even in public, usually directed at family, sometimes at strangers like waiters, store clerks.	May occur with AD or other dementias.	Typical of AD/No referral.	?

Subdomain: DISINHIBITION

Question: 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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Gets angry and might yell, even in public, usually directed at family, sometimes at strangers like waiters, store clerks.	May occur with AD or other dementias. If loss of inhibition is driven by anger, mainly directed at family, this is a non-specific, and non-diagnostic, general sign of irritability.	Typical of AD/No referral.	?
Some surprisingly rude behavior (e.g., leaves family gatherings or dinner table abruptly, ignores some relatives at social gatherings).	Concerning for FTD.	Consider referral.	!
Any answer that clearly suggests forgetting social rules (see prompts).	Very concerning for FTD.	Consider referral.	!

Subdomain: DELUSIONS

Question: 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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Think people are stealing from them.	Common in AD.	Typical of AD/No referral.
Think spouse is having an affair.	Common in AD.	Typical of AD/No referral.
Think people who have died are still alive.	Common in moderate AD.	Typical of AD/No referral.
Think they have special powers, come from another planet.	Unusual in AD. Typical of non-degenerative psychiatric syndromes. Literature not clear on which dementias this goes with.	Consider referral.
Complex bizarre belief systems (e.g., vast government conspiracy against them).	Unusual in AD. Typical of non-degenerative psychiatric syndromes. Literature not clear on which dementias this goes with.	Consider referral.

Subdomain: HALLUCINATIONS

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Hearing voices, name called, sounds in house.	Significance unclear, likely follow for changes, would not dissuade from AD diagnosis.	Typical of AD/No referral.
Seeing people, seeing little people, animals.	Probably unusual in AD, suggestive of DLB.	Consider referral.
Seeing shapes and patterns on uniform surfaces (e.g., wall looks wavy or has patterns).	Probably unusual in AD, suggestive of DLB. Often occurs at night, when in bed.	Consider referral.

Subdomain: OBSESSIONS/COMPULSIONS

Question: Have you (they) become fixated on certain ideas that they can't get out of their head or 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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Open and closes drawers a lot, looks for things a lot.	Typical in AD.	Typical of AD/No referral.	?
Very fixated on upcoming events, worried about being prepared hours in advance.	Often seen in AD.	Typical of AD/No referral.	?
Driven to persistently do certain activities all the time (play specific games, watch specific programs).	Concerning for FTD.	Consider referral.	!
Rigid fixation on time, everything has to happen exactly as planned (e.g., meals at specific times).	Concerning for FTD.	Consider referral.	!
Fixated on certain people (e.g., famous people, certain types of people).	Concerning for FTD.	Consider referral.	!

Subdomain: SLEEP

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Get up a lot to urinate, but fall back to sleep.	No relation to dementia.	No referral.
Awake more at night, often confused or disoriented. Sleeping during the day.	Typical of AD.	Typical of AD/No referral.

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Sometimes talks in his sleep.	Probably no relation to dementia.	No referral.
Yes, moves in bed, hits, yells out.	Suggests REM sleep behavior disorder, associated with DLB.	Consider referral.

Question: Do you (they) snore?
Evidence of breathing stoppages?
Sleepy during the day?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Yes, snoring, breathing stoppages.	No relation to dementia, but consider referral for sleep apnea. Can explain mild cognitive complaints.	Consider referral for sleep apnea.

Subdomain: EATING BEHAVIORS

Question: Have there been changes in eating habits?
Prompts: Eating much more or less?
Weight gain, weight loss?
Fixation with certain foods?
Fixation with sweets or carbohydrates?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
A bit more liberal with fattening foods.	Probably no relation to dementia.	No referral.	✓
Forgets to eat, forgets they've eaten. May lose weight.	Common in AD.	Typical of AD/No referral.	?
Craving sweets, hoarding candies or other foods.	Concerning for FTD, consider referral.	Consider referral.	!
Eating voraciously, finishing everything on plate without thinking about it	Concerning for FTD, consider referral.	Consider referral.	!
Stuffing mouth.	Concerning for FTD, consider referral.	Consider referral.	!
Fixated on certain foods or faddish dietary habits.	Concerning for FTD, consider referral.	Consider referral.	!

Subdomain: LOSS OF EMPATHY

Question: Do they 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).

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Any change in behavior that seems like a marked difference compared with before, fitting in category (see prompts), if not obviously accounted for by depression (with frank admission of sadness/ anhedonia by patient).	Concerning for FTD, consider referral.	Consider referral.

Subdomain: JUDGMENT/GULLIBILITY

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Particular person has taken advantage of them (e.g., taking money from them staying in their house).	Typical of AD.	Typical of AD/No referral.
Buying lots of magazines, saying "yes" to many solicitors, agreeing to questionable business arrangements (like paying money in advance in situation where this is not normally done).	Concerning for FTD, consider referral.	Consider referral.

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.

Subdomain: PARKINSONISM AND RESTING TREMOR

Question: Do you have a tremor?
Prompts: Has your hand, arm, chin, leg been shaking involuntarily?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
No.	Consistent with AD.	Typical of AD/No referral.
Yes.	Defer to exam.	If present, refer to specialist. More concerning if at rest.

Subdomain: RIGIDITY

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging. Do not consider normal joint stiffness due to arthritis.	No referral.
No.	Rigidity is not consistent with AD.	Typical of AD/No referral.
Yes.	Defer to exam.	If present, refer to specialist.

Subdomain: BRADYKINESIA

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No.	Mild slowing due to age is normal. Do not consider changes explained by orthopedic conditions.	No referral.	✓
No.	Mild slowing may be normal, but there should be no motor changes with AD.	Typical of AD/No referral.	?
Yes.	Defer to exam. Bradykinesia is a feature of parkinsonism and may reflect a movement disorder.	If present, refer to specialist.	!

Subdomain: PARKINSONIAN AND GAIT ABNORMALITY

Question: Have you had a shuffling gait?
Prompts: Have you had a stoop?
Do you drag your feet when you walk?
Are your steps shorter or do you get stuck when walking?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No.	Mild stoop may be normal.	Screen for other orthopedic issues.	✓
No.	There should be no motor changes with AD.	Typical of AD/No referral.	?
Yes.	Defer to exam.	If present, refer to a specialist.	!

Subdomain: FREQUENT FALLS

Question: Have you fallen down?
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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Changes in balance are common in aging, but falls should not be frequent.	No referral. Use of cane or walker explained by an orthopedic or other problem are okay.
No.	Falls are not common early in AD.	Typical of AD/No referral.
Yes.	Frequent falls are not common early in AD and may be due to neurologic, orthopedic, sensory or cardiac causes.	If present and not explained or due to prior diagnostic issue, refer to specialist.

Subdomain: UNILATERAL WEAKNESS

Question: 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?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Some reduced strength throughout is normal but should not be asymmetrical.	No referral. May be due to known prior diagnosed and evaluated condition.
No.	Focal weakness is not consistent with AD.	Typical of AD/No referral (may be due to pre-existing condition).
Yes.	Even subtle change may indicate prior ischemic stroke.	If present and not explained by previously diagnosed condition, refer.

Subdomain: MYOCLONUS

Question: Do you have jerks in your limbs?
Prompts: Do your arms or legs jerk involuntarily?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No.	The jerking upon falling asleep is normal.	No referral.	✓
No.	Myoclonus is not consistent with AD except in late stages. Do not consider "falling asleep" jerking as abnormal.	Typical of AD/No referral.	?
Yes.	Myoclonus is common in the late stages of all forms of dementia.	Refer if debilitating or clusters into seizures.	?
Yes.	Not common in the early stages of dementia.	Refer, could be consistent with CJD.	!

Subdomain: MOTOR NEURON DISEASE

Question: Do you have twitching of your muscles?
Have you lost muscle mass?
Are your muscles weaker?
Prompts: Have any of your muscles become smaller?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)	
No.	Minor global changes in muscle mass are normal.	No referral.	✓
No.	No focal motor changes are consistent with AD.	Typical of AD/No referral.	?
Yes.	Defer to exam.	Refer for fasiculations or unexplained or focal muscular atrophy.	!

Subdomain: ALIEN LIMB

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
No.	Should not be present in AD.	Typical of AD/No referral.
Yes.	Defer to exam.	If present, refer. This may be alien limb associated with CBD.

Subdomain: DYSARTHRIA

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

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
No.	This is not consistent with AD.	Typical of AD/No referral.
Yes.	Defer to exam.	If present, refer to specialist, unless explained by previous injury/disease.

Subdomain: DYSPHAGIA

Question: Have you had trouble swallowing?
Prompts: Have you choked when eating/drinking?
Coughed when eating/drinking?
Solids?
Liquids?
Pills?

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No.	Normal aging.	No referral.
No.	Not present in early stages of AD.	Typical of AD/No referral.
Yes.	Dysphagia may occur in end stage of all forms of dementia. Early may reflect other neurodegenerative disease.	Refer to specialist.

Domain: Family History

Questions: 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, schizophrenia, bipolar, depression

Answer	Interpretation	Recommendation	
One parent with dementia or Parkinson's, age of onset mid-60s or older.	Consistent with normal aging. Greatest risk of AD is age.	No referral.	✓
One sibling with dementia or Parkinson's, age of onset before age 65.	Common. However, if this patient has symptoms, that is second person in same generation with symptoms, probe for symptoms in the other family member, if atypical symptoms (e.g., had personality problems at presentation).		?
Two or more members of family (e.g., two siblings, one parent and one sibling) with dementia or Parkinson's *AND* age of onset before age 65.	Person may at risk even if they themselves do not have meaningful symptoms.	Consider referral for genetic counseling if patient is concerned about their family history.	!

Domain: Function

Subdomain: INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs)
(management of finances, medications, shopping, cooking, household chores, driving)
*Do not consider physical limitations (eyesight, hearing)

Component: 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, following recipes?
Do you manage your own medications?
Are you still paying your own bills without difficulty?
Are you still managing household chores or projects?
Are you still driving?

Answer	Interpretation	Recommendation
Still able to do but may take me longer. No problems taking my medications, use a pill box. Still paying bills, may take a bit longer. Still driving, no accidents or concerns from informant.	Consistent with normal aging.	Reassure.
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.	Consistent with AD. Need to confirm with informant as patients may deny. Informant reports concerns or a loss of independence.	Typical of AD/No referral. If no informant, consider home visit or OT eval to confirm.
Is able to perform activities but doesn't seem interested or doesn't care about doing them.	Not typical of AD , may reflect apathy of FTD rather than ability to perform.	Refer to dementia specialist.

Subdomain: BASIC ACTIVITIES OF DAILY LIVING (BADLs)
(dressing, bathing/grooming, eating, toileting)
*Do not consider physical limitations (eyesight, hearing)

Component: 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?

Answer	Interpretation	Recommendation
Still able to bathe, dress appropriately and independently – may be a little less often. Continent of bowel and bladder.	Consistent with normal aging.	No referral.
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.	Typical in AD.	Typical of AD/No referral (do not consider changes due to physical limitation).
Early difficulty getting clothing on due to changes in perception rather than ability, especially if out of proportion to other deficits.	May be typical of DLB or PCA with prominent visual difficulties.	Refer to dementia specialist.

Physical and Neurological Examination

Subdomain: GENERAL APPEARANCE

Component: Personal hygiene and dress

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Soiled clothing.	Typical of AD if significant functional impact (history indicates needs help with dressing and bathing). Could be indicative of atypical dementia if early.	Refer if attention to hygiene is very bad, but other functions are much less impaired.	?
Malodorous (urine, feces).	Typical of AD if significant functional impact (history indicates needs help with dressing and bathing). Could be indicative of atypical dementia if early.	Refer if attention to hygiene is very bad, but other functions are much less impaired.	?

Component: Signs of trauma

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Bruising on face, torso.	Could indicate falls, if supported by history. Could also be sign of physical abuse.	Refer if history indicates significant number of falls (more than 4/year). Physicians are mandatory reporters for elder abuse.	?

Subdomain: CRANIAL NERVES

Component: Cranial nerves 3,4,6

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Extraocular movements are impaired.	Not typical of AD. Occurs in PSP, and Wernicke's encephalopathy.	Refer to neurology.	!

Subdomain: MOTOR

Component: Bulk

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Atrophy. Fasciculations.	Not typical of AD. May indicate ALS.	Refer to neurology unless findings are previously documented and explained.	!

Component: Tone

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Cogwheel rigidity.	Parkinsonian features only common in late stage AD. If early in the course of dementia could be DLB, PD.	Refer to neurology if early in the course.	!
Paratonia.	Failure to relax during passive movement of the limbs – common in normal aging. Also common in AD.	No referral.	✓

Component: Power

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Hemiparesis (facial asymmetry, unilateral weakness, pronator drift).	Not typical in AD. May indicate stroke.	Refer to neurology unless findings are previously documented and explained.	!
Focal weakness in any muscles.	Parkinsonian features only common in late stage AD. If early in the course of dementia could be DLB, PD.	Refer to neurology unless findings are previously documented and explained.	!

Component: Tremor

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

Component: Other Parkinsonian Motor Features

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)	
Masked facies. Hypophonia. Micrographia. Bradykinesia.	Not typical in AD. Parkinsonian features occur in Parkinson disease, dementia with Lewy bodies, and in other dementias in late stage.	Refer – if early in the course of dementia or debilitating.	?

Component: Myoclonus

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

Subdomain: REFLEXES

Component: Deep tendon reflexes

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)
Reflex asymmetry.	Not typical in AD.	Refer if unexplained or in combination with hemiparesis.

Subdomain: STANCE

Component: Posture and Stance

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

Subdomain: GAIT

Component: Walking

Finding	Interpretation	Indications for Referral (for Diagnostic Purposes)
Reduced arm swing. Shuffling gait.	Parkinsonian features not typical in AD until late stage.	Refer any gait abnormalities to neurology and physical therapy. !
One leg stiff and foot doesn't come off ground well. Shuffling gait.	Not typical of AD, hemiparetic gait.	Refer to neurology and physical therapy unless previously explained. !
Failure to lift feet off the ground.	Not typical of AD, called "magnetic gait," can be a sign of NPH.	Refer to neurology. !

Domain: Cognition

Subdomain: MoCA SCORE

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
27–30 with history indicating minimal subjective complaints and no functional impairment.	Normal aging.	No referral.
<21 with history indicating significant subjective complaints *and* functional impairment.	Consistent with dementia.	Bring back for full assessment.
>21 with history indicating significant subjective complaints and functional impairment.	Unusual pattern, may indicate atypical dementia or inaccurate history.	Refer to neuropsychologist for additional cognitive testing and/or to dementia specialist.
<27 with history indicating minimal subjective complaints and no functional impairment.	Could be normal or mild cognitive impairment, additional testing indicated.	Refer to neuropsychologist for additional cognitive testing and/or to dementia specialist.
<21 but no reported change in function.	Could be due to other non-neurological causes but not typical of AD.	Refer to dementia specialist.

ALERT: *LOW LEVEL OF EDUCATION, ENGLISH AS A SECOND LANGUAGE, NON-ENGLISH SPEAKING MAY MAKE THE RESULTS DIFFICULT TO INTERPRET AND RESULT IN FALSE POSITIVES. RECOMMENDATIONS INCLUDE RELYING MORE ON INFORMANT INFORMATION OR REFERRING TO A DEMENTIA SPECIALIST.*

Domain: Labs and Imaging

Subdomain: CT OR MRI (Review MRI for amount and anatomy of volume loss, white matter changes may be present)

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
No mass, hemorrhage or infection. Mild global volume loss consistent with age. Mild white matter changes.	Normal aging.	Reassure, no referral needed. ✓
Global volume loss, perhaps more notable in parietal lobes. Small hippocampus. Mild white matter changes.	Consistent with Alzheimer's disease.	Typical of AD/No referral. ?
Global volume loss, greater than expected for age.	Often read for AD, potentially consistent with any dementia, or aging.	Consider history. Refer if aytpical for AD. ?
Some enlarged ventricles, concerning for NPH.	If concern has been raised, should be directly assessed by neurologist.	Refer to neurology. !
Atrophy primarily in the frontal and/or temporal regions accompanied by clinical symptoms atypical for AD (apathy, personality changes, language dominant syndrome).	Could be bvFTD or atypical dementia.	Refer to dementia specialist . !
Significant white matter disease, strokes.	Could be co-pathology with AD but want to rule out vascular diseases.	Refer to dementia specialist. !

Subdomain: LAB WORK (CBC, METABOLIC PANEL, TSH, B12)

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Should be normal or at baseline for patient considering other medical conditions.	Consistent with normal aging.	No referral.
Normal. If abnormal, typical cognitive symptoms persist after correction.	Consistent with normal aging or AD.	No referral.
Abnormal – symptoms resolve after correction.	Continue to monitor but may be reversible deficit.	Refer if cognitive symptoms persist after correction.

Subdomain: RPR

Answer	Interpretation	Indications for Referral (for Diagnostic Purposes)
Normal.	Typical of normal aging, or AD.	No referral.
Positive.	May indicate acute or chronic infection.	Requires referral to specialist.

DISCUSSING THE DIAGNOSIS OF 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

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've 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's 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 isn't 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've 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's 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 don't 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 can't 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 don't 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's 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.

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.

At the Conclusion of Assessment When a Diagnosis of Dementia is Made

This script (5–10 minutes) can be used after the diagnosis of dementia is made and reporting to the California State Department of Health (DPH) is required by law using a Confidential Morbidity Report (CMR). The DPH then notifies the DMV who will contact the patient directly via mail. The important points are:

- Liability and safety risk of driving with cognitive problems
- Physician legal requirement to report "at risk" individual
- Lack of reliability of cognitive tests to predict driving ability
- Procedure – reporting to DPH, notification by DMV, forms, testing

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. There is a lot of data that tells us that patients with dementia have a higher likelihood of having accidents. In some cases, this could be because their driving skills have gotten worse. In other cases, it could be that another driver made a mistake and the person with dementia wasn't able to compensate as much as they normally would have. Even though our cognitive testing can show that people have problems with their thinking, they can't accurately predict who is having trouble driving. That something that really has to assessed directly. Therefore, one of my responsibilities according to state law is to notify the department of public health when medical conditions that could impair driving such as dementia are diagnosed, so that a proper assessment can be made. Once the public health department receives the notice of diagnosis, they alert the DMV. And, as it should be, the DMV is then responsible for determining if you are a safe driver usually by requiring both a written and road test. I know that this can be difficult but you should know that many patients with mild dementia take the test and pass it, which can reassure all of us about your safety – and if you do not pass, it is much better to have discovered this and potentially prevented an injury to you or someone else. This really is for the safety of us all and is meant to reduce your risk and the potential liability that could bring. So, just to be clear, according to state law after today's visit I will notify the department of public health that you have been diagnosed with dementia and they will notify the DMV who will in turn contact you. I'll explain what happens next, but first, do you have any questions?

You may want to advise them to not drive until they are contacted by the DMV depending on your comfort with their level of impairment and concerns about safety.

In several weeks, I don't know exactly when, you will get a letter from the DMV (check who gets the mail). You then have three options:

1. *you can relinquish your license and get a California ID card,*
2. *you can make an appointment for an assessment, or*
3. *if you ignore the letter your license will be automatically suspended.*

The letter will require completion of a 5-page form by you and a medical provider. I am happy to fill out the medical provider portion, unless you want another physician to do so. If you decide to request an assessment and show the DMV that you are safe to drive I suggest you prepare. You will need to take both the written and road test. There are practice tests online, and there are also driver evaluation programs. These are different from driving schools and are run by an occupational therapist who specializes in assessing driving skills and providing adaptations or assistance to help people continue to drive safely. I can provide a referral but want you to know that it will cost several hundred dollars and is not covered by insurance.

It is often comforting to acknowledge knowing how difficult this news is to hear and re-enforcing that your role as provider is just to notify them of a person who may be at risk.

Tips to Share with Informant Who Has Concerns about Patient Driving

1. Take the car key away from the patient and remove other copies from the house.

2. Remove the car from the garage/driveway/property. Make up a story – someone's car has been recalled or is being serviced and they need to "borrow" the car to get to school/work.

3. If you can't remove the car, disable it so it won't start. Disconnect the battery or take out the air filter.

4. Family, or anyone, can anonymously report concerns about the driving safety of any driver to the DMV.

MEDICATION FOR TREATMENT SCRIPTS

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

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 boosting 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 impair-ment), 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 interact. 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 and the Alzheimer's Association. It is important to let both your pharmacist and me know what supplements you are taking if you decide to take some.

SCRIPT FOR DISCUSSION OF 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

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 is 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 and Caregiver Resource Center of California can be an invaluable resource for caregivers.

SCRIPT TO DISCUSS POSSIBLE PARTICIPATION IN RESEARCH

The script (3 minutes) below assumes you have discussed the diagnosis of Alzheimer's disease, including the fact that it is a neurodegenerative disease caused by the accumulation of toxic proteins, and you have also discussed the role of current treatments, cholinesterase inhibitors, and possibly memantine. Bullet points to be sure to cover are:

- Observational research
- Interventional research including treatment trials, discussion of placebo
- Referral process

Now that we've discussed the diagnosis and the available treatments, it's also important to think about the role of research and whether you would like to participate in research studies. As you can understand from the way we discussed your problem, there is still a lot to learn about these diseases, like how to recognize them better and also how to treat them better. There is a lot of research going on in [or near] our community.

You can generally think about two kinds of research. One kind is where the research is just focused on learning more about these diseases through special tests to assess people's thinking abilities, blood tests, and sometimes brain imaging, like MRIs and similar tests. This kind of research is very important. There is also research where we are testing new kinds of treatments, including treatments that might clear away the abnormal proteins that we talked about in the brain. Of course, if you join these types of drug studies, you may not get on the medication, but on the placebo, or "fake medicine." These types of studies are the only way we will know if these drugs work. Sometimes, you have a chance to go on the real medicine once you are in the study for a few months. That depends on a lot of factors. In most research studies, you would not pay anything to participate in the research, and you would not pay for any of the procedures.

If you are interested in either of these kinds of research, I would be happy to refer you to [name the center], where they can answer all your questions about research participation. The main reason you should do this is if you want to help us to learn more about these diseases and help us to discover better treatments, but it is also a good way for you to meet experts who know a lot about these diseases and learn more from them if you want.

GUIDANCE ON MAKING A REFERRAL

Specialty clinics may have providers with specific expertise. Processing of the referral, including identifying the best clinician and deciding what testing might be needed, will be more efficient if pertinent information is provided. Once the decision is made that a specialty evaluation is necessary, the following components can be most helpful in ensuring a timely and successful referral.

Goals for referral (include one or more)

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

What to include

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

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

State Alzheimer's Disease Centers – ten academic sites that evaluate cognitive complaints

Federal Alzheimer's Disease Research Centers

American Academy of Neurology – find a neurologist near you

Alzheimer's Association – local chapters can often make referrals to MD with expertise

Northern California Neuropsychology Forum – find a neuropsychologist

American Academy of Clinical Neuropsychology – search for clinical neuropsychologist

GUIDANCE ON 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 after patient questions	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 patient questions	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

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 after patient questions	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 • Video	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 Visit	Codes and National Reimbursement Rates	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	Length of visit: Frequency of visit: Not specified, can be added on to AWV	Codes: 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

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 **Toolkit sections** • N/A	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.