



## Dementia and Cognitive Impairment Diagnosis and Treatment Guideline

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**Last guideline approval:** December 2012

Guidelines are systematically developed statements to assist patients and providers in choosing appropriate health care for specific clinical conditions. While guidelines are useful aids to assist providers in determining appropriate practices for many patients with specific clinical problems or prevention issues, guidelines are not meant to replace the clinical judgment of the individual provider or establish a standard of care. The recommendations contained in the guidelines may not be appropriate for use in all circumstances. The inclusion of a recommendation in a guideline does not imply coverage. A decision to adopt any particular recommendation must be made by the provider in light of the circumstances presented by the individual patient.

## Definitions and Epidemiology

**Memory loss** is a normal part of the aging process and usually involves a decreased ability to retrieve information. Memory loss due to aging does not impact activities of daily living. People with memory loss often make use of adaptive strategies such as list making and sticky notes to preserve independence and safety.

**Mild cognitive impairment** is a syndrome defined as cognitive decline greater than expected for an individual's age and education level that does not interfere notably with activities of daily living. It is not a diagnosis of any type. People with mild cognitive impairment are at higher risk to progress to dementia.

**Dementia** is a disorder characterized by problems with memory and at least one other cognitive function (learning, reasoning, language, spatial ability and orientation, and handling complex tasks) that are severe enough to interfere with activities of daily living. Dementia may have different etiologies.

**Alzheimer's disease** is the most common form of dementia (60–80%) and is characterized by pathological changes in the brain that result in loss of memory, thinking, and language skills, as well as changes in behavior, and that ultimately lead to a complete loss of functional ability. It is the most common form of dementia in the elderly (Alzheimer's Association 2012).

**Non-Alzheimer's dementias** are disorders characterized by problems with memory and cognitive function plus other unique clinical features. (See [Table 4b](#) for more information.)

**Stages of dementia**—Although there are no official categories, for the purpose of this guideline, we are defining dementia in four stages.

### Early stage

There are clear symptoms in several areas:

- Forgetfulness of recent events.
- Impaired ability to perform challenging mental arithmetic—for example, counting backward from 100 by 7s.
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills, or managing finances.
- Forgetfulness about one's own personal history.
- Becoming moody or withdrawn, especially in socially or mentally challenging situations.

### Mid stage

Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with dementia may:

- Be unable to recall their own address or phone number, or the high school or college from which they graduated.
- Become confused about where they are or what day it is.
- Have trouble with less challenging mental arithmetic—for example, counting backward from 40 by subtracting 4s or from 20 by subtracting 2s.
- Need help choosing proper clothing for the season or the occasion.
- Still remember significant details about themselves and their family.
- Still require no assistance with eating or using the toilet.

### Late stage

Memory continues to worsen, personality changes may take place, and individuals need extensive help with daily activities. At this stage, individuals may:

- Lose awareness of recent experiences as well as of their surroundings.
- Remember their own name but have difficulty with their personal history.
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver.
- Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet.
- Experience major changes in sleep patterns—for example, sleeping during the day and becoming restless at night.

- Need help handling details of toileting—for example, wiping, disposing of tissue properly, and flushing the toilet.
- Have increasingly frequent trouble controlling their bladder or bowels.
- Experience major personality and behavioral changes, including suspiciousness and delusions (such as believing that their caregiver is an impostor), and compulsive, repetitive behavior (such as hand-wringing or tissue shredding).
- Tend to wander or become lost.

### End stage

In the final stage of the disease, individuals may:

- Be able to say words or phrases but may need help with much of their daily personal care, including eating and using the toilet.
- Lose the ability to respond to their environment or to carry on a conversation.
- Lose the ability to smile, to sit without support, and to hold up their heads.
- Lose the ability, eventually, to control movement:
  - Reflexes become abnormal.
  - Muscles grow rigid.
  - Swallowing is impaired.

Dementia prevalence increases dramatically with age. The prevalence of dementia is 3–11% in people older than 65, and 25–47% in people older than 85 (USPSTF 2003).

## Brief Introduction to the Framework of Family-Centered Care

There are four common scenarios in which patients present with memory, cognitive, or dementia concerns. The needs of patients and their families differ depending upon which of the four scenarios they are in. When primary care physicians (PCPs) recognize the appropriate scenario, it is easier to deliver effective clinical care.

The following scenarios provide the framework for the family-centered approach to tailoring care for patients with dementia.

### Scenario 1—Preserving memory and maintaining vitality

**Patient/family:** Claire is 70 and reads a lot about health care and disease prevention, using that information to keep herself and her husband, Cliff, in good health. She and Cliff are busy retirees; they both volunteer with several organizations, have an active circle of friends, and spend time with their children and grandchildren, most of whom live nearby. At this visit, she has questions about memory loss—in recent months, she has had a few instances of forgetting things, including where she parked her car and which day it was (she eventually remembered). She’s concerned and wants to talk about preserving her memory and preventing dementia. She has read about studies looking at whether statins and antioxidants can prevent dementia, and wants to know what kinds of mental activities she—and maybe Cliff, too—might take up to help preserve cognitive function.

**PCP:** Patients like Claire typically are healthy and often lead functional lives. They are worried about developing Alzheimer’s and want to know everything they can do to keep their minds and independence. So, the conversation is about preservation and prevention.

Discuss age-related changes in memory, and validate that they are not necessarily a sign of disease. Encourage Claire to maintain a healthy diet, regular physical activity, and her and Cliff’s social connections. Also talk about keeping an eye on her blood pressure. In addition, she might try taking up new and challenging mental activities, such as a language or musical instrument. (Note that commercial products marketed at seniors for retaining memory remain unproven.)

### Scenario 2—Presentation of nonspecific symptoms

**Patient/family:** Sam and his wife, Ruby, come to his appointment together. Sam is 82 and has been feeling apprehensive and not sleeping well. He often feels tired and cold, and Ruby says he has mentioned feeling dizzy on a number of occasions. She also feels that he has been withdrawing and that he doesn’t seem as interested in his woodworking projects or in their usual after-dinner walks as he used

to be. As she describes his symptoms, she makes quick glances at Sam, who isn't very talkative and looks mostly at the floor or at Ruby. She doesn't mention dementia or Alzheimer's, but asks about a number of other possible diagnoses, including depression, panic attacks, or some other kind of anxiety disorder.

**PCP:** In patients older than 75, new-onset, nonspecific symptoms in a previously healthy person—commonly paired with anxiety—are often the heralding sign of the onset of dementia. These patients and/or families are typically focused on the vague symptoms, and it is the PCP's job to realize that such a focus is hiding the true issue, which is the onset of significant memory loss and functional problems. Sometimes patients and/or their family members are thinking about dementia but are afraid to ask about it. Many times, though, the families are not aware that dementia is present, unless specifically asked questions about memory and function by the PCP. With Sam, it would be helpful to bring up the topic of memory. Ask if it is OK to focus on how he is thinking and functioning daily, whether he is having trouble remembering things, and if you can conduct a memory/cognitive assessment.

When the topic is offered, many patients are relieved to have the discussion. In this scenario, they and their families want a structured approach to diagnosis, and the more transparent the process, the better. In the end, they want to know “Do you think I might have Alzheimer's?” If you suspect a positive diagnosis, do not hesitate to tell the patient and his/her family. Often, using the term “Alzheimer's”—rather than “dementia”—is highly effective, because people have a general awareness of what that means and that there are next steps they need to take.

### Scenario 3—Developing a care plan

**Patient/family:** Carol, 79, and her husband, Mike, moved here from Los Angeles about 9 months ago to live closer to four of their five children. Carol's daughter Heather made this appointment, saying she, her siblings, and their father know that things are not right with Carol. All four have come, with Mike, to Carol's appointment, asking to speak with you privately before you see Carol. Heather reports that Carol asks her children's names every time they get together; Steven has noticed that Carol regularly refers to the family dog as a cat; and Elise and Peter say that it takes their mother twice as long as it should to get to their houses when she visits, even allowing for bad traffic, and that she's very vague about where she has been in between. Mike still works part time in the family business and is worried about leaving Carol alone. He says Carol has seen doctors several times in the past couple of years but that her symptoms of memory loss and confusion have been described as part of the normal aging process. The family wants to know what they should do about the days when Carol is on her own and how to handle telling her that she cannot drive any longer. When they have tried bringing up the subject, Carol gets upset and angry, and yells that nothing is wrong with her.

**PCP:** Carol's family has been waiting for a physician to formally name the problems that she is having. This scenario has a lot of content and need in it: diagnostics and—once the family has had time to digest the diagnosis—a conversation about care planning and the need for advanced planning.

Note that families in this situation will almost universally be shocked by the diagnosis of dementia or Alzheimer's. So, in this first visit, focus on the structured approach to diagnosis and the diagnosis-with-empathy presentation.

In a second visit—after the family has had time to process—tackle the care plan (i.e., housing, driving, home-care workers), what dementia looks like, and how Carol can have a nice life. Gather information about who the primary caregiver is, and identify problems, needs, resources, and strengths of that person. The care plan also should have intended outcomes and be revisited periodically. (See also the [Caregiver Support](#) section.)

Then discuss the role of acetylcholinesterase inhibitors. The drug part should be last, as it is not very effective and you do not want to create false hope. When these patients and their families are also dealing with behavior problems (i.e., argumentative, stubborn, yelling), behavioral skills for managing the problems and possibly using sedatives and antipsychotics may be discussed, too. But the key takeaways are: don't short-change diagnostics and conversations about care and safety, and do the drugs after.

## Scenario 4—Easing guilt and worry, and supporting the caregiver

**Patient/family:** Archie was diagnosed with Alzheimer’s six years ago, at age 78. He still lives at home with his wife, Sarah, who has been his primary caregiver with occasional help from their daughter, Gloria, and son-in-law, Jackson. Sarah has been regularly taking Archie to adult day care for several years, where he enjoyed loud discussions with other attendees and watching old movies about simpler, more conservative times. She feels she has done a good job caring for him, but in the past year, it has become more difficult. He has trouble remembering who she is, and needs a lot more help with everyday tasks such as dressing and toileting. He no longer wants to go to day care, instead insisting on watching TV for hours at a time and falling asleep for most of it. Meals have become an issue because Archie wants to eat only meat and raw carrots, and only in his easy chair, rather than at the dining table.

Sarah, who is 80, is here today because she is tired. She is tired of trying to persuade Archie to go to day care, to get him to eat more balanced meals, and to make sure he gets some exercise. She feels bad that she gets angry when he behaves like a 2-year-old while she’s trying to dress him and that she gets annoyed when she has to repeat who she is a dozen times a day. But mostly she worries that she isn’t doing enough to keep Archie healthy and mentally active.

**PCP:** Sarah wants to hear from a professional that she is doing a great job as caregiver and that she has done everything she can. Archie may live for years still, so she needs “permission” to not worry that she is missing something and to be assured that what Archie is experiencing is a normal part of the dementia—and, often, aging—process. She needs to hear that it is OK that Archie does not get as much mental and physical activity as he used to, that he can sleep for 6 extra hours a day without harm.

The need for a PCP to lift the burden of worry about not doing enough is a key clinical task in this scenario. (Like in the third scenario, many families will appreciate diagnostics and an explicit diagnosis if it has never been done previously, but that is not the primary need here.) The key take-away is to recognize that reassuring caregivers they are doing everything right—that they can let go of worry and guilt—is of high clinical value and is essential for good care for patients at this time.

Sarah also needs to hear that she must take care of herself, too, and that there are resources to help her do that. Discuss her needs and the problems she is experiencing to identify resources that might help. (See the [Caregiver Support](#) section.)

## Prevention

### Recommendations

<b>Eligible population</b>	<b>Recommendations</b>
Middle-aged and older people	Vascular and other modifiable risk factors for dementia should be reviewed and, if appropriate, treated: <ul style="list-style-type: none"><li>▪ Smoking</li><li>▪ Excessive alcohol consumption</li><li>▪ Obesity</li><li>▪ Diabetes (treat to avoid frequent hypoglycemia)</li><li>▪ Hypertension</li><li>▪ Elevated cholesterol</li><li>▪ Sedentary lifestyle</li></ul>

### Options that are not recommended

There is evidence that medications (e.g., donepezil, memantine) and dietary supplements (e.g., ginkgo biloba, resveratrol) are not effective at treating memory impairment, preventing dementia, or delaying the onset of dementia.

## Screening

Universal screening for dementia is not recommended. The U.S. Preventive Services Task Force finds that there is insufficient evidence to recommend for or against routine screening for older adults (USPSTF 2003).

## Assessment

### Recommendations

**Table 2. Targeted assessment for dementia**

Recommended for patients with:

- Declines in independent living and safety associated with memory or cognition changes.
- Signs of mild cognitive impairment.
- Learning disabilities.
- Stroke or neurological condition, such as Parkinson's disease.

### Assessment tools

Many different tools are available for assessing cognitive function. The choice of which tool to use is less important than consistently using the same one to measure changes over time.

Tables 3a and 3b describe and compare validated tools to assess for dementia. (Links in Table 3a go to websites from which copies of the tools can be obtained.)

Table 3a. Cognitive assessment tools

Table 3b. Comparison of cognitive assessment tools

**Table 3a. Cognitive assessment tools**

Tool	Benefits	Limitations
Mini-Cog <sup>1</sup> <a href="http://dementia.americangeriatrics.org/#tools">dementia.americangeriatrics.org/#tools</a>	Short time to administer.	Positive score triggers further testing with one of the other screening tools.
Mini-Mental State Examination (MMSE) <a href="http://www4.parinc.com/products/Product.aspx?ProductID=MMSE">www4.parinc.com/products/Product.aspx?ProductID=MMSE</a> <sup>2</sup>	One of the most widely used tests; high specificity.	Low sensitivity.
Montreal Cognitive Assessment (MoCA) <a href="http://www.mocatest.org/">www.mocatest.org/</a>	Most comprehensive test; high sensitivity.	Longer administration time; low specificity.
General Practitioner Assessment of Cognition (GPCOG) <a href="http://www.gpcog.com.au/">www.gpcog.com.au/</a>	Incorporates functional status; short administration time.	Cannot be used without an informant.

<sup>1</sup> Within Group Health, available as Epic SmartPhrase **.minicog**.

<sup>2</sup> Obtain copies only from the distributor (do not copy yourself). Also available in abbreviated form as an Epic Documentation flow sheet within Group Health.

Table 3b. Comparison of cognitive assessment tools <sup>1</sup>				
	Mini-Cog	MMSE	MoCA	GPCOG
<b>Time to administer</b>	2–4 minutes	~ 8 minutes	~ 10 minutes	~ 4–6 minutes
<b>Interpretation</b>	A score below 3 is suggestive of dementia, and indicates the need for additional dementia screening.  A score of 3 or above might indicate low yield from further testing at this time.	A score lower than 24 is suggestive of dementia or delirium. <sup>2</sup>	A score lower than 26 is suggestive of dementia or mild cognitive impairment. <sup>2</sup>	Patient assessment: A score of 4 or below suggests cognitive impairment; for a score of 5–8, conduct informant interview.  Informant interview: A score of 3 or below suggests cognitive impairment.
<b>Suggested situation in which to use tool</b>	Diagnosis is <b>not</b> suspected, and patient/family needs reassurance.	Diagnosis is suspected, and patient/family needs confirmation.	Need confirmation with high certainty whether or not patient has dementia.	Patient history is unreliable, and need a sense of caregiver burden.
<sup>1</sup> Interpret scores taking into full account the factors known to affect performance, including educational level, skills, prior level of functioning and attainment, language and sensory impairment, psychiatric illness, and physical /neurological problems. <sup>2</sup> Score may need to be adjusted to account for level of education.				

## Assessing functional status

Functional status refers to a patient’s ability to perform activities of daily living and is directly influenced by health conditions such as dementia. Change in functional status can be valuable for monitoring response to treatment and for care planning.

Assess the patient’s ability to perform:

- Basic activities of daily living, such as bathing, dressing, grooming, and toileting.
- Instrumental activities of daily living, such as taking care of the house, shopping, and paying bills. (For a list of instrumental activities to ask about, see the Functional Activities Questionnaire [[provider.ghc.org/open/caringForOurMembers/patientHealthEducation/screeningSchedules/dementiaQuestionnaire.pdf](http://provider.ghc.org/open/caringForOurMembers/patientHealthEducation/screeningSchedules/dementiaQuestionnaire.pdf)]).

## Diagnosis

### Overview

A diagnosis of dementia should be made only after a thoughtful assessment to exclude other causes. Such an assessment includes detailed history taking, cognitive- and mental-state examination, physical examination, and a review of medications.

Routine testing for genetic markers of medical conditions known to cause dementia, such as Huntington’s chorea, is not recommended because false positives may occur and would be emotionally and financially devastating. There are no clear data to support or refute ordering routine laboratory studies, such as a complete blood count, electrolytes, glucose, and renal and liver function tests.

A diagnosis of dementia **cannot** be made solely on the basis of the results of any of the cognitive assessment tools, and it requires that functional status correlates well with the results.

Table 4a. Diagnosing dementia using DSM-IV criteria  
 Table 4b. Additional criteria for determining dementia type

<b>Table 4a. Diagnosing dementia using DSM-IV<sup>1</sup> criteria</b>
<ul style="list-style-type: none"> <li>▪ Memory impairment.</li> <li>▪ At least one of the following:               <ul style="list-style-type: none"> <li>– Aphasia.</li> <li>– Apraxia.</li> <li>– Agnosia.</li> <li>– Disturbance in executive functioning.</li> </ul> </li> <li>▪ Cognitive deficits significantly interfere with work, social activities, or relationships.</li> <li>▪ Cognitive deficits do not occur exclusively during delirium.</li> </ul>
<sup>1</sup> Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association).

**Table 4b. Additional criteria for determining dementia type<sup>1</sup>**  
*Note:* Mixed causes—typically vascular dementia and Alzheimer’s disease—become increasingly more common in late-life dementias. PCPs should not feel obliged to come up with a single diagnosis in all cases.

<b>Dementia type</b>	<b>Prevalence<sup>2</sup></b>	<b>Common signs/symptoms</b>
Alzheimer’s disease	About 50%	<ul style="list-style-type: none"> <li>▪ Gradual onset with continuing decline.</li> <li>▪ Social withdrawal.</li> <li>▪ Paranoia.</li> <li>▪ Anxiety.</li> <li>▪ Not caused by identifiable medical, psychiatric, or neurologic condition.</li> </ul>
Vascular dementia	About 25% <sup>3</sup>	<ul style="list-style-type: none"> <li>▪ Focal neurological signs or laboratory evidence of cerebrovascular condition.</li> <li>▪ Patients have white-matter changes on imaging (although many patients with Alzheimer’s disease also have such changes). In general, patients with vascular dementia have a more stepwise decline, while patients with Alzheimer’s have a more gradual decline.</li> </ul>
Lewy body dementia	15%	<ul style="list-style-type: none"> <li>▪ History of fluctuating cognitive performance.</li> <li>▪ Well-formed visual hallucinations (unrelated to dopaminergic therapy).</li> <li>▪ History of parkinsonism emerging simultaneously with cognitive impairment.</li> <li>▪ Parkinson’s-associated dementia is characterized by onset of Parkinson’s disease symptoms before dementia onset.</li> </ul>
Dementia due to other causes	5%	Evidence from history, physical exam, or laboratory findings of a specific medical condition causing cognitive deficits (head trauma, HIV disease, Parkinson’s disease, Huntington’s chorea, Pick’s disease, Creutzfeldt-Jakob disease). <sup>4,5</sup>

<sup>1</sup> Adapted from Diagnostic and Statistical Manual of Mental Disorders, 4th ed, APA Press, Washington DC, 1994.  
<sup>2</sup> Burns 2009.  
<sup>3</sup> Includes mixed-cause cases (vascular and Alzheimer’s dementias).  
<sup>4</sup> There are no clear data to support or refute ordering routine laboratory studies, such as complete blood count, electrolytes, glucose, and renal and liver function tests.  
<sup>5</sup> There is no evidence for routine use of genetic markers. False positives may occur and would be emotionally and financially devastating.

## Use of imaging

Imaging is generally not necessary as part of a diagnostic workup for most patients with dementia symptoms and a normal neurological exam. For patients younger than 70 years old who have symptoms with atypical features or who had sudden onset of dementia symptoms, consider neuroimaging to identify those who might have reversible causes of dementia (e.g., tumor, subdural hematoma, normal pressure hydrocephalus) (see Table 5).

In current clinical practice, brain CT and MRI are used. MRI is more sensitive than CT for evaluating atrophy, vascular lesions, and lesions due to inflammation and infection. Consider a virtual consult with Neurology if you are unsure of which imaging modality to use.

<b>Signs/symptoms</b>	<b>Alternative diagnosis</b>	<b>Testing/investigation</b>
<ul style="list-style-type: none"> <li>▪ History of head injury</li> <li>▪ Headache</li> <li>▪ Lethargy</li> <li>▪ Loss of consciousness after head injury</li> </ul>	Traumatic brain injury	<ul style="list-style-type: none"> <li>▪ Head CT without contrast, up to 7 days after injury</li> <li>▪ If more than 7 days, consider using contrast CT or MRI</li> <li>▪ PT/PTT or platelets (to test for bleeding disorders)</li> </ul>
<ul style="list-style-type: none"> <li>▪ Stepwise, sudden deterioration in cognition</li> <li>▪ Episodes of confusion</li> <li>▪ Aphasia</li> <li>▪ Slurred speech</li> <li>▪ Focal weakness</li> </ul>	Cerebrovascular disease	<ul style="list-style-type: none"> <li>▪ Brain MRI with gadolinium</li> <li>▪ Virtual consult with Neurology</li> </ul>
<ul style="list-style-type: none"> <li>▪ Rapid onset and fluctuating course</li> <li>▪ Short duration</li> <li>▪ Disturbance of consciousness that often waxes and wanes between agitation and lethargy</li> <li>▪ Hallucinations</li> <li>▪ Visual impairment</li> </ul>	Delirium	<ul style="list-style-type: none"> <li>▪ Medication review, including supplements and herbals</li> <li>▪ Urine drug screen</li> <li>▪ Thyroid screen</li> <li>▪ RPR</li> <li>▪ HIV</li> <li>▪ B12</li> <li>▪ Look for infections (e.g., bladder, pneumonia)</li> <li>▪ Virtual consult with Neurology</li> </ul>

## Imaging that is not recommended

Pre-symptomatic diagnostic imaging—such as SPECT (single-photon emission computed tomography), CSF (cerebral spinal fluid), tau protein, and PET scan, including amyloid scan—is not recommended, especially because of the difficulties associated with false positives.

Patients may have heard—and ask—about these tests. However, although the tests are currently being used in clinical research, they should not be used for diagnostic purposes. Diagnosis of dementia comes from patient history.

## Alternative diagnoses to consider

Table 6. Diagnoses to exclude before developing treatment recommendations		
Signs/symptoms	Alternative diagnosis	Testing/investigation
<ul style="list-style-type: none"> <li>▪ Feeling down, depressed, or hopeless, or expressing little interest or pleasure in usual activities (anhedonia)</li> <li>▪ Complaints of memory loss</li> <li>▪ Decreased concentration</li> <li>▪ Feels worse in the morning and hopeless</li> </ul>	<p>Depression</p> <p>Depression may accompany early dementia</p> <p>Older adult patients may even have psychotic depression, with delusions or hallucinations (less common) that may raise the question of dementia</p>	Patient Health Questionnaire (PHQ-9)
<ul style="list-style-type: none"> <li>▪ Fatigue and weakness</li> <li>▪ Cold intolerance</li> <li>▪ Hoarseness</li> <li>▪ Constipation</li> <li>▪ Dry skin</li> <li>▪ Depression</li> <li>▪ Weight gain</li> </ul>	Hypothyroidism	Thyroid screen <sup>1</sup>
<ul style="list-style-type: none"> <li>▪ Paresthesia</li> <li>▪ Memory loss</li> <li>▪ Gait disturbance</li> </ul>	Vitamin B12 deficiency	B12 <sup>1</sup>
<sup>1</sup> Cases of dementia with reversible causes (e.g., hypothyroidism, vitamin B12 deficiency) are rare (less than 1%).		

## Conversations about a diagnosis of dementia

Conversation 1a. Delivering a diagnosis of dementia

Conversation 1b. Do I need to see a neurologist?

Conversation 1c. Do I need an MRI or PET scan?

<b>Conversation 1a. Delivering a diagnosis of dementia</b>	
<b>Key considerations</b>	<ul style="list-style-type: none"> <li>▪ Explain the biology of the disease and what to expect.</li> <li>▪ Maintain independence as much as possible.</li> <li>▪ Create a safe environment.</li> </ul>
<b>Talking points</b>	<ul style="list-style-type: none"> <li>▪ “Memory changes are due to abnormal accumulation of proteins in the brain, which interfere with the essential functions of thinking and processing. Basically, these proteins clog things up.”</li> <li>▪ “Most people who have dementia don’t end up in nursing homes—they can live at home with family, be reasonably content, and have nice lives.”</li> <li>▪ “Eventually, dementia will cause a worsening in your ability to handle regular tasks, such as shopping, finances, and medications. But we’ll talk regularly, and we’ll manage that.”</li> <li>▪ “Dementia is not hereditary in most cases.”</li> <li>▪ “Dementia is a progressive condition with no cure, but we have treatments for symptoms. And proper care and planning can greatly alleviate the burden of dementia.”</li> <li>▪ “It is important for you and your family to plan for the future, and it is especially important for you to make legal plans. The sooner legal planning starts, the more you may be able to participate. Legal planning includes advance directives.” (Within Group Health, advance directives are available in Epic.)</li> </ul>

<b>Conversation 1b. Do I need to see a neurologist?</b>	
<b>Key considerations</b>	<ul style="list-style-type: none"> <li>▪ In general, most patients do not need to see a neurologist, but Group Health neurologists are willing to see anyone who wants to be seen.</li> <li>▪ For a patient with unusual presentation, consult Neurology.</li> </ul>
<b>Talking point</b>	“Dementia can be managed well in primary care, where clinicians are most familiar with you and your family. The situation is similar to diabetes, for which most patients do not need to see an endocrinologist.”

<b>Conversation 1c. Do I need an MRI or PET scan?</b>	
<b>Key considerations</b>	<ul style="list-style-type: none"> <li>▪ For the majority of cases, a dementia diagnosis can be made from the patient’s history, so imaging is not necessary.</li> <li>▪ If a patient has memory loss plus warning signs (<a href="#">Table 5</a>), then imaging is indicated.</li> </ul>
<b>Talking point</b>	“Let’s go through the warning signs/symptoms that would require immediate evaluation to see if you have any. If not, we likely do not need to order imaging.”

## Treatment

### Goals

The type of support the patient and family/caregiver need will evolve with the progression of the disease. The family should be aware that inevitable disease-related deficits will develop in memory, behavior, mood, and function (e.g., incontinence, immobility, confusion).

As part of the care plan, it is important for the patient and family/caregiver to establish advance directives as soon as possible. (Within Group Health, advance directives are available in Epic.)

**Table 7. Goals of treatment for dementia**

Disease stage	Treatment goals
Mild cognitive impairment/ memory loss	<ul style="list-style-type: none"> <li>▪ Maintain function, safety, and independence.</li> <li>▪ Reduce or cease medication that may be contributing to decreased cognition (see <a href="#">Table 9</a>).</li> </ul>
Early-stage dementia	<ul style="list-style-type: none"> <li>▪ Maintain function and independence while preserving safety.</li> <li>▪ Reduce or cease medication that may be contributing to decreased cognition (see <a href="#">Table 9</a>).</li> </ul>
Midstage dementia	<ul style="list-style-type: none"> <li>▪ Preserve safety, function, and independence.</li> <li>▪ Develop skills that support continued living at home and delay institutionalization.</li> </ul>
Late-stage dementia	Preserve safety, comfort, and dignity.
End-stage dementia	Consider hospice referral.

Online resources for information on dementia and Alzheimer’s disease include:

- Alzheimer’s Association ([www.alz.org/](http://www.alz.org/)).
- Alzheimer’s Disease Education and Referral Center ([www.nia.nih.gov/alzheimers/](http://www.nia.nih.gov/alzheimers/)).
- NIH SeniorHealth ([nihseniorhealth.gov/](http://nihseniorhealth.gov/)).

These resources also provide information on caring for people with dementia or Alzheimer’s.

## Treatment for impaired cognitive function

### Lifestyle modifications and nonpharmacologic options

The following studied interventions have resulted in benefits to cognitive function:

- Exercise—Group Health currently offers both the EnhanceFitness and SilverSneakers fitness programs ([www.ghc.org/classesAndEvents/seniorFitness.jhtml](http://www.ghc.org/classesAndEvents/seniorFitness.jhtml)). Many other exercise programs targeting seniors are offered in the community.
- Activity and socialization—Introducing pleasant activities daily can improve mood and increase quality of life. Consider ways to increase socialization, including day treatment and occupational therapy programs.

### Pharmacologic options

In patients with dementia, there is no evidence that medications are effective at improving cognition; however, medications may be helpful in slowing the rate of decline in cognitive function in some patients.

If you are using medications, it is not unreasonable to start at diagnosis, provided you do the following:

- Develop functional and/or behavioral goals with the patient and family/caregiver to help assess whether the medications are providing benefit. Patient goals might include managing a checkbook, maintaining a prescribed medication schedule, increasing social interaction; family/caregiver goals might include improving quality of life and facilitating the ease of caregiving.
- Discontinue anticholinergic medication before starting acetylcholinesterase inhibitors. (See [Table 9](#) for list of medications to avoid in patients with dementia.)
- Create a plan to monitor medication safety and effectiveness (see the [Follow-up and Monitoring](#) section for more details). Medication should be continued only as long as a patient’s global, functional, and behavioral conditions remain at a level where the drug is considered to be having a worthwhile effect.

See also the [prescribing notes](#) that follow Table 8.

**Table 8. Medications for patients with dementia**

*Note:* Side effects may be difficult to detect in patients who cannot remember to report symptoms. For information on side effects, see the Group Health Drug Formulary, the Healthwise® Knowledgebase, or other resources.

Eligible population	Line	Medication	Initial dose	Maximum dose
Mild cognitive impairment	Medications are not recommended. Meticulous review of current medication list is recommended to determine any medications that may be clouding cognition or may be eligible for a trial “holiday” (see <a href="#">Table 9</a> ).			
Early- to midstage dementia	1 <sup>st</sup>	Donepezil	5 mg daily x 4 weeks, then increase to 10 mg daily if tolerated	10 mg daily <sup>1</sup>
	2 <sup>nd</sup>	Galantamine immediate release (NF)	4 mg twice daily x 4 weeks, then 8 mg twice daily x 4 weeks, then increase to 12 mg twice daily if tolerated	12 mg twice daily
		Galantamine extended release (NF)	8 mg daily x 4 weeks, 16 mg daily x 4 weeks, then increase to 24 mg daily if tolerated	24 mg daily
	2 <sup>nd</sup>	Rivastigmine immediate release (NF)	1.5 mg twice daily x 2 weeks, 3 mg twice daily x 2 weeks, 4.5 mg twice daily x 2 weeks, then increase to 6 mg twice daily if tolerated	6 mg twice daily
		Rivastigmine transdermal patch (NF)	4.6 mg daily x 4 weeks, then increase to 9.5 mg daily if tolerated	9.5 mg daily
Midstage dementia no longer or too slowly responding to an acetylcholinesterase inhibitor	<b>Add</b>	Memantine (PA)	5 mg daily x 1 week, then 5 mg twice daily x 1 week, then 5 mg in the morning and 10 mg in the evening x 1 week, then 10 mg twice daily if tolerated	10 mg twice daily
Late-stage dementia	Medications may pose more harm than benefit for patients with this level of dementia. Consider discontinuing medication when patients are largely chairbound or bedbound or when the benefit from medication is no longer easing caregiver burden.			
<sup>1</sup> Donepezil 23-mg sustained-release tablet is not recommended, as it provides only a small benefit in cognitive function but does not increase patient functioning and causes an increase in side effects. Within Group Health, see Donepezil 23 mg Clinician FAQ ( <a href="http://incontext.ghc.org/rx/med/documents/donepezil_faq.pdf">incontext.ghc.org/rx/med/documents/donepezil_faq.pdf</a> ).				

### Prescribing notes for Table 8 (Medications for patients with dementia)

#### Combination of memantine and acetylcholinesterase inhibitor (e.g., donepezil)

During midstage dementia, memantine may be added to ongoing acetylcholinesterase inhibitor therapy with the intention of using the combined therapy to ease caregiver burden and to improve engagement of the patient with daily activities and social interactions. If needed, consult with Neurology or Behavioral Health/Mind Phone when considering the combination. As with initiation of acetylcholinesterase inhibitor therapy, any new start should be accompanied by a planned 6- to 8-week follow-up visit to determine if the desired effect (improvement or slowing of rate of decline) has occurred.

### Galantamine dosing for renal impairment

- Moderate impairment (creatinine clearance 30–60 mL/min): Maximum dose is 16 mg daily.
- Severe impairment (creatinine clearance 5–29 mL/min): Use is not recommended.

### Galantamine dosing for hepatic impairment

- Moderate impairment (Child-Pugh score of 7–9): Maximum dose is 16 mg daily.
- Severe impairment (Child-Pugh score of 10–15): Use is not recommended.

### Rivastigmine transdermal patch dosing for renal impairment

Moderate to severe impairment (GFR less than 50 mL/min): Maximum dose is 4.6 mg.

### Rivastigmine transdermal patch dosing for hepatic impairment

Mild to moderate impairment (Child-Pugh score 5–9): Maximum dose is 4.6 mg.

### Memantine dosing for renal impairment

- No adjustment needed for mild to moderate impairment.
- Severe impairment (creatinine clearance 5–29 mL/minute): Maximum dose 5 mg twice daily.

## Conversation about medications to treat impaired cognitive function

Conversation 2. Shared decision making for treating impaired cognitive function	
<b>Key considerations</b>	<ul style="list-style-type: none"><li>▪ Set realistic expectations for what benefits medication may provide: better recognition of faces and names, less caregiver burden (patient is more agreeable with caregiving).</li><li>▪ Set clear criteria for when to stop medication.</li></ul>
<b>Talking points</b>	<ul style="list-style-type: none"><li>▪ “These medications do not restore independence.”</li><li>▪ “Over time, the disease will progress, even on these medications.”</li><li>▪ “Not everyone responds to these medications; however, some people respond quite well for a time.”</li><li>▪ “If the patient is bedbound and interacting minimally, the risks of medication may outweigh the benefit.”</li></ul>

## Medications to avoid

Table 9. Medications to avoid in all patients with dementia	
Medication	Rationale
<b>Tricyclic antidepressants (TCAs)</b> Amitriptyline, amoxapine, clomipramine, desipramine, doxepin, imipramine, nortriptyline, protriptyline, trimipramine	Strong anticholinergic and sedative effects leading to orthostatic hypotension, confusion, and falls.
<b>Antispasmodics</b> Atropine, belladonna alkaloids, dicyclomine, hyoscyamine, scopolamine, propantheline	Strong anticholinergic and sedative effects. Associated with orthostatic hypotension, confusion, and increased fall risk. Uncertain effectiveness.
<b>Antimuscarinics</b> Darifenacin, fesoterodine, flavoxate, oxybutynin, solifenacin, tolterodine, trospium	Strong anticholinergic effects. Poorly tolerated by older adults.
<b>Skeletal muscle relaxants</b> Carisoprodol, cyclobenzaprine, meprobamate, metaxalone, methocarbamol, orphenadrine, tizanidine	Poorly tolerated by older adults because of strong anticholinergic effects, sedation, and risk of fracture. Effectiveness at tolerable dosages is questionable. Within Group Health, see also High-Risk Medications in the Elderly: Skeletal Muscle Relaxants [PDF].
<b>Antihistamines</b> Brompheniramine, chlorpheniramine, clemastine, cyproheptadine, diphenhydramine, hydroxyzine, loratadine	Greater risk of confusion, dry mouth, constipation, and other anticholinergic effects and toxicity. Clearance reduced with advanced age, and tolerance develops when used as a hypnotic.
<b>Antiemetics</b> Dimenhydrinate, meclizine, promethazine	Strong anticholinergic effects. Poorly tolerated in older adults.
<b>H2-receptor antagonists</b> Ranitidine, cimetidine, famotidine	Adverse effects on central nervous system (CNS).
<b>Antiparkinsonian anticholinergics</b> Benztropine, trihexyphenidyl	Strong anticholinergic effects. Not recommended for prevention of extrapyramidal symptoms with antipsychotics.
<b>All conventional antipsychotics &amp; clozapine</b> Haloperidol, chlorpromazine, fluphenazine, loxapine, perphenazine, pimozide, thioridazine, thiothixene, trifluoperazine	Increased risk of cerebrovascular accident and mortality.
<b>Antiarrhythmics</b> Disopyramide	Potent negative inotrope; may induce heart failure in older adults. Strong anticholinergic effects.
<b>Narcotic analgesics</b> Meperidine, pentazocine	Increased CNS effects leading to increased confusion and toxicity risk. Safer alternatives available.
<b>Anxiolytics</b> All benzodiazepines	Older adults have increased sensitivity to benzodiazepines and slower metabolism of long-acting agents. In general, all benzodiazepines increase risk of cognitive impairment, delirium, falls, and fractures. Within Group Health, see also Beers Criteria for Potentially Inappropriate Medications in Older Adults Update Part 3: Focus on Treatments for Insomnia.
<b>Sleep agents</b> Zolpidem	Benzodiazepine-receptor agonists have adverse events similar to those of benzodiazepines in older adults. Minimal improvement in sleep latency and duration. Within Group Health, see also Beers Criteria.

## Treatment for behavioral and psychological symptoms of dementia

### Overview

The International Psychogeriatric Association defined behavioral and psychological symptoms of dementia (BPSD) as “disturbed perception, thought content, mood or behavior that frequently occur in patients with dementia” (IPA 1999 Update Consensus Conference).

Behavioral symptoms are usually identified on the basis of observation of the patient, and include physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing, and shadowing.

Psychological symptoms are usually and mainly assessed on the basis of interviews with patients and family; these symptoms include anxiety, depressive mood, hallucinations, and delusions. A psychosis of Alzheimer’s disease has been accepted since the 1999 IPA conference.

Family members should be made aware that behavioral symptoms can occur during phases of dementia and are not permanent.

When considering treatment, also assess the impact of BPSD on the caregiver and the housing situation. If the patient’s housing is in jeopardy because of BPSD, it is important to shift to a dual focus: patient-centered **and** caregiver-centered interventions:

- Psychoeducation and mutual goals to maintain housing.

**or**

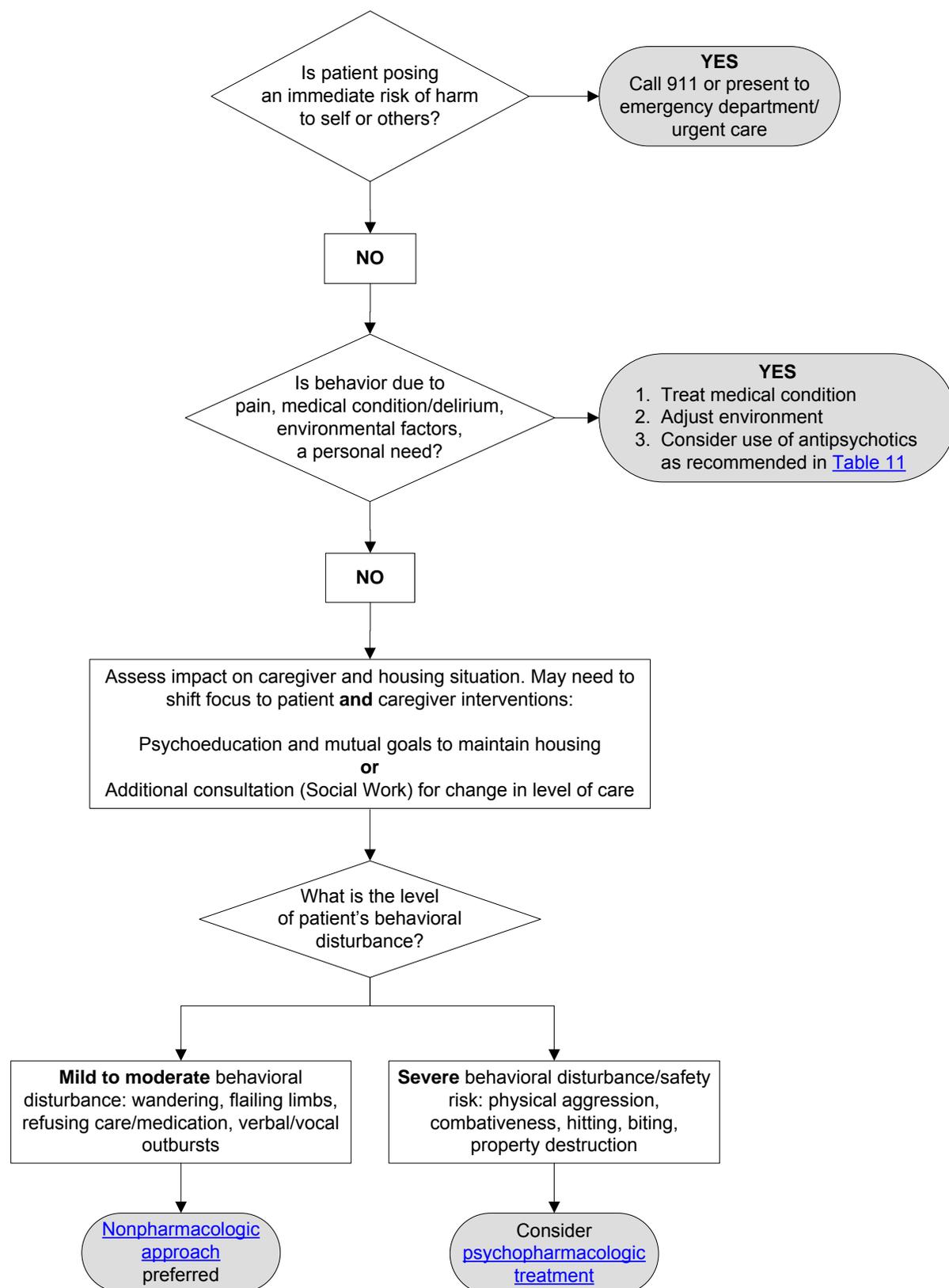
- Consultation with Social Work to help with changing housing needs.

In determining a patient’s behavioral issues, PCPs may find it helpful to use a caregiver survey such as the Revised Memory and Behavioral Problems Checklist ([psycnet.apa.org/journals/pag/7/4/622.pdf](http://psycnet.apa.org/journals/pag/7/4/622.pdf)) (Teri 1992). It addresses the frequency of different types of behaviors and how troubling the behaviors are to the caregiver.

The flowchart in Figure 1 describes treatment options for BPSD.

Figure 1.

Figure 1. Treating Behavioral and Psychological Symptoms of Dementia



## Nonpharmacologic options

Table 10. Options for treating mild to moderate behavioral disturbances	
Behavior	Approach
Verbal/physical outbursts, flailing limbs	<ul style="list-style-type: none"> <li>▪ Evaluate what might be contributing to the patient’s behavior (e.g., pain, fatigue, medication side effects, environmental factors), and treat and/or change.</li> <li>▪ Sensory/relaxation activities: aromatherapy (such as lavender or lemon oil), music therapy, pet therapy, exercise training, massage or touch therapy (National Collaborating Centre for Mental Health, 2006).</li> </ul>
Wandering (leaving the house)	<ul style="list-style-type: none"> <li>▪ Keyed deadbolt for entry to <b>and</b> exit from the house.</li> <li>▪ Lock box for keys.</li> <li>▪ ID bracelet and/or picture ID.</li> <li>▪ MedicAlert® + Alzheimer’s Association Safe Return® program, a nationwide emergency response service (<a href="http://www.alz.org/care/dementia-medical-alert-safe-return.asp">www.alz.org/care/dementia-medical-alert-safe-return.asp</a>).</li> </ul>
Refusing care/medication	<ul style="list-style-type: none"> <li>▪ Explore “keys” to unlock cooperation (e.g., activities the patient enjoys, or finds calming or distracting).</li> <li>▪ Discuss with family hiding medication in food.</li> </ul>

## Pharmacologic options

There are no FDA-approved medications for the treatment of BPSD. Treatment effects for all medications are modest and must be balanced with safety concerns.

Conventional and atypical antipsychotics both have FDA black box warnings for use in patients with dementia, mainly due to increased risk of death from heart attack and stroke. Antipsychotic medications also are associated with worsening symptoms in patients with dementia with Lewy bodies.

The medications in Table 11 should be considered only if the patient presents with severe behavioral or psychological problems that are not responding to behavioral interventions. The medications in Table 11 can be used on a scheduled basis or on an as-needed basis. Target symptoms should be identified, quantified, and documented in the patient chart.

We recommend time-limited treatment with antipsychotics and regular review of the indication (every 3 months or according to clinical need). Tapering these medications very gradually after a period of behavior stabilization is advised.

Consult the Mind Phone (Behavioral Health) for a more individualized treatment plan.

### **Avoid using haloperidol in treatment of BPSD**

Avoid prescribing haloperidol (Haldol) to treat behavioral and psychological symptoms of dementia because evidence suggests that mortality is higher with haloperidol in the dementia population than with the antipsychotics listed in Table 11.

See also [Table 9](#) for a list of additional medications to avoid in patients with dementia.

**Table 11. Medications for treating severe behavioral disturbances/safety risks**

Note that requests for medication commonly are a result of housing issues or a caregiver's own stressful experiences with the patient's behavior. Be sure to ask if housing is at risk or if the caregiver is under duress—medication (or changes to medication) may not be the best solution in these cases.

Drug class & target symptoms	Line	Medication	Initial dose	Maximum dose
<b>Antidepressants</b> For agitation, depression, anxiety	1st	Escitalopram <sup>1</sup>	2.5 mg daily x 7 days, then 5 mg daily x 7 days	10 mg daily
		Sertraline	25 mg daily x 7 days, then 50 mg daily x 7 days	100 mg daily
	2nd	Fluoxetine	5 mg daily x 7 days, then 10 mg daily x 7 days	30 mg daily
	3rd	Citalopram <sup>1</sup>	5 mg daily x 7 days, then 10 mg daily x 7 days	20 mg daily
<b>Antidepressants</b> For insomnia	1st	Trazodone	25–50 mg daily (titrate in 25-mg increments as clinically indicated)	200 mg daily
	2nd	Mirtazapine	7.5 mg daily (titrate in 7.5-mg increments as clinically indicated)	30 mg daily
<b>Antipsychotics</b> <sup>2</sup> For delusions, hallucinations, aggression, agitation	1st	Quetiapine	12.5–25 mg twice daily (titrate in 25-mg increments as clinically indicated)	200 mg daily
	2nd	Risperidone	0.25–0.5 mg daily to twice daily (titrate in 0.5-mg increments as clinically indicated)	2 mg daily
	3rd	Olanzapine	2.5–5 mg daily (titrate in 5-mg increments as clinically indicated)	10 mg daily
	4th	Aripiprazole (PA)	5 mg daily (titrate in 5-mg increments as clinically indicated)	15 mg daily
<b>Antiepileptics</b> For aggression, disinhibition	1st	Divalproex delayed release	125 mg daily x 7 days, then 125 mg twice daily x 7 days, then 125 mg every morning & 250 mg every evening x 7 days, then 250 mg twice daily	1,000 mg daily
	2nd	Carbamazepine	100 mg daily x 7 days, then 100 mg twice daily x 7 days, then 100 mg every morning & 200 mg every evening x 7 days, then 200 mg twice daily	600 mg daily

<sup>1</sup> Evidence suggests that both escitalopram and citalopram are associated with QT interval prolongation starting at the recommended initial dose, with the strongest evidence existing for citalopram at doses exceeding 40 mg per day. Shared decision making is recommended to review the risks and benefits of these medications with the patient. Use caution in patients with congenital long QT syndrome, bradycardia, hypokalemia or hypomagnesemia, recent acute myocardial infarction, uncompensated heart failure, or in those taking interacting medications (QT-prolonging or CYP2C19 inhibitors).

<sup>2</sup> The rank order is based on data regarding efficacy. Two retrospective cohort studies suggest that mortality risk may be lower with quetiapine compared with risperidone. Assess cerebrovascular and cardiovascular risk factors, discuss possible risk of mortality, and document discussion.

## Conversation about medications to treat severe behavioral disturbances

### Conversation 3. Will medications help control behavioral symptoms of dementia?

<b>Key considerations</b>	<ul style="list-style-type: none"> <li>▪ Use nonmedication approaches as the foundation—primarily caregiver training and support (see the <a href="#">Caregiver Support</a> section)—then add medications.</li> <li>▪ There is increasing research evidence of the effectiveness of nonpharmacologic interventions (i.e., caregiver support). These may be equally effective and definitely safer than medications (Brodaty 2012).</li> <li>▪ Conventional and atypical antipsychotics both have FDA black box warnings for use in patients with dementia, because of increased risk of death from heart attack and stroke.</li> </ul>
<b>Talking points</b>	<ul style="list-style-type: none"> <li>▪ “These medications have modest benefits in controlling behavior problems, but they have severe side effects.”</li> <li>▪ “If the behavioral symptoms are impacting your loved one’s current housing situation, these medications may not help. A social worker may be able to help you with your housing issues.”</li> <li>▪ “Medications are a short-term intervention that must be regularly re-evaluated.”</li> </ul>

## Follow-up and Monitoring

### Medication monitoring

Note that side effects may be difficult to detect in patients who cannot remember to report symptoms. For information on side effects, see the Group Health Drug Formulary, the Healthwise® Knowledgebase, or other resources.

**Table 12. Medication monitoring for patients with dementia**

Assessment	Frequency
Ask patient and caregiver/family about medication effectiveness and side effects.	6–8 weeks after initiating medications, and every 6 months thereafter.
Assess whether treatment goals have been met.	

## Progression monitoring

**Table 13. Progression monitoring for patients with dementia and for caregivers/families**

Assessment	Frequency
Evaluate mood: <ul style="list-style-type: none"> <li>▪ How is the patient feeling?</li> <li>▪ How is the caregiver feeling?</li> </ul>	Every 6 months, to assess progression with patient and caregiver. These visits can be by phone or by e-mail.
Assess the current living situation: <ul style="list-style-type: none"> <li>▪ Is the living situation working?</li> <li>▪ Is the patient going to adult day care?</li> <li>▪ Should the patient or caregiver/family be referred to Social Work?</li> </ul>	
Address behavioral problems and safety concerns: <ul style="list-style-type: none"> <li>▪ Verbal/physical outbursts.</li> <li>▪ Wandering.</li> <li>▪ Refusing care/medication.</li> <li>▪ Driving.</li> </ul>	Patients should be seen in person at least annually.
Assess how patient is handling any sleep dysfunction: <ul style="list-style-type: none"> <li>▪ What is the patient's sleep/wake cycle or pattern?</li> </ul>	
Assess caregiver's ability to manage care: <ul style="list-style-type: none"> <li>▪ Is there continued understanding of what caregiver needs to know and/or have to care for patient?</li> <li>▪ Are there any new or different services or resources available to help caregiver?</li> </ul>	
Remind about advance directives: <ul style="list-style-type: none"> <li>▪ Have advance directives been established?</li> <li>▪ Are advance directives still how patient/family want them to be?</li> </ul> (Within Group Health, advance directives are available in Epic.)	

## Referrals to Specialists

Referral to a specialist for diagnostic consultation and a treatment plan to be followed in primary care may be considered if any of the following criteria apply:

### Social Work

- Documented diagnosis of dementia with concerns about safety, behavioral problems, or housing.
- Caregiver burden/stress.

### Behavioral Health and/or Mind Phone

- Early diagnosis with reactive depression.
- Suspected pseudo-dementia.
- Need for psychosis management.
- Diagnosis is complex or remains unclear after basic workup.

### Neurology

- Cognitive loss is early onset (before age 70).
- Diagnosis is complex or remains unclear after basic workup.
- Treatment is complex (e.g., due to comorbidities).

Referral to a neurologist is generally not required in most cases of dementia.

## Speech, Language & Learning Services

Consider referral to SLLS early on for a baseline cognitive communication evaluation when diagnosis remains unclear after basic workup. Evaluation may be repeated in 6–12 months to confirm whether the condition is static or progressive.

## Genetics

- Symptoms of dementia occurring before age 60, and with two or more relatives with onset of dementia before age 60.
- First- or second-degree relative with a known mutation in PSEN1/2 or APP.

Genetic testing might be helpful when results would affect treatment decisions for the patient or reproductive decisions by younger family members.

A referral to Genetics is **not** likely to be helpful for first-degree relatives of individuals whose dementia onset occurred after age 60, as there are no specific genetics tests to be done. Concerned family members might find the Family and Genetics page ([www.alz.org/alzheimers\\_disease\\_causes\\_risk\\_factors.asp#familyhistory](http://www.alz.org/alzheimers_disease_causes_risk_factors.asp#familyhistory)) on the Alzheimer's Association website to be reassuring.

## Hospice

Consider hospice referral in late-stage dementia for patients who meet clinical review criteria for the Hospice Program ([www.ghc.org/all-sites/clinical/criteria/pdf/hospice.pdf](http://www.ghc.org/all-sites/clinical/criteria/pdf/hospice.pdf)).

## Caregiver Support

Being a caregiver for a patient with dementia is extremely difficult. Remind caregivers that their own health is important. Give caregivers reassurance that they are doing a good job and that they are doing everything they can do.

## Caregiver education

Group Health education materials describing resources for caregivers include:

- Dementia: Information for caregivers during the early stages ([provider.ghc.org/open/caringForOurMembers/patientHealthEducation/conditionsDiseases/dementiaEarlyStages.pdf](http://provider.ghc.org/open/caringForOurMembers/patientHealthEducation/conditionsDiseases/dementiaEarlyStages.pdf))
- Dementia: Information for caregivers during the later stages ([provider.ghc.org/open/caringForOurMembers/patientHealthEducation/conditionsDiseases/dementiaLaterStages.pdf](http://provider.ghc.org/open/caringForOurMembers/patientHealthEducation/conditionsDiseases/dementiaLaterStages.pdf))

The following online resources also provide caregiver information, tips, and resources:

- The Alzheimer's and Dementia Caregiver Center ([www.alz.org/care/overview.asp](http://www.alz.org/care/overview.asp)) on the Alzheimer's Association website.
- The Caregiving page ([www.nia.nih.gov/alzheimers/topics/caregiving](http://www.nia.nih.gov/alzheimers/topics/caregiving)) on the Alzheimer's Disease Education and Referral Center's website.
- The Caring for Someone with Alzheimer's section ([nihseniorhealth.gov/alzheimerscare/dailyactivities/01.html](http://nihseniorhealth.gov/alzheimerscare/dailyactivities/01.html)) on the NIH Senior Health website (also includes videos).

## Monitoring for caregiver stress

Assess caregivers for continued ability to care for the patient and to ensure that their own health is not being compromised.

Refer caregivers to Social Work or Behavioral Health, or to a community resource:

- If they are experiencing fatigue, depression, anxiety, anger, or other stress-related signs.
- For counseling, education, or training, and help with planning for future changes in patient needs.

The following websites provide assistance in finding community resources:

- Community Resource Finder ([www.communityresourcefinder.org/](http://www.communityresourcefinder.org/)), a service of the Alzheimer's Association.
- Eldercare Locator ([www.eldercare.gov/](http://www.eldercare.gov/)), a service of the U.S. Administration on Aging.

## Tips for caregivers on dealing with behaviors

### Dealing with verbal and physical outbursts

- Remain calm. Be reassuring and positive. Speak slowly and in a soft tone.
- Consider what might be contributing to the patient's behavior. Is he/she tired, overstimulated by noise or an overactive environment, or picking up on your own stress or irritability?
- Rule out pain as the cause.
- Think about what happened right before the behavior that may have triggered it.
- Try a relaxing activity, or shift to a different activity—the immediate situation may have unintentionally caused the response.
- Decrease level of danger. Avoid harm to yourself by standing away from the patient.
- See the Aggression and Anger page on the Alzheimer's Association website ([www.alz.org/care/alzheimers-dementia-aggression-anger.asp](http://www.alz.org/care/alzheimers-dementia-aggression-anger.asp)).

### Dealing with wake/sleep disturbances

- Make a safe and comfortable sleep environment (i.e., temperature, nightlights, appropriate door/window locks).
- Maintain a schedule. A regular routine of waking up, meals, and going to bed allows for more restful sleep.
- Identify and limit triggers—such as TV, loud music—especially during evening hours.
- See the Sleep Issues and Sundowning page on the Alzheimer's Association website ([www.alz.org/care/alzheimers-dementia-sleep-issues-sundowning.asp](http://www.alz.org/care/alzheimers-dementia-sleep-issues-sundowning.asp)).

### Dealing with unsafe driving

- Acknowledge patient's distress and threat to independence.
- Ensure safety of patient and others.
- Consider a professional driving assessment, if there is family conflict over the issue.
- Create an action plan to prevent unsafe driving, because this will worsen over time.
- See the Dementia & Driving Resource Center on the Alzheimer's Association website ([www.alz.org/care/alzheimers-dementia-and-driving.asp](http://www.alz.org/care/alzheimers-dementia-and-driving.asp)).

## Evidence Summary

To develop the Dementia Guideline, Group Health has:

- Adapted some recommendations from externally developed evidence based guidelines, and
- Reviewed evidence using an evidence-based process, including systematic literature search, critical appraisal, and evidence synthesis

### Adapted recommendations

- National Institute for Health and Clinical Excellence and Social Care Institute for Excellence  
Dementia: The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. National Institute for Health and Clinical Excellence website.  
<http://www.nice.org.uk/nicemedia/live/10998/30320/30320.pdf>. Published 2007. Amended 2011. Accessed November 2011.

## Group Health evidence summary

### Montreal Cognitive Assessment (MoCA)

Four observational studies were identified that compared the performance of the MoCA for diagnosing patients with Alzheimer's disease (AD) or mild cognitive impairment (MCI) with the Mini-Mental State Exam (MMSE).

Three of the studies used a clinical diagnosis and one used neuropsychological testing as the gold standard for diagnosing Alzheimer's and MCI. Results from these studies suggest that the MoCA has a higher sensitivity and lower specificity than the MMSE for detecting MCI and Alzheimer's.

The following table shows the range of sensitivity and specificity of the MoCA and the MMSE identified in the included studies (Damian 2011, Luis 2009, Nasreddine 2005, Smith 2007).

	MoCA cutoff of 26	MMSE cutoff of 26	MMSE cutoff of 25
<b>Sensitivity for MCI</b>	83% to 100%	17% to 18%	17%
<b>Sensitivity for AD</b>	94% to 100%	25% to 78%	36%
<b>Sensitivity for MCI/AD</b>	97% to 98%	--	30%
<b>Specificity</b>	35% to 87%	100%	96% to 97%

### General Practitioner Assessment of Cognition (GPCOG)

An observational study that included 283 patients evaluated the sensitivity and specificity of the GPCOG compared with DSM-IV for diagnosing dementia. Results from this study suggest that the GPCOG has a sensitivity of 85% and a specificity of 86% (Brodaty 2002).

## Acetylcholinesterase inhibitors

### Mild cognitive impairment (MCI)

The published evidence does not support the use of acetylcholinesterase inhibitors for treating patients with mild cognitive impairment.

Results from several randomized controlled trials (RCTs) suggest that in patients with MCI, acetylcholinesterase inhibitors do not significantly improve cognitive function or reduce the rate of progression from MCI to dementia. Results from three meta-analyses pooling data from these trials showed a minimal yet statistically significant reduction in the rate of progression to dementia with the use of acetylcholinesterase inhibitors for 2 years; however, this reduction was not clinically significant. There was a high rate of adverse events, which included nausea, vomiting, diarrhea, dizziness, weight loss, syncope, fatigue, asthenia, muscle spasms, insomnia, abnormal dreams, headaches, peripheral edema, tremors, and others (Diniz 2009, Sobów 2007, Winblad 2008).

### **Concomitant use of acetylcholinesterase inhibitors and anticholinergic medication**

A recent retrospective cohort study examined the extent of concomitant use of acetylcholinesterase inhibitors and anticholinergic medication, and the clinical consequences of dual use in a population-based setting. Although the concomitant use of acetylcholinesterase inhibitors and anticholinergic medication did not affect the rate of nursing-home placement or death, results from this study suggest that in clinical practice, approximately 37% of patients receiving acetylcholinesterase inhibitors are also prescribed an anticholinergic medication. The median duration of concomitant use was 3.7 months (Boudreau 2011).

## References

- Alzheimer's Association. 2012 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2012;8(2):131-168.
- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV*. 4<sup>th</sup> ed. Washington, DC: 1994.
- Boudreau DM, Yu O, Gray SL, Raebel MA, Johnson J, Larson EB. Concomitant use of cholinesterase inhibitors and anticholinergics: prevalence and outcomes. *J Am Geriatr Soc*. 2011;59(11):2069-2076.
- Brodaty H, Arasaratnam C. Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. *Am J Psychiatry*. 2012;169(9):946-953. doi: 10.1176/appi.ajp.2012.11101529.
- Brodaty H, Pond D, Kemp NM, et al. The GPCOG: a new screening test for dementia designed for general practice. *J Am Geriatr Soc*. 2002;50(3):530-534.
- Burns A, Iliffe S. Dementia. *BMJ*. 2009;338:b75.
- Damian AM, Jacobson SA, Hentz JG, et al. The Montreal Cognitive Assessment and the mini-mental state examination as screening instruments for cognitive impairment: item analyses and threshold scores. *Dement Geriatr Cogn Disord*. 2011;31(2):126-131.
- Diniz BS, Pinto JA Jr, Gonzaga ML, Guimarães FM, Gattaz WF, Forlenza OV. To treat or not to treat? A meta-analysis of the use of cholinesterase inhibitors in mild cognitive impairment for delaying progression to Alzheimer's disease. *Eur Arch Psychiatry Clin Neurosci*. 2009;259(4):248-256.
- Luis CA, Keegan AP, Mullan M. Cross validation of the Montreal Cognitive Assessment in community dwelling older adults residing in the Southeastern US. *Int J Geriatr Psychiatry*. 2009;24(2):197-201.
- Nasreddine ZS, Phillips NA, Bédirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*. 2005;53(4):695-699.
- National Institute for Health and Clinical Excellence, Social Care Institute for Excellence. Dementia: The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. National Institute for Health and Clinical Excellence website. <http://www.nice.org.uk/nicemedia/live/10998/30320/30320.pdf>. Published 2007. Amended 2011. Accessed November 2011.
- Smith T, Gildeh N, Holmes C. The Montreal Cognitive Assessment: validity and utility in a memory clinic setting. *Can J Psychiatry*. 2007;52(5):329-332.
- Sobów T, Kłoszewska I. Cholinesterase inhibitors in mild cognitive impairment: a meta-analysis of randomized controlled trials. *Neurol Neurochir Pol*. 2007;41(1):13-21.
- Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, Vitaliano PP. Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. *Psychol Aging*. 1992;7(4):622-631.
- U.S. Preventive Services Task Force (USPSTF). Screening for dementia: recommendations and rationale. USPSTF website. <http://www.uspreventiveservicestaskforce.org/3rduspstf/dementia/dementtrr.htm>. Published 2003.
- Winblad B, Gauthier S, Scinto L, et al. Safety and efficacy of galantamine in subjects with mild cognitive impairment. *Neurology*. 2008;70(22):2024-2035.

## Guideline Development Process and Team

### Development Process

To develop the Dementia Guideline, Group Health adapted recommendations from externally developed evidence-based guidelines and reviewed additional evidence using an evidence-based process, including systematic literature search, critical appraisal, and evidence synthesis. For details, see Evidence Summary and References.

This edition of the guideline was approved for publication by the Guideline Oversight Group in December 2012.

### Team

The Dementia Guideline development team included representatives from the following specialties: behavioral health, family medicine, neurology, nursing home and hospice services, and pharmacy.

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