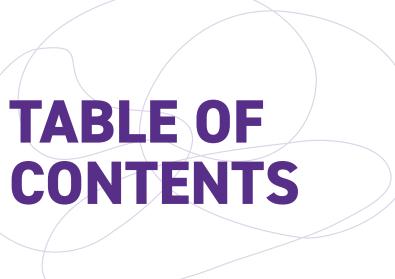




Early Detection of Dementia Toolkit - Health Systems





WHY EARLY DETECTION MATTERS



Nearly 7 million Americans have some form of dementia.¹ Over 95% of people living with dementia are 65 or older, and prevalence increases dramatically with age.² Because age is such a powerful risk factor, as the proportion of older adults in the United States increases over the next few decades, many more people will develop dementia and require care. Their unmet needs³,⁴ are already showing us how we need to change the way we care for people.

Early detection is a necessary step in reducing potentially preventable crises through proactive care. The most familiar type of crisis in dementia is caused by changes in emotions, behavior, and relationships that may occur as part of the disease process, strain family caregivers, and lead to disruptions in care. Less well known are preventable health crises – those related to new or worsening medical conditions that commonly co-occur with dementia. Others are crises resulting from or exacerbated by remediable social and economic disadvantage, which tends to be differentially distributed across communities and magnifies influence on historically and persistently marginalized groups. Early detection and proactive care are the first steps toward helping individuals, their families, and their communities learn how to live well with dementia as a manageable chronic condition.

WHO WE ARE - BOLD CENTER

The BOLD Public Health Center of Excellence on Early Detection of Dementia (PHCOE EDD) is led by a team from the Division of Geriatric Medicine and Palliative Care and the Department of Population Health at NYU Langone in collaboration with the Keck School of Medicine at USC.

Our mission is to make early detection of dementia routine practice nationwide, simplifying the process of detecting cognitive impairment and helping develop comprehensive care pathways to mitigate its impacts on individuals, families, communities, and health care delivery. Detecting impairment before a crisis occurs and then acting on effective principles of care promotes better health and wellbeing for older adults and their care partners.

Our Center aims to broaden understanding of dementia as a chronic condition that can be managed when patients are supported by a network of public health, clinic, and community-based initiatives. We strive to empower organizations and champions within them to develop programs that increase brain health awareness, improve early detection capacity, and open the door to more comprehensive dementia care that preserves better quality of life for longer. This toolkit provides practical approaches and resources to help clinicians become comfortable having conversations about brain health and using screening tools to assess cognitive function.

To partner with us on an initiative, get in touch via email: nyuboldcenter@nyulangone.org.

WHO IS THIS TOOLKIT FOR?



We hope this toolkit brings something of value to anyone who wants to learn about recognizing dementia in health care settings – outpatient clinics, hospitals, emergency departments, and other services. You may be someone who wants to know what dementia detection and diagnosis are about. You may be a community service worker advising clients at risk for dementia, a public health worker seeking a closer connection with a medical care provider, or a front-line clinician who wants to know why detection matters or improve your ability to work with people experiencing cognitive impairment. You might also be a person with current concerns or future worries about your own memory. This toolkit is designed to assist you in thinking about the value of early detection of dementia and how to develop an initial plan.

WHAT IS DEMENTIA?



"Dementia" refers to a group of adult-onset medical disorders caused by impairment of brain function for which the defining symptoms are cognitive – problems with memory, thinking, planning, judgment, language, and awareness of one's own functioning. Sometimes the first noticeable signs are changes in social or behavioral functioning.

Dementia results from damage to the brain, most often by disease processes like Alzheimer's disease and related disorders, exposure to certain toxins, or – as recently highlighted by studies of athletes playing contact sports and survivors of war – by major or repeated brain injury.² Clinically significant cognitive decline can remain invisible to all but the person's closest family and friends even as it undermines everyday functioning. It is one of the major causes of disability in later life, yet is often unnoticed in health care and community settings until it has been progressing for several years.

People living with dementia are usually aware of some changes in their memory or other mental abilities. They may underestimate the extent of the change and its effect on their everyday lives. Even if they do recognize a problem, they may forget (or not want) to mention it to their primary care clinician or otherwise. Signs

of dementia may not be obvious in routine medical appointments scheduled for unrelated reasons.

"Subjective Cognitive Decline" (SCD) is different from dementia. It refers to a person's own experience and awareness of changes in memory or thinking. SCD can be caused by many different conditions and is much more common than dementia. However, when a person senses a change in mental function – they are more forgetful or distractible, have trouble paying attention or planning complex activities, or have other symptoms related to memory or thinking – it's important that they tell a professional about this and follow through with recommended evaluations.

SCD does not indicate the presence of a specific disorder or cause. But it's important: SCD can be an early warning sign of future decline in cognitive function in some people⁷, and it shouldn't be ignored or discounted.

This toolkit supports a comprehensive approach to early detection of dementia in a clinical setting and includes resources to make your efforts effective.

Resources

Please click on each link to visit these resources

<u>Subjective Cognitive Decline – A Public Health Issue</u>

<u>ADRD Full Report 2023 and Infographic – Alzheimer's Association</u>

(Spanish Version)

EARLY DETECTION OVERVIEW



Early detection of dementia means identifying affected people before a crisis occurs, even if they are not aware of a problem or don't share their concerns with anyone. Because many people living with dementia do not spontaneously report symptoms⁸ – such as changes in their memory, thinking, or ability to carry out everyday activities – successful early detection strategies use several different and complementary approaches.

Clinicians can start by asking the patient about memory and other symptoms and then measure cognitive performance using one of many screening tools available. They may also discuss functioning with someone who knows the patient well and use "proxy" or "informant" screens to look for changes in everyday functioning. Changes in everyday functioning that result from cognitive impairment are necessary for diagnosing any form of dementia.

Both patient-focused (direct testing) and proxy-completed screening have value and reinforce each other; a best practice for early detection is to use them in combination. Other, more detailed tests of cognition, function, and physical health status may be recommended to look for possible causes once a cognitive problem is found.

Resources

Please click on each link to visit these resources

Advancing Early Detection - CDC

- Advancing Early Detection: A Healthy Brain Initiative Issue Map
- HBI Road Map

Earlier Diagnosis - Alzheimer's Association

- Biomarkers for Earlier Detection
- Brain Imaging/Neuroimaging
- Cerebrospinal Fluid (CSF) Proteins
- Blood and Urine Tests
- Genetic Risk Profiling
- Mild Cognitive Impairment (MCI) | (Spanish Version)

The Importance of Early Detection

Dementia affects many aspects of a person's life and the lives of loved ones. By the time dementia can be diagnosed, affected people already need the help of someone else to manage at least some activities that are essential for successful, safe, independent everyday living. Many of these essential activities, such as maintaining a household, scheduling self-care activities and appointments, and sustaining important personal relationships, require cognitive abilities that are impaired in dementia.

Professionals increasingly believe that it's important to detect cognitive impairment at milder stages before a person must rely on others to be their "prosthetic memory." Early detection helps people start preparing for potential changes while they are still able to think ahead and express their values and goals.¹⁰

Signs and Symptoms of Dementia

Dementia can come to the attention of the person affected, a family member, or a clinician in several ways. A person may notice changes in their memory, or a loved one may be surprised by behavior that isn't usual for the person: unexpected financial errors, an unexplained fender-bender, an episode of confusion in a familiar place. A clinician may notice that a previously dependable patient is missing visits without notice, or that a long-term problem, like previously well-managed high blood pressure or diabetes, is no longer well-controlled. The clinician may suspect that forgetting to refill or take medications regularly may be the problem.

In addition, other information routinely collected in health care systems may show patterns that suggest impaired cognition. These include increases in missed outpatient appointments or unexpected increases in emergency department visits or unplanned hospitalizations. These changes have been recognized among people who do poorly on a cognitive screening test or assessment but have not received a clinical diagnosis of dementia.

Detection Vs. Diagnosis of Dementia

Most cognitive screening tests – including most of those described in this toolkit – are simple ways of detecting a possible problem with cognition. Screening tests do not diagnose any condition but can point to the need for expanded evaluation, which includes more detailed cognitive examination and additional medical tests.

Resources

Please click on each link to visit these resources

<u>Early Detection and Diagnosis – Alzheimer's Association</u>

<u>Why Get Checked? – Alzheimer's Association | (Spanish Version)</u>

- Medical Benefits
- Emotional and Social Benefits
- More Time to Plan for the Future
- Cost Savings

Indicators That Suggest Possible Cognitive Impairment

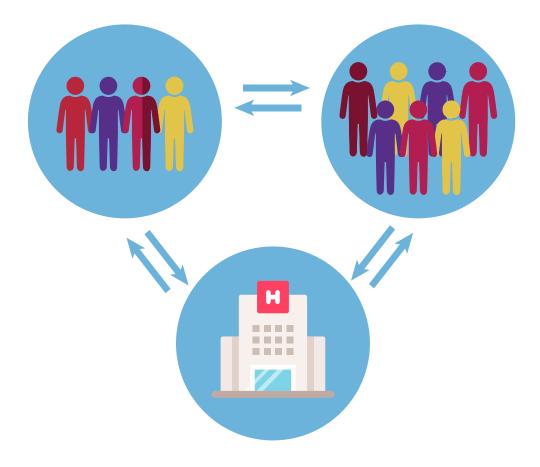
People living with dementia often forget what they intend or plan to do in the future (prospective memory loss). This can lead to missed medical or other appointments unless someone else is "remembering for" the person. It also limits a person's ability to follow a plan of care at home, such as starting or stopping a medication, recording symptoms, keeping up with fluid intake or a proper diet, or monitoring weight, blood pressure, or blood sugar.

If the clinician has only a brief or limited relationship with the patient, these kinds of changes can be easy to miss. Health system data from electronic medical records can help. That's because these administrative data reveal concerning patterns among patients with dementia and those who do poorly on a brief cognitive assessment, regardless of whether they have received a clinical dementia diagnosis.

Considerations for Special Populations

Some non-dementia conditions are characterized by cognitive deficits. Examples include intellectual and developmental disabilities and some serious and persistent mental illnesses. Some conditions, for example Down syndrome, predispose people to developing Alzheimer's disease. Special types of cognitive assessments may be required to detect cognitive decline in these patients.

Ecological Model of Dementia Detection



We use an ecological model as a framework for dementia detection. This model is often applied in public health and is based on the idea that behaviors are influenced by a multiplicity of interacting factors – biological, psychological, social, cultural, organizational, community, physical environmental, and policy.

Dementia can be detected wherever people living with it are – at home in the kitchen, in the supermarket, at the bank, on the bus, at the park, at the food bank, in the senior center, during a blood draw for lab tests. However, a clinician is needed to make a medical diagnosis of dementia and identify what conditions and factors, reversible or permanent, are causing it.

The table below covers the roles that health systems, communities, individuals, families, and friends can play in dementia detection.

Person, group, or organization	Role
Individuals, families, and friends	People with symptoms of cognitive decline and their family or friends who notice signs of cognitive decline should bring those concerns and observations to a professional equipped to evaluate the situation.
Health systems	Clinicians – usually physicians, nurse practitioners, or physician assistants – are charged with diagnosing dementia in their patients, but this process is smoother when initiated by a question or concern from a patient or family member. Some doctors have adopted routine screening approaches, using, for example, the Medicare Annual Wellness Visit (AWV) as a vehicle. The AWV requires screening for cognitive impairment, but the clinician or health care system determines how to implement it. The simplest method is first to ask about symptoms (see "Pre-Screening Conversations" and the KAER toolkit), and then use a screening tool with the patient or family member. There is not yet a consensus about whether to use screening tools with patients who don't report symptoms, although doing so can increase recognition of dementia.
Communities	We do not expect strangers who observe possible signs of dementia to report them to anyone, and it would usually be considered an invasion of privacy to do so in the absence of an obvious danger. However, there are exceptions. Workers in community-based aging and service organizations are often in an excellent position to observe signs of dementia. Some organizations, including many Area Agencies on Aging (AAAs) have developed training programs for staff to recognize possible dementia. What is missing in most settings is a standardized way to make that information actionable – for example, to help organize a focused visit to a clinician. AAAs can be found in most communities. To find the AAA nearest you, use the Elder Care Locator.

Considerations for Developing a Dementia Detection Program

Routine Screening for All Patients

Experts disagree about whether to administer cognitive screening tests to people who have no cognitive complaints or in the absence of concerns raised by a loved one or a clinician. The US Preventive Services Task Force – a body that evaluates evidence about clinical care processes and treatments – has found that there is not enough evidence that general population screening for cognitive impairment improves overall outcomes or decision making. The Task Force concluded, however, that using cognitive screening tests can improve rates of recognition and diagnosis of dementia. Among the evidence gaps that need to be filled by new research is what clinical, patient, and family outcomes are important and subject to change as a result of screening in the absence of an identified signal of cognitive impairment, be it subjective cognitive decline, observation by people within the individual's social or relationshlp network who know him/her well, or a signal detected by analysis of administrative health system data. In the absence of such data, selective application of testing is a reasonable 'middle ground.'

Selective Testing for Patients Concerned About Their Cognitive Function or for Whom Others Express a Concern

Researchers have not studied whether people with dementia detected by screening do better in the long run than people whose dementia becomes apparent in the course of routine clinical care. Many clinicians and systems have chosen a middle way – to recommend use of a validated cognitive screening tool when a concern is raised.

Selective Testing for People in High Risk Groups

Other experts recommend that clinicians caring for older adults routinely ask about memory without waiting for them to mention it on their own. Doing so recognizes the importance of cognitive function for health and well-being, and the relationship of aging to risk for cognitive decline. Various algorithms have been developed to identify subgroups of older adults at higher risk for cognitive decline. Most algorithms include, age, co-morbid conditions, healthcare utilization patterns,

education and functional decline (where available). Others use machine learning to extract patterns from medical notes. Clinicians should be alert to identifying patients at higher risk during medical visits.

One example of a high-risk clinical presentation warranting cognitive testing:

A 78-year-old man sees his doctor for an evaluation because he has fallen three times in the past 6 months. Although he wasn't seriously injured, his activity and mobility were restricted by pain for some days after his last fall. After a conversation about how he fell and how falling has affected him, the doctor thinks about possible causes for falls among older adults. Knowing that recurrent falls may be related to dementia, she uses a cognitive screening tool in addition to examining the patient for signs of injury and mobility limitations. Detecting dementia in this patient is important because fall prevention in people with dementia often differs from fall prevention for other people. Screening results can help the doctor tailor a plan to improve this patient's safety, comfort, and everyday functioning.

"Screening" Vs. "Case Finding"

"Screening" commonly refers to testing an entire population for a problem. "Case finding" focuses on populations considered at higher than average risk. This enables targeting resources toward subgroups of people rather than whole populations. We might decide to test all older adults simply because their risk of having cognitive impairment or dementia is much higher than that of younger people – this would be "screening" using an age criterion. On the other hand, we could choose to test only those older adults who have other problems we know are associated with higher risk of cognitive impairment – this would be considered "case finding." Our patient above illustrates this idea: we know that cognitive impairment predisposes older adults to falling. In this case, falling may be a signal that points to possible cognitive impairment that had not yet been recognized.

However, in practice, clinicians actually "screen" patients for many conditions at every face-to-face encounter. They do this when they ask questions about a patient's or family member's concerns, a patient's symptoms, and what patients do day-to-day. Screening is also happening when a medical assistant takes a blood pressure measurement or asks questions about pain, or when a clinician

orders a blood sugar test. Screening can also occur outside of medical settings, for example, at a health fair or through specialized online portals. Screening for cognitive impairment can be done in these and other settings.

— It Starts With a Conversation -

In general, a good strategy for detecting cognitive impairment in a health care setting starts with a conversation between a patient, a clinician, and, whenever possible, a family member. This approach creates an opportunity to talk about brain health, elicit any concerns that might be neglected in a routine visit for some other problem, and offer support. It allows for normalizing the discussion of brain health as an important part of overall health. It sets the stage for introducing options for assessing cognition, identifying possible cognitive impairment, and making collaborative decisions about next steps.

Resources

Please click on each link to visit these resources

Introduction to Alzheimer's and Dementia

About Dementia - CDC | (Spanish Version)

What Is Alzheimer's Disease? - CDC | (Spanish Version)

What Is Alzheimer's Disease? - NIA | (Spanish Version)

<u>Inside the Brain – A Tour of How the Mind Works – Alzheimer's Association</u> | (Spanish Version)

<u>Understanding Alzheimer's and Dementia – Alzheimer's Association</u>

Alzheimer's Disease Fact Sheet - NIA | (Spanish Version)

Frequently Asked Questions About Alzheimer's Disease - NIA

Alzheimer's Signs and Symptoms

Recognizing Symptoms of Dementia and Seeking Help – CDC (Spanish Version)

10 Warning Signs of Alzheimer's - CDC | (Spanish Version)

10 Early Signs and Symptoms of Alzheimer's – Alzheimer's Association

(Additional Perspectives) | (Spanish version)

Guide for Those Who Have Noticed Changes in Themselves in English

– Alzheimer's Association

Guide for Those Who Have Noticed Changes in Others in English

– Alzheimer's Association | (Spanish Version)

What Is Dementia? Symptoms, Types, and Diagnosis - NIA

What Are the Signs of Alzheimer's Disease? - NIA

Forgetfulness: Normal or Not? - NIA

What Is Mild Cognitive Impairment? - NIA

Memory, Forgetfulness, and Aging: What's Normal and What's Not? – NIA

(Spanish Version)

Alzheimer's Causes and Risk Factors

What Causes Memory Loss? Assessing Symptoms and Seeking Help

- Alzheimer's Association

How Alzheimer's Changes the Brain Video - NIA

<u>Causes of Alzheimer's Disease – NIA</u>

What Happens to the Brain in Alzheimer's Disease? - NIA

What Causes Alzheimer's Disease? - NIA | (Spanish Version)

Assessing Risk of Alzheimer's Disease - NIA | (Spanish Version)

Assessing Risk of Alzheimer's Disease Infographic -NIA

<u> Alzheimer's Disease Genetics Fact Sheet – NIA</u>

Other Causes of Dementia

<u>Frontotemporal Disorders - NIA</u>

What Are the Symptoms of Frontotemporal Disorders? Causes, Symptoms, and Treatment – NIA

What Is Lewy Body Dementia? Causes, Symptoms, and Treatments – NIA

Diagnosing Lewy Body Dementia: for Professionals – NIA

Alzheimer's and Dementia – NIA

Alzheimer's Prevention

Preventing Alzheimer's Disease: What Do We Know? – NIA

Preventing Cognitive Decline Video- National Academies Of Sciences,

Engineering, and Medicine – Health and Medicine Division

What Do We Know About Diet and Prevention of Alzheimer's Disease? – NIA

Alzheimer's Diagnosis

How Is Alzheimer's Disease Diagnosed? – Alzheimer's Association

Medical Tests- for Diagnosing Alzheimer's – Alzheimer's Association

Visiting You Doctor (When Seeking a Diagnosis) – Alzheimer's Association

Alzheimer's and Priority Populations

<u>Minorities and Women Are at Greater Risk for Alzheimer's Disease – CDC</u> (Spanish Version)

<u>Alzheimer's Disease in People With Down Syndrome - NIA</u>

<u>Alzheimer's Disease and Down Syndrome Overview - NDSS</u>

Aging and Down Syndrome: A Health and Well-Being Guidebook - NDSS

Alzheimer's Disease and Down Syndrome: A Practice Guide for Caregivers

(Spanish Version)

<u>Down Syndrome and Alzheimer's Disease – Alzheimer's Association</u> | (Spanish Version)

Normalizing Discussions About Detecting Dementia

Key Considerations for Clinicians:

- Patients want to talk about their thinking and memory. Brain health is important to everyone.
- Brain health discussions are meant to provide information about health behaviors that support brain function.
- A good brain health discussion is individualized it relates to the patient as a person and their current state of health and habits.
- Talking about it opens the door to discovering any concerns the patient may have about cognition. When a concern is present:
 - 1. Introduce the topic of cognitive testing as an objective method for looking into those concerns.
 - Know and say why you want to evaluate cognition

 explain your reasons.
 - 3. Present opportunities for promoting health, staying safe,

Choosing an Approach to Early Detection



Clinical practices or health care systems can create criteria for initiating cognitive assessment based on their programmatic goals or staff capacity. Here are some possible approaches to deciding when and how to discuss brain health and cognitive testing with patients. Think about others!

- Offer to discuss cognition with all older patients to motivate brain health behaviors.
- Include questions about thinking and memory for all older patients at annual visits.
- Offer a cognitive assessment when a patient has had an accident (e.g., a fall or motor vehicle crash) or a new decline in function.
- Offer a cognitive assessment if you see unexplained weight loss or poor management of chronic conditions.

- Offer a cognitive assessment whenever you're concerned about someone's memory.
- Offer a cognitive assessment whenever a patient or another person mentions any concern about the patient's memory.
- Offer a cognitive assessment to patients with a family history of dementia or other problems that put them at higher risk of cognitive impairment.
- Establish a baseline assessment for future reference.

Talking About Brain Health



Many older adults are relieved when their doctor wants to discuss the importance of brain health. Very few older adults refuse – most welcome a conversation and want their doctors to know if they are having a problem. In one clinical study, fewer than 5% of patients declined a simple cognitive assessment – the MiniCog (Appendix A).¹²

- Keep it simple plan what to say
 - 1. Conversation aids help: simple statements build confidence and make talking about cognition easier.
 - a) First ask about the person's own perception of their memory and thinking.
 - b) Know what to say whether the result suggests impairment or not.
 - 2. Have a plan for follow-up regardless of the results.
- Focus on the person
 - 1. Avoid "catastrophic thinking."
 - 2. Identify and acknowledge individual strengths.
 - 3. Help build a foundation for living well.
- Center on relationships that will last the journey
 - 1. The person and their loved ones.
 - 2. Your role.

You are traveling this journey together.

PRE-SCREENING: HOW TO TALK ABOUT BRAIN HEALTH AND COGNITIVE ASSESSMENT



Pay Attention to Your Body Language



Preparing for cognitive screening is as important as screening itself. The process starts with creating time and space, having a positive framework, and knowing what to say. Using short, simple statements eases concerns.

Conversations about thinking and memory can be deeply personal. Awareness around possible sensitivities is crucial to a successful experience and new understanding. Otherwise, the conversation may be received as abrupt or intrusive. One person may be in search of answers or looking for help, but another may be unaware or want to avoid the issue.

Try using the following steps:

- Build Trust
- Use Positive Framing
- Pay Attention to Your Body Language
- Prepare Short, Simple Statements



Build Trust

Building trust is easier when you have prior interactions and know the patient, but that's not always possible. Making regular cognitive assessment "normal" along with other assessments common in clinical care – e.g., checking vision, hearing, blood pressure, gait and balance, sleep, nutrition, routine labs – would smooth the process. Then there's less need to focus on establishing the rationale, but the elements of a successful conversation remain the same.

Trust comes from rapport with and communicating genuine concern for the patient as an individual. Trust strengthens relationship and a sense of safety. Strengthen the foundation of relationship of care over time by using a personal approach and treating the patient as a partner in their treatment and care.

Simple things help minimize distractions, like:

- Sit at eye level
- Make good eye contact
- "Check in" with questions like:
 - o "Is this room/seat comfortable for you?"
 - "Am I speaking clearly enough?"
 - "What questions do you have about this?"



Use Positive Framing and Pay Attention to Your Body Language

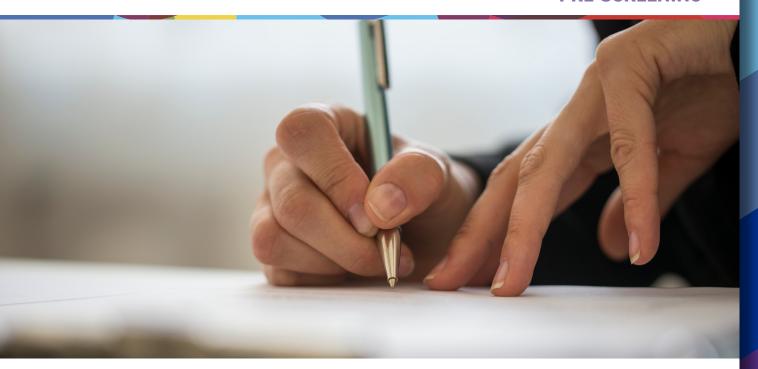
What you say leading up to an assessment can make it easier to explain the results in a positive way. Blood pressure screening provides a familiar and useful analogy.

In one instance, the examiner might say, "Let's check your blood pressure because if you have hypertension, it is important to get treatment. Elevated blood pressure can lead to strokes."

This statement is true, but it creates unnecessary fear. By saying, "Can we check your blood pressure? This will tell us whether blood pressure is something we should work on as part of staying healthy." The facts are the same, but reframing the issue turns the conversation in a positive direction.

Also note: "we," not "you," conveys partnership – "We are doing this together." Asking whether a patient has concerns about memory, thinking, or changes in their ability to do everyday tasks and linking brain health assessments to conducting daily tasks makes the conversation about what matters to them, instead of personal worth or disability. It is a great place to start a conversation about cognition, as it makes the topic relevant to everyday life.

Paying attention to body language – your own and the patient's – is a foundation of good clinical care. A warm, attentive, and unhurried manner go a long way toward easing difficult conversations, no matter what must be discussed. A few tips include directly facing the patient, making eye contact, offering undivided attention, keeping an open posture (e.g. arms uncrossed, palms open) and attending to signs of distress in the patient's body language – posture, voice, and facial expressions.



Prepare Short, Simple Statements

Start the conversation with simple statements that help the process go more smoothly and lead to a better experience for everyone. Some people feel vulnerable when asked to perform mental tests – they may interpret them as tests of intelligence, ability, or personal agency. The process may incite a patient's fears about loss of freedom, such as having their driver's license revoked. Moreover, cognitive assessments can feel insulting because for them some questions seem too simple or obvious (even if the same questions will be hard for others).

Introduce a Conversation About Cognition: Sample Openers.

- Doing all that we can to keep our brains healthy is important for all of us.
- Sometimes we are concerned about our own ability to remember things.
- Sometimes other people seem more concerned than we are about ourselves.
- Do you have any concerns about this? If yes, can you tell me more about that?
- I want to do all I can to help you stay healthy.
- Do you know anyone who has trouble with their memory or thinking? Can you say more about that?

Prepare for Cognitive Assessment.

When preparing a general opening statement, it helps to include the following elements:

- Get permission, say why, and normalize the process.
- Convey respect and caring.
- Address any sensory changes that could negatively affect results of cognitive assessment (hearing or vision loss).
- Anticipate what will follow explain the assessment procedure and how long it will take.
- Say what information you'll share afterward. This is especially important to avoid embarrassment if the respondent is unable to answer correctly.

The statement below incorporates all of the elements of trust building, preparing, explaining what you are asking the patient to do and why, and anticipating the discussion of results afterward. Feel free to adapt it, making sure to include all eight elements.

Examples.

- "I would like to talk with you about your thinking and memory.
- Would that be OK with you?
- I want to start with a few questions to help me get a sense of how you are doing.
- This is something that I like to do with all my patients.
- It gives us a place to start, to know whether we should talk beyond just this conversation.
- Is where we are sitting comfortable enough for you?
- Am I speaking clearly enough for you to hear me without having to make an effort?
- OK! This should take us less than 5 to 10 minutes.
- Some of the things I will ask you may be very easy or obvious to you and some things may be more difficult. Shall we start?"

Additional Things to Consider:

"Am I speaking clearly enough for you to hear me without having to make an effort?" which is very different from saying, "Are you able to hear me OK?" The former places the responsibility (and potential criticism) on the examiner and the latter places it on the patient.

Clinicians need to be sure patients can hear well enough to be screened because poor hearing makes it harder for patients to demonstrate their true ability. When listening requires additional effort, clinicians need to eliminate background noise, ensure adequate lighting so the patient can augment hearing with lip reading and facial expressions (a universal part of understanding conversations).

Having a personal amplifier, sometimes referred to as a "pocket talker", is an effective mitigating strategy for patients with hearing loss.

Think too about vision loss – although it's rarely so severe that it's impossible for patients to do screening tests that involve a visual component.

Consider the Context

Cognitive capability exists on a continuum – even when overall cognitive function is impaired, each person has different strengths and weaknesses. Dementia represents a decline from a previous level of functioning, so prior functioning must always be taken into account.

Some situational influences can temporarily reduce performance on cognitive screening or assessment tools and lead to 'false positive' results. Examples include:

- Preoccupation with worry unrelated to usual cognitive functioning (e.g., a seriously ill family member in the ICU).
- · Major sensory or motor impairment.
- Unfamiliarity with test components due to very low education or low literacy.
- Clinical conditions that temporarily interfere with performance, such as acute illness or serious mood disorders.

The simplest way to identify such potential interferences is to follow the conversational guidance provided above and observe the patient – when in doubt, ask: "You seem (worried) (like you're not feeling well) today. Is there something I need to know?" If the clinician suspects any such interference, it's usually better to defer screening temporarily until the situation stabilizes.

Other situations that can increase "false positive" results include very low education and long-term intellectual disabilities. Soliciting information about changes, from someone who knows the person very well, is especially important in these situations.

Conversely, some background factors can lead to "false negative" results on screening tests. An individual with mild cognitive deficits who is having a very good day, has high levels of education, or very high native cognitive ability can score in the normal range on screening tools. This does not rule out the presence of cognitive impairment – when there is concern, more detailed, lengthy assessment may be needed.

SCREENING: HOW TO ADMINISTER COGNITIVE ASSESSMENTS



The Difference Between "Detection," "Assessment," and "Diagnosis"

Signals of possible cognitive impairment may be detected anywhere, especially in community settings like banks, coffee shops, or pharmacies. For instance, a pharmacist may notice missed refills of long-term medications, or a change in a person's behavior when picking up medication. Assessment is the logical next step after a signal is detected: the pharmacist can encourage that person or someone close to that person, such as a friend or family member, to follow up with a clinician for a cognitive assessment – getting a diagnosis requires a clinical evaluation. Some people may be referred to a specialist, but most can be evaluated by their primary care clinician.

Tools Used to Detect Cognitive Impairment

Brief assessment tools are used to identify the likelihood that cognitive impairment is present. They can detect changes in cognitive functioning that are likely to affect a person's everyday functioning. Some clinicians use them to monitor changes in cognitive functioning over time. There are two basic ways to assess patients for cognitive impairment:

With the patient: Performance-based screening tools are administered to patients. Examples of performance-based screening tools include:

- Mini-Cog (Appendix A)
- Saint Louis University Mental Status Examination (SLUMS; Appendix A)
- <u>Clock Drawing Test</u> (CDT; Appendix A)

With someone who knows the patient well: Function-based screening tools are administered to another person who reports their observations about the patient (e.g., care partner, family member, close friend):

<u>8-Item Informant Interview</u> (AD8; Appendix A)

- Quick Dementia Rating System (QDRS; Appendix A)
- Functional Activities Questionnaire (FAQ; Appendix A)
- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE; Appendix A)

Both approaches have value and are often used in combination. Other tests may be recommended to look for possible contributing factors once a problem is identified.

Who Can Do Brief Cognitive Assessments?

The administration of brief screening or assessment tools is not limited to clinicians. Many can be administered by any person who has completed training for that tool. Some trainings are short and simple; others take considerable effort and skill.

Why Does Detecting Cognitive Impairment Matter?

Undetected cognitive impairment can lead to adverse health outcomes. Detecting it earlier and taking appropriate action can decrease the occurrence of the following:

- Poor chronic disease control
- · Missing new onset medical problems
- · Errors in home use of medications
- Inappropriate medication prescribing
- Delirium
- Avoidable accidents and injuries
- Preventable emergency visits
- Poor continuity of care
- Caregiver stress
- Family conflict
- Financial loss
- Scam susceptibilities
- · Missed cases of elder mistreatment

Choosing the Right Cognitive Assessment Tool

The "Best" Tool Is the One That Works Best in Your Setting, With Your Capacity and Programmatic Goals.

The tools listed in our toolkit are promoted by the American Geriatrics Society (AGS), the Gerontological Society of America (GSA), and/or United States Preventive Services Task Force (USPSTF). They have been tested and validated across various communities and settings (e.g., clinics, community settings).

No single screening or assessment tool is perfect for all uses. You may start by using one and later add or change to another as needs evolve. Please refer to Appendix A for an overview of brief tools.

AFTER SCREENING: NEXT STEPS



Navigating Conversations About Brain Health After Cognitive Assessment

Discussing brain health is a crucial part of ensuring patients' overall health, regardless of their current cognitive functioning, and it should be part of ongoing care.

Detailed conversations with patients about their lives and day-to-day activities provide context for interpreting the results of cognitive screening tests. Those conversations also establish mutual expectations of partnership in ensuring care with the best opportunity to maintain health. Regardless of how a patient scores on a test, all patients should be made aware of lifestyle behaviors that support brain health and cognitive functioning is always appropriate. When results of a screening test suggest cognitive impairment, follow-up and continuity of care are essential: the work is never completed in a single visit. Once cognitive impairment is detected, it will become a component of the patient's overall health care for the rest of their life. This is a journey for both clinicians and for their patients and families.

Primary care is exactly the vehicle for such a journey, and primary care clinicians are the ideal companions along the way: primary care prioritizes the long-term relationships between patients, their families, and clinicians. When impairment is detected, being prepared to discuss next steps is important for ongoing care. Next steps may include additional medical testing, referral for highly specialized diagnostic assessment, offering print or online educational materials and tips, or recommending organized community-based supportive and educational services for patients and families.

Such resources can include highly specialized diagnostic assessment, organized community-based supportive and educational services for patients and families, or state or local resources and are integral to high-quality long-term care.

What to Do if Screening Suggests Cognitive Impairment

Below are some examples of key points to discuss with patients when results of cognitive screening suggest possible impairment:

- Ask patients for their impressions first "How do you think you did?" or "Do you have any concerns about your memory or being able to think clearly?"
- Emphasize that the results are a measure of how they did on one test on one day.
- Gather more context about their cognitive abilities by asking about everyday activities – this is an important step in establishing the history of their cognitive health.
- Talk about whether, what, and when additional evaluation might be helpful, and start a process of shared decision making.

How to Talk About Screening Results

As you work with your patients using the key points highlighted above, recognize that how you approach the problem matters – probably more than you know. Here are some general suggestions to make post-screening conversations more comfortable:

- Be "emotionally intelligent." Recognize that being faced with signs of a potentially serious condition is difficult and often scary. Empathy and compassion not "catastrophizing" take little time and make all the difference. "I know this can be hard to hear. Would you like to talk about what this means to you right now?"
- Establish the feeling of partnership. Use "us" and "we" language.
- Promote trust and a sense of continuity "We'll work on this together."
- Identify strengths of the patient and their care partners. The better you know
 the patient and family, the easier this is. If you're not acquainted enough to call
 out specific strengths, prepare to learn. "You've coped with hard things before,
 I know. What do you think will help you deal with this situation now?" "You have a
 strong relationship we'll talk about how you can help each other as we
 go along."
- Find the "half-full cup." Nobody wants to learn that their brain isn't working
 well any more yet people can live well for a long time in spite of it, as long as
 the problem is understood and hidden fears and worries are brought to light
 and addressed.

Diagnostic Evaluation, Needs Assessments, and Referrals

In the event of a positive dementia screening, clinicians should conduct a further diagnostic evaluation. The components of that evaluation generally include ruling out or treating conditions that might cause signs of cognitive impairment but do not represent a disease of the brain (e.g., Alzheimer's disease). In general, such reversible causes are uncommon;¹³ it is more common to find incidental abnormalities that should be addressed in their own right (e.g., low vitamin B12 level, abnormal thyroid function) but for which correction does not produce notable cognitive improvement.

Symptoms of depression and anxiety are common with cognitive impairment and should be evaluated and addressed in their own right. More detailed cognitive assessment can be useful in establishing a "baseline" against which cognitive functioning can be followed over time. Clinicians should also consider whether a medical condition or medication may be affecting cognition. Structural brain imaging (e.g., CT scan, MRI) is often used as part of the diagnostic evaluation, although results do not always contribute to making a specific diagnosis or creating a care plan. Some patients may be referred to a specialist, but primary care clinicians can complete a basic diagnostic workup.

To develop a tailored care plan following a dementia diagnosis, clinicians should work closely with the patient and the patient's social support system (e.g., family, close friends, care partner) to thoroughly assess the patient's medical and psychosocial needs.

Care planning should include needs-based referrals to local, state, and national organizations that offer services such as respite care, resources on best practices for caregiving, and community wellness centers. For instance, NYU's Alzheimer's and Related Dementias (ADRD) Family Support Program offers individual and family consultation with social workers, music and dance therapy, a memory café, as well as referrals to support groups and other community organizations.

Ongoing Communication With the Patient and Family

Clinical communication is an integral component of care following recognition of cognitive impairment or diagnosis of dementia. This care is best when it involves the patient, care partner(s), and clinician(s) in an ongoing relationship.¹⁴ Here are some tips to keep in mind:

- Explain terminology "Let's talk about this word that people often use called dementia". Ask if the person or care partner have questions they want to discuss.
- Ensure continued partnership on their journey "We will work on this together."
- Emphasize the positive Coming to terms with having cognitive impairment is a process; it can undermine sense of self and worth. Knowing the clinician will "have their back" makes it easier.
- How you set the stage for living well matters. "There are things we can do to help you be as healthy and happy as possible. We'll talk about that as we go along."
- Talk about/coach how to manage co-existing medical and mental health conditions.
- Talk about/coach proper diet and good sleep as important to living well with dementia.
- Work together on a plan for physical activity and learn how to schedule pleasurable events that sustain social engagement, and thinking about how to manage changing needs over time.

SUMMARY

This BOLD Early Detection Toolkit provides strategies and resources to guide you in customizing dementia detection efforts to your needs and setting. This toolkit supports a comprehensive approach to early detection of dementia and to becoming more "dementia-capable." While screening tools are an important resource for detection, the conversations before and after testing can form the foundation of an ongoing program of care and help patients realize the full benefits of early diagnosis.

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Promoted by:

✓ American Geriatrics Society

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Detection of cognitive impairment

Where to find it

https://Mini-Cog.com

Who can administer this tool?

Can be administered by non-clinicians with minimal training

Time needed to administer tool

Up to 3 minutes

Who is this tool intended for ?

Patient

Training requirements

10 minutes, individual or group, or Mini-Cog video (www.actonalz.org)

Strengths

Includes memory test and clock drawing. Brief, relatively free of bias due to language or education constraints, easy to use in non-specialist settings. Explicit rules for administration and scoring embedded in test form. Free.

Limitations

Patients without regular exposure to analog clocks, or limited experience with drawing or writing, or those with low levels of educational attainment may find this challenging even if they don't have dementia. Memory threshold score compensates for this limitation.

Other considerations

Versions under development for patients unfamiliar with analog clocks.

Language or cultural adaptations?

Available in multiple languages

SAINT LOUIS UNIVERSITY MENTAL STATUS EXAMINATIONS (SLUMS)

Promoted by:

- **✓** American Geriatrics Society
- **☑** Gerontological Society of America
- **☑** U.S. Preventive Services Task Force

Purpose of tool

Screening for cognitive impairment; may be used to identify several common cognitive problems in dementia, and to track progression

Where to find it

Saint Louis University School of Medicine website

Who can administer this tool?

Social services staff, program coordinators, licensed nurses, nurse practitioners, occupational therapists, residence supervisors, and other health care professionals who have viewed the training video

Time needed to administer tool

10 + minutes

Who is this tool intended for ?

Patient

Training requirements

SLUMS Training video

Strengths

Similar to Mini-Mental State Exam; adds executive function component

Limitations

Relatively little published data on use

Other considerations

Includes component with culture-bound story recall; cultural adaptation needed for story recall portion and possibly other elements

Language or cultural adaptations?

Available in multiple languages

CLOCK DRAWING TEST (CDT)

Promoted by:

✓ American Geriatrics Society

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☑ U.S. Preventive Services Task Force

Purpose of tool

Detection of cognitive impairment; some use in research to track progression

Where to find it

No single site due to multiple versions and scoring systems

Who can administer this tool?

Use by non-clinicians not reported

Time needed to administer tool

< 1 minute (but up to several minutes if the person has severe impairment)

Who is this tool intended for ?

Patient

Training requirements

Depends on purpose of use and scoring system selected

Strengths

Requires many different cognitive abilities working together

Limitations

Many scoring systems from simple to highly complex; Mini-Cog CDT is best validated of the simple scoring methods

Other considerations

Severe vision loss or dominant hand motor impairment may interfere

Language or cultural adaptations?

People without regular exposure to analog clocks, limited experience with drawing or writing, or illiteracy may not be able to do this even if they don't have dementia

8-ITEM INFORMANT INTERVIEW (AD8)

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Detecting common symptoms of cognitive impairment

Where to find it

Washington University website

Who can administer this tool?

Self, knowledgeable partner, or interviewer

Time needed to administer tool

3+ minutes; requires variable thinking time before responding

Who is this tool intended for ?

Informant (e.g., care partner, family, friend, etc.)

Training requirements

Unknown

Strengths

Brief; requires minimal training to administer

Limitations

Lack of knowledgeable partner may limit use for ongoing monitoring as a person's awareness of deficits diminishes

Other considerations

Derived from the Clinical Dementia Rating (CDR), a standard research tool for staging levels of impairment in United States

Language or cultural adaptations?

Unknown but being used in many languages

QUICK DEMENTIA RATING SYSTEM (QDRS)

Promoted by:

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Purpose of tool	Training requirements
Mainly for staging the level of cognitive impairment	Requires minimal training
Where to find it	Strengths
https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC4484882/	Brief simple format
Who can administer this tool?	Limitations
Knowledgeable partner provides answers; may be given as interview	Absence of knowledgeable partner
Time needed to administer tool	Other considerations
3-5+ minutes; requires respondent thinking time	Can be completed before a visit or by phone or video
Who is this tool intended for ?	Language or cultural adaptations ?
Informant (e.g., care partner, family, friend, etc.)	Not studied

FUNCTIONAL ACTIVITIES QUESTIONNAIRE (FAQ)

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Purpose of tool

Identify cognitive impairment based on independent activities of daily living (IADL)

Where to find it

https://www.alz.org/careplanning/down-loads/functional-activities-questionnaire.pdf

Who can administer this tool?

Knowledgeable partners usually provide answers; anyone can ask the questions.

Time needed to administer tool

1-3 minutes

Who is this tool intended for ?

Informant (e.g., care partner, family, friend, etc.)

Training requirements

None

Strengths

High sensitivity and reliability; can discriminate among different stages of cognitive decline

Limitations

Not all IADL apply to all people (social, cultural variation); can adjust scoring to compensate.

Other considerations

Ease of use across multiple settings; tracking change over time

Language or cultural adaptations?

Little published experience; needs more study

SHORT FORM OF THE INFORMANT QUESTIONNAIRE ON COGNITIVE DECLINE IN THE ELDERLY (SHORT IQCODE)

Promoted by:

✓ American Geriatrics Society

☑ U.S. Preventive Services Task Force

Purpose of tool	Training requirements
Identification and staging of cognitive impairment based on change from 10 years earlier	Not reported
Where to find it	Strengths
https://www.alz.org/media/documents/short -form-informant-questionnaire-decline.pdf	Relatively unaffected by education or proficiency in one's usual language
Who can administer this tool?	Limitations
Clinicians, clinical and research staff	Requires informant who has known the person for years
Time needed to administer tool	Other considerations
5+ minutes, requires thinking time	Measures a single general factor of cognitive decline
Who is this tool intended for ?	Language or cultural adaptations ?
Informant (e.g., care partner, family, friend, etc.)	Available in multiple languages

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