THE ALZHEIMER'S Project
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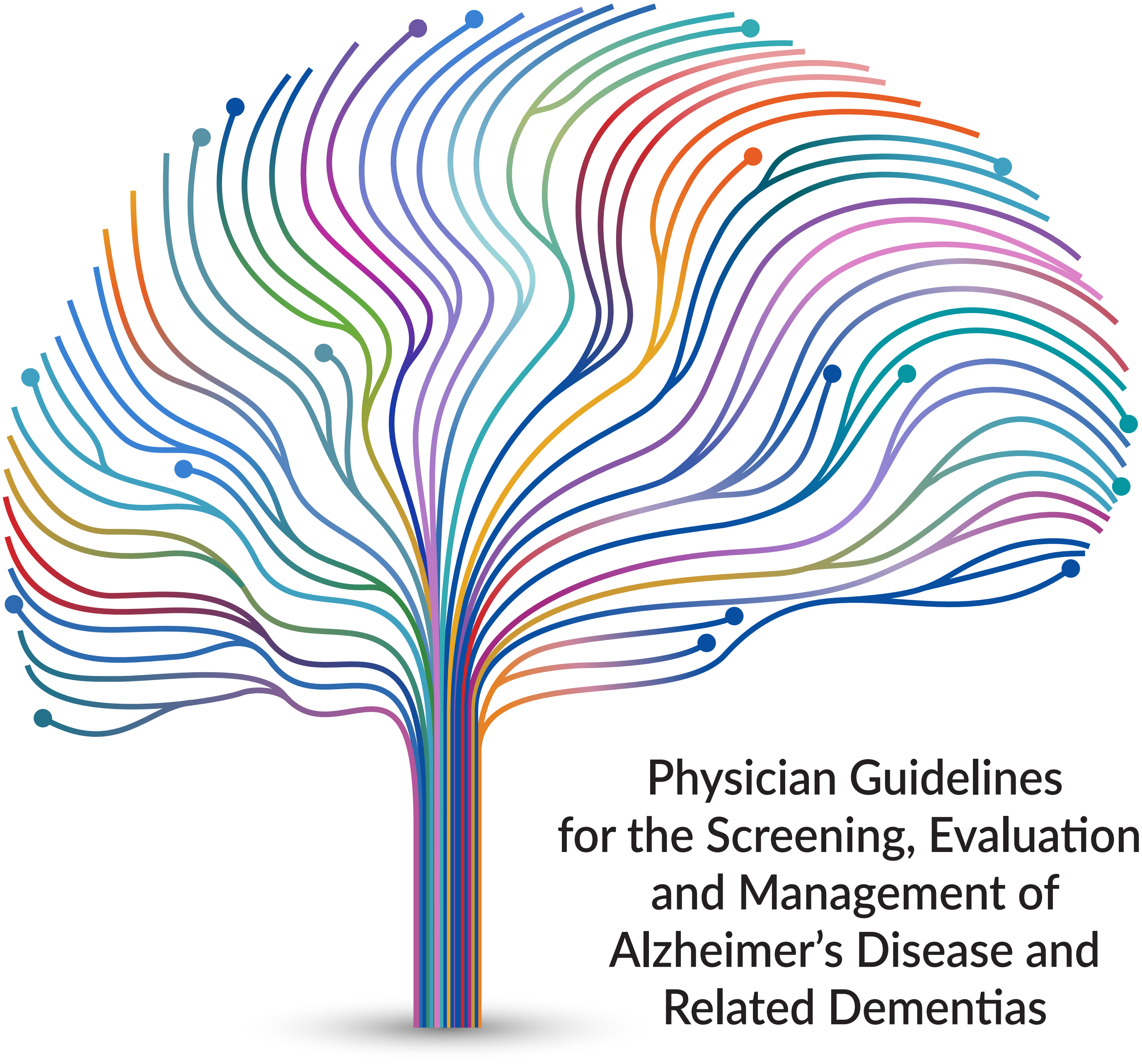

Physician Guidelines for the Screening, Evaluation, and Management of Alzheimer's Disease and Related Dementias

Created By The Alzheimer's Project Clinical Roundtable

June 2024 | Fourth Edition

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Background of The Alzheimer's Project

The Alzheimer's Project, is a regional initiative established in 2014 by the San Diego County Board of Supervisors to address the toll of Alzheimer's and related dementias on families, communities and our healthcare systems. The Clinical Roundtable was one of four groups established to address these issues. The Clinical Roundtable brings together neurologists, geriatricians, geriatric psychiatrists, geriatric psychologists, and primary care providers to assess current clinical practices, and develop/modify best practices standards for primary care physicians, internists, psychiatrists, nurse practitioners, and physician assistants caring for older adults in their practices. The Clinical Roundtable has continued to meet regularly over the past 10 years to provide ongoing review of new information, updates to the Guidelines, and resources for clinical practitioners. This is the fourth edition (2024) of the Clinical Guidelines.

Focus of the Clinical Roundtable

- Development and adoption of standards for screening, evaluation and diagnosis of Alzheimer's disease and related dementias, as well as for the management of long-term care and the behavioral and psychological symptoms and issues experienced by those afflicted.
- Education of primary care practitioners and their staff on standards and guidelines leading to countywide achievement of best practices.
- Identification of resources for providers and their staff to inform and support family caregivers.
- Creation and dissemination of tools for effective communication with patients and their caregivers.
- Facilitation of system adoption, including resources for modification of electronic medical record systems to assist/improve provider experience.

The algorithms were created after review of practices throughout the country, and all instruments recommended in these Guidelines were selected based on a thorough review of research literature, consideration of workflow of practices across San Diego County, and access to resources.

The tools presented have been created to assist primary care providers for identifying and managing patients with memory loss and dementia, as well as family members and caregivers affected by this disease. Primary care providers practicing internal and family medicine significantly outnumber specialists including neurologists, geriatricians and psychiatrists combined. Therefore, as the incidence and prevalence for memory disorders continue to rise to unprecedented levels, it is inevitable that screening, evaluation, diagnosis, and treatment of many patients with Alzheimer's disease and related disorders will be managed by primary care providers.

The Clinical Roundtable encourages the use of these tools to facilitate a more uniform approach among San Diego County healthcare providers based on clinical standards of practice to improve patient care and outcomes.

Many of the patients living with dementia can be effectively cared for and their dementia managed throughout the course of their disease by their often long-time primary care providers. These tools and additional training are offered to increase the capacity of primary care providers in that regard. However, when the clinical presentation suggests a condition other than typical Alzheimer's disease or if the presentation of a particular patient is concerning to the practitioner, referral to a specialist is recommended.

These guidelines are intended to be a living document that will change as advances are made in the field. It is planned that the Clinical Roundtable will convene for periodic review of research literature and assessment of practice in the community to update these guidelines. Further, practitioners provide feedback on the algorithms, specific screening and evaluation instruments, and their impact on provider increased capacity due to use of the guidelines.

Acknowledgments

The members of the Alzheimer's Project Clinical Roundtable wish to acknowledge, first and foremost, the members of the San Diego County Board of Supervisors who, in May 2014, unanimously voted to launch the Alzheimer's Project. The initiative's goals included raising research funds to enhance drug development, implementing standardized guidelines for physicians to diagnose and treat patients, providing support to family and professional caregivers, and increasing the knowledge and understanding of the disease throughout the community. The Alzheimer's Project is an ambitious and nationally unique effort, and has placed our County at the vanguard of the fight against this global problem.

Alzheimer's disease and related dementias currently impacts the lives of 250,000 family members who are caring for the region's approximately 100,000 individuals living with Alzheimer's and related dementias and is the number three cause of death in our County.

The Clinical Roundtable would not have been able to accomplish the development and adoption of countywide standards of care without the dedication of many clinical practitioners and care community members affiliated with various health systems in San Diego County. We would like to thank the leadership of our respective organizations for their support as we have dedicated time and energy to this effort.

—
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Synopsis

The Clinical Guidelines detailed in this publication are meant to be an enduring resource for primary care providers who see, screen, diagnose and manage patients with cognitive decline on an ongoing basis. This synopsis gives an overview of each section that is covered more thoroughly in the Clinical Guidelines.

Cognitive impairment and dementia are under-diagnosed in older adults across the United States. Early detection of cognitive impairment allows the opportunity to address reversible or modifiable factors, safety risks, inclusion of a care partner/s, as well as improve overall healthcare, discuss advance care planning and consider appropriateness for pharmacologic and nonpharmacologic treatments. Screening may also help to reassure someone with cognitive concerns whose cognition in fact is normal.

Dementia is an acquired decline in memory and/or other areas of cognition or behavior, of sufficient magnitude to cause impairment of social or occupational functioning. Alzheimer's disease is the most common type of dementia. Mild Cognitive Impairment (MCI), is marked by focal or multifocal cognitive impairment with minimal impairment of instrumental activities of daily living (IADL) that does not cross the threshold for a dementia diagnosis. MCI may, but does not generally, lead to Alzheimer's disease or other forms of dementia, or may dissipate. A chart on page 23 shows the differences between normal aging, MCI and dementia.

Screening for dementia *(Pages 7-14)*

The content provided in these Provider Guidelines is recommended for individuals exhibiting symptoms of dementia, however universal screening of all adults 65 and older is optional based on provider and health system capacity. There is a growing emphasis from Medicare and Medicaid (MediCal) to include cognitive screening with all annual wellness visits, and information here is consistent with those requirements. Reference information is available in the Reference and Resource section of this guide.

Medicare does not specify a screening instrument; the initial conversation may be as simple as asking the patient if they have noticed changes in their memory over the past few months. Medicaid/MediCal lists a variety of approved instruments in the Dementia Care Aware model.

Screening includes a brief patient history, use of a validated cognitive screening instrument as part of the examination, and a functional assessment. The use of the AD8 is considered part of the history, and not the examination. While some health systems are using a patient-completed AD8 as part of the Medicare AWV, it does not replace the use of a validated screening instrument. Since functional impairment is critical to an adequate assessment, evaluation of the IADLs is important. The identification and documentation in the EMR of a care partner is important if further follow-up is appropriate.

If a screen is positive, medical factors, depressive symptoms and a brief panel of laboratory tests should be considered to determine if there may be treatable or reversible factors. Hearing and vision should also be considered as factors to address. Several RED FLAG symptoms or features are listed, as examples of situations where a more detailed evaluation should be considered, regardless of the results of the screening. A positive screen, with or without an attempt to determine and correct reversible factors, should lead to an evaluation.

Next Steps: Evaluation *(Pages 15-29)*

Evaluation is more detailed and time-consuming than screening. The clinician performing an evaluation should have a thorough knowledge of diagnoses of cognitive disorders such as Alzheimer's disease and other types of dementia, and should also be comfortable disclosing a diagnosis of Alzheimer's disease or other dementia to patient and family.

An accurate diagnosis of cognitive impairment, dementia and its etiology can help to guide the patient and family regarding planning, accessing family and community resources, appropriate use of symptomatic treatment and the potential for disease-modifying anti-amyloid treatment.

Benefits of Assessing for MCI or Dementia

- Assist with planning for the future
- Identify treatable or reversible factors (e.g., vascular risk, sleep, medications) and lifestyle interventions (e.g., physical activity, diet)
- Opportunities for early therapy initiation (e.g., with anti-amyloid immunotherapy) or for clinical trials

An evaluation typically will consist of at least one detailed visit to obtain the necessary elements of history, examination, cognitive assessment using validated assessment tools, and appropriate laboratory testing, neuroimaging and other consultation or tests as appropriate. It is strongly recommended to obtain collateral history from an informant to document cognitive, functional and behavioral symptoms whenever possible.

Once the practitioner has confidence in a diagnosis of dementia, the practitioner should be prepared to conduct a discussion of the results of the evaluation and disclosure of the likely diagnosis, the prognosis, and an outline of treatment options with the patient and family members.

A longer or follow-up appointment would include discussion of safety concerns including kitchen appliances, home safety and firearms/other weapons, medications, finances (to avoid elder abuse scams), and driving. Driving is the only safety issue where there is a legal requirement of the provider to report to another agency; in this case the DMV for their review and potential testing. Referrals to information and community resources is also important, and may be more appropriate for follow-up visits.

Referrals to neurology and additional testing may be appropriate when specific clinical expertise is required.

Treatment Options *(Pages 30-31)*

After a diagnosis and disclosure of Alzheimer's disease or related dementia, many patients and caregivers may be looking for therapeutic options. Both non-pharmacologic and pharmacologic interventions may be chosen by the practitioner and patient/family. Like many chronic conditions, healthy diet, physical activity, and social interaction have been proven to be the most effective therapies for Alzheimer's disease and related dementias.

Cholinesterase inhibitors have been extensively studied for symptomatic effects on cognition in Alzheimer's disease. Clinical trials and studies show significant but small benefits vs. placebo among individuals with mild through severe Alzheimer's. Overall, they may stabilize cognition or slow its manifestation but do not slow the progression of the underlying disease.

Cholinesterase inhibitors are used in mild dementia; the most common cholinesterase inhibitors are: donepezil (Aricept®), rivastigmine (Exelon®) available in transdermal patch form, and galantamine (Razadyne®). Memantine (Namenda®) has been shown to have small benefits on cognition and behavior in people with moderate to severe AD, either alone or added to a cholinesterase inhibitor. An assessment of risks and benefits with discussion of side effects is important. Medications should be curtailed if side effects are not tolerated or once the medications are no longer effective.

Monoclonal antibodies that target abnormal forms of amyloid and help to remove amyloid from the brain have undergone extensive clinical trials in the past decade and have been shown to have a statistically significant (but clinically modest) impact on delaying progression of Alzheimer's disease in generally healthy patients. Some general observations have emerged: Antibodies that target amyloid and remove it from the brain need to be given at high enough doses that they clear much or all of the amyloid detectable by PET scan over a relatively short period. Treatment is more likely to show clinical benefit when started in patients with mild symptoms (therefore MCI or mild dementia). Treatment with anti-amyloid antibodies is associated with risks, the most common of which are visible on MRI, and are categorized as Amyloid Related Imaging Abnormality (ARIA). Management of MAB treatment is best done by a specialist and team with expertise and knowledge about Alzheimer's disease, ARIA and about tracking changes in AD symptoms and severity and in biomarkers over time.

Care Management through the Stages of Disease *(Pages 32-41)*

Care planning should place adequate emphasis on community-based and psychosocial supports for patients and their care partners/family members. Since an individual may experience the disease on average 7-10 years, needs will change over time. When caring for the patient, the provider is also caring for the caregiver. Community resources are increasing in response to the increased number of families facing the effects of dementia.

This section identifies the most common issues to address with patients and care partners at various stages in the disease process, including advance care planning, palliative care and hospice for the later stages.

Addressing Behavioral Symptoms of Dementia *(Pages 42-66)*

Over the course of the disease, patients may experience a variety of psychiatric and psychological changes. The first of these is often withdrawal from social activities and depression. Disease progression may include anxiety, agitation, wandering, hallucinations and aggression. The Guidelines detail how to differentiate the symptom from the cause using the DICE Method: Describe, Investigate, Create a care plan, and Evaluate. By identifying if the cause is medical, psychiatric, psychological, physical, or a combination of all these factors, the practitioner can determine the best non-pharmacologic interventions. Should medications be necessary, employing the psychobehavioral metaphor (ASSUME the patient does not have dementia, ASSESS psychiatric signs, ALIGN symptoms to best fit psychiatric syndrome) may help with selection of the most appropriate class of medication. Non-pharmacologic strategies should always be employed prior to the use of pharmacologic interventions.

Caring for the Care Partner *(Pages 67-73)*

When caring for the individual with dementia, the practitioner is also caring for the family members and other care partners. Therefore, it is important to identify key signals that the caregivers may need more assessment, support, and both medical and psychological treatment. It is good to know who the caregivers are, what are the impacts of caregiving, and what steps can be used to support caregivers. Cultural and ethnic backgrounds and experiences affect the needs and preferences of the family. Providing education and support through the years will reduce burden and stress, and enhance the physical and mental health of caregivers. This will include recommendations for social and physical supports such as support groups, respite care, and self-care. The care plan developed by providers will cover the psychosocial needs as well as medical concerns.

Billing for Services *(Pages 74-76)*

Medicare and Medicaid (MediCal) have similar but different service requirements and reimbursement codes. This section gives an overview of billing requirements for screening, evaluation and care planning for the two government payers. Practitioners should check with their billing specialists and insurers for the most up-to-date information, as requirements change frequently.

Screening for Dementia

Background

Cognitive impairment and dementia are under-diagnosed in older individuals. This can lead to safety and health consequences, and also delays adequate evaluation and potential treatment. In addition to supporting a diagnosis of cognitive impairment, screening and evaluation of cognition may identify reversible conditions contributing to cognitive changes, or may help to reassure someone with cognitive concerns whose cognition in fact is normal.

While the content provided in these Provider Guidelines is recommended for individuals exhibiting symptoms of dementia, universal screening of all adults 65 and older is optional based on provider and health system capacity. There is a growing push by Medicare and MediCal for universal screening, however it is worth noting that a literature review has concluded that a full screening is still controversial, amid an evolving landscape. These Guidelines are consistent with requirements from Medicare and Medicaid (MediCal) to include cognitive screening with all annual wellness visits. Reference information is available in the Reference and Resource section of this guide.

It is important for providers to remember that screening tools are simply that, tools, and are not replacements for active assessment by the trained practitioner.

The terms dementia, MCI, Major Neurocognitive Impairment and Mild Neurocognitive Impairment are defined here with some interchangeability. The current DSM-5 terminology is not uniformly used.

Dementia is an acquired decline in memory and/or other areas of cognition or behavior, of sufficient magnitude to cause impairment of social or occupational functioning.

DSM-5 has developed the term Major Neurocognitive Decline (MNCD), used with a variety of billing codes to describe dementia and related conditions. Major Neurocognitive Disorder (Dementia) as defined by the DSM-5 includes:

- Cognitive deficits in one or more areas of cognition, such as memory, language, visuospatial abilities, (apraxia, aphasia, agnosia), or executive function)
- Cognitive defects must impair social or occupational functioning
- Gradual onset and progressive cognitive decline
- Not due to other CNS cause of dementia, substance abuse, or systemic conditions that can cause dementia
- Not due to delirium
- Not accounted for by another Axis 1 disorder.

Starting the Conversation

When to Begin Discussion of Cognition in an Older Adult:

- *Annual Wellness Visit,*
- *Warning Signs expressed by patient and/or family member,*
- *Patient who forgets appointments or is noncompliant with medications,*
- *Upon observation by a healthcare professional during a scheduled office visit.*

Annual Wellness Visit

Medicare beneficiaries are eligible for an Annual Wellness Visit (AWV), which is separate from the Initial Preventive Physical Examination or other routine physical checkups. The prescribed components of an AWV includes a review of the beneficiary's potential risk factor for depression, using an appropriate screen such as the PHQ-2 or PHQ-9, as well as a check for cognitive impairment, as follows:

> *"Detect any cognitive impairment the beneficiary may have: Assess the beneficiary's cognitive function by direct observation, with due consideration of information obtained via beneficiary reports and concerns raised by family members, friends, caretakers, or others."*

The Annual Wellness Visit includes a Health Risk Assessment (HRA), and provider discretion will guide the implementation and use of the HRA questionnaire. Each insurance payer may specify their own HRA questionnaire. While Medicare does not currently identify or prescribe a particular cognitive screening test, many practitioners use the Mini-Cog test, as recommended in these Guidelines.

Medicaid (MediCal) specifies an annual Cognitive Health Assessment, and is more specific in its Dementia Care Aware guidelines for utilization of the billing code 1494F for older adult patients who do not qualify for Medicare. The Cognitive Health Assessment (CHA) should include cognitive and functional screen tests for both patient and an informant, e.g., a Mini-Cog or GPCOG AND ADL/IADL for patient, along with an AD8 or IQCODE plus a GPCOG Information Interview for the Informant.

Of note, a number of institutions have opted to use the AD8 as their preferred screening tool for the annual wellness visit. While this tool does have good sensitivity (>84%) and specificity (>80%) for detection of Alzheimer's disease, it is important to note that these percentages are only when the AD8 is administered to an informant, not the patient. The tool is significantly less effective at detecting disease when administered to the patient themselves. It is recommended to consider the AD8 as an optimal screening tool one can add to augment the history element of the patient evaluation but best practice would be to perform some objective cognitive screen such as the Mini-Cog, and not solely rely on the AD8 if the AD8 was administered to the patient themselves. An AD8 is considered part of the patient history, and is not considered a cognitive exam instrument.

Screening prompted by other concerns

Family members may notice changes in cognition or function before patients do. People with MCI or mild dementia may retain some awareness of their decline in abilities, but as memory loss worsens, denial or unawareness that there is a problem (anosognosia) becomes increasingly common.

A physician or their office staff may notice problems, for example, patients missing appointments, calling for refills of medications erratically, or having difficulty giving a completely coherent history.

When the practitioner detects any cognitive impairment in either an AWV, a routine physical checkup, or other appointment, he/she may find it an appropriate opportunity to either begin a discussion, or suggest a follow-up appointment to discuss concerns of the patient, family member or physician. A thorough history with careful focus on cognitive function will be helpful.

During an appointment with only the patient in attendance, the patient may be unaware of or deny symptoms of memory loss. It is therefore important to obtain collateral history from family or close friends. The AD8 may be sent home with the patient for completion by a family member prior to the next visit, or included in the After Visit Summary. By completing the survey outside of the medical office, the family member has more time to recall specific concerns, and can provide this valuable information to the provider without disclosing too much in front of their loved one.

Having the Conversation

Recommended initial questions to ask older patients regarding their concerns about their memory or cognition are:

- *Are you worried about your memory?*
- *Have you noticed a change in your memory that concerns you?*
- *During the past few months, have you had any increasing problems with your memory?*

It is important to focus on change in function or abilities over the past six months to two years.

The Gerontological Society of America's KAER Toolkit suggests, "By raising this topic, PCPs will communicate to their older adult patients that brain health and changes in memory and cognition that may occur in aging are important aspects of their overall health.

Raising the topic will also help to normalize attention to cognition in primary care and encourage older adults to be aware of changes in their cognition and to tell their PCP about cognition-related concerns, if any. Many older adults are reluctant to express such concerns to their PCP, in part because of fear and stigma often associated with dementia. A frank yet sensitive introduction to the topic by the PCP is a highly appropriate first step to kickstart the cognition conversation. This approach can open the way for older adults to reveal any cognition-related concerns they may have."

The K in KAER stands for Kick Starting the conversation about cognitive impairment. This may include questions about cognition-related function, such as difficulty paying bills or directions to a familiar place.

Practitioners can refer to the 10 Warning Signs to direct the conversation. Tools, including short videos on suggested interactions, are available on the website, https://championsforhealth.org/alzheimers.

A list of symptoms and processes for screening in primary care are described by the California Department of Public Health in the Dementia Care Aware program: About - Dementia Care Aware. The California DPH also offers information at https://www.takeonalz.com/find-a-path-forward/formal-diagnosis/.

Listening and acknowledging concerns of a patient's family member or caregiver is usually most informative, as the individuals with cognitive decline often may not recognize their deficits. If the family member is present at the appointment, watching their body language may inform the provider when concerns cannot be verbalized.

Some key messages to impart to older adults include:

- *The brain ages, just like other parts of the body.*
- *Cognitive aging is not a disease, and is not the same as Alzheimer's disease or other dementia. It is a natural, lifelong process that occurs for everyone, and is different for each person.*
- *There are steps individuals can do that may promote and support their cognitive health.*

Individuals concerned about their memory may be among the "Worried Well" and need reassurance that their experience is part of normal aging. Tracking concerns over time will help the practitioner to determine when to assess or reassess cognitive function.

An algorithm for screening

An algorithm for screening was created by clinicians with expertise in Neurology, Geriatric Medicine, Geriatric Psychiatry, Psychiatry and Geriatric Psychology representing different San Diego health care systems. The Clinical Roundtable members reviewed guidelines and studies of different screening tests and questionnaires, as well as screening algorithms proposed by organizations across the country, including major universities and the Alzheimer's Association.

The goal was to develop an algorithm of when screening should be considered, and what brief instruments have reasonable evidence for use. Additional goals were to define a brief workup and focused management that should follow a positive screen, and to determine whether there are potentially treatable factors that should be addressed before undertaking or referring the patient for a more detailed evaluation.

Intended use

Primary care physicians, internists, psychiatrists, nurse practitioners, and physician assistants/associates caring for older adults in their practices can use the algorithm to carry out a focused screening. The intended use is in older patients where there is suspicion of cognitive decline. This type of screening could potentially be used in other settings, for example in an Emergency Room or preoperatively to rule out other conditions presenting as disorientation or dementia. Other medical staff in the practice can be trained to assist the screening by conducting portions of the algorithm, including the MiniCog and collecting informant information while rooming the patient.

Efficacy

The screening instruments selected are the MiniCog, a brief direct test of cognition; and the AD8, a questionnaire for an informant. These may be used separately or together. Studies suggest that a combination of direct cognitive testing and informant assessment is more accurate in detecting cognitive decline than either one alone. These screening tests may be conducted in three to five minutes, and may be conducted by a healthcare professional such as RN or MA during the rooming process to improve efficiency of the appointment.

Studies of the Mini-Cog suggest that it has sensitivity of over 80% and specificity ranging from 60 – 80% to detect dementia. As previously mentioned, the AD8 has good sensitivity and specificity exceeding 80% when administered to an informant but is less reliable when administered to the patient themselves. A hallmark of cognitive impairment is anosagnosia, and hence the patient may not recall the cognitive symptoms they have experienced leading to a false negative AD8 when the test is administered to the patient. The Mini-Cog, and the AD8 when administered to informants have results that compare favorably with other widely used tests for evaluation such as the Mini-Mental State Examination (MMSE).

Mild cognitive impairment (MCI) or mild neurocognitive disorder (MNCD) refers to a lesser degree of cognitive decline than dementia. These conditions may be caused by many different factors. Brief screening tests or questionnaires are less sensitive for MCI or MNCD than for dementia.

How to utilize the tool

An algorithm for cognitive screening indicates the types of symptoms that may trigger a screen, and the process of using the MiniCog, AD8, and functional assessment. These instruments and scoring keys are included in this document, and are available online. Scoring cut-offs for these instruments are listed.

If a screen is positive, medical factors, depressive symptoms and a brief panel of laboratory tests should be considered to determine if there may be treatable factors. Hearing and vision should also be considered as factors to address.

If a screen is negative, there is a decreased chance that dementia is present but does not rule out MCI. The clinician may decide to pursue a more detailed evaluation anyway, for example if there are issues such as decisions about driving, work or finances. If the screen is negative, the clinician may decide to rescreen the patient during follow-up at six months or one year.

Several RED FLAG symptoms or features are listed, as examples of situations where a more detailed evaluation should be considered, regardless of the results of the screening. A positive screen, with or without an attempt to determine and correct reversible factors, should lead to an evaluation.

Recommended Screening Instruments

Mini-Cog

https://mini-cog.com/download-the-mini-cog-instrument/ Normal range: ≥ 4 (see page 84)

Mini-Cog other languages

https://mini-cog.com/mini-cog-in-other-languages/

Informant/Family Questionnaire

AD8: https://alz.org/media/documents/ad8-dementia-screening.pdf

Normal Range: 0 - 1 (see page 87)

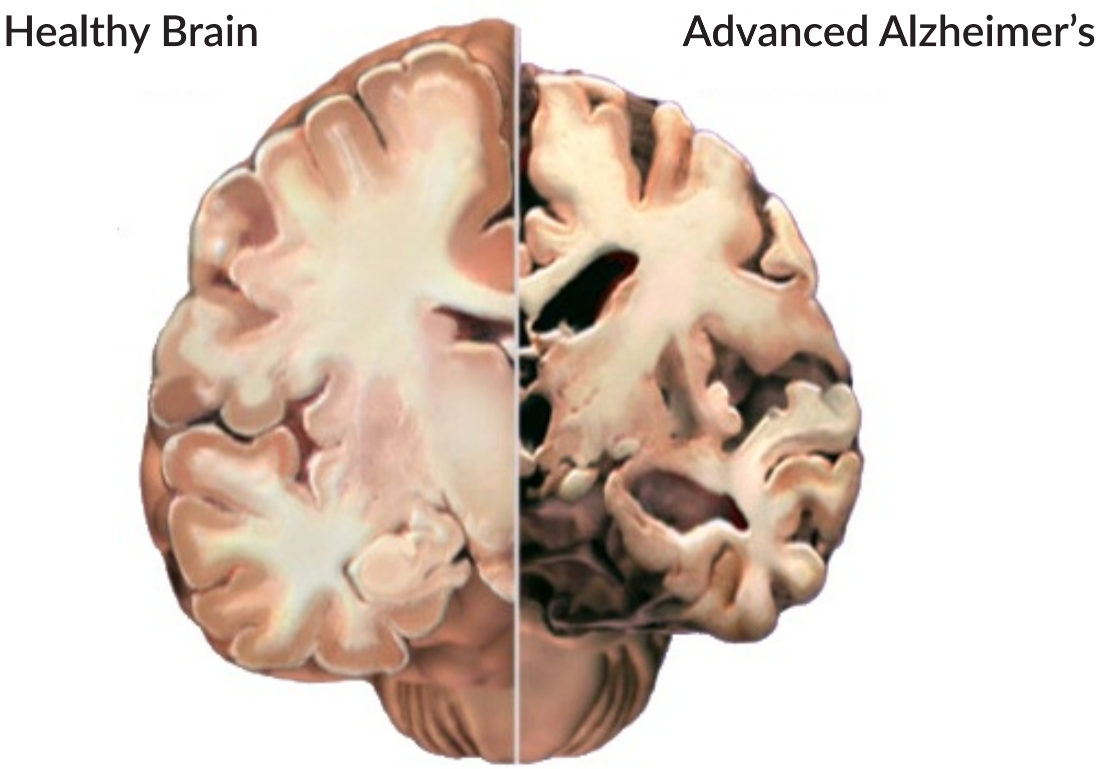
Patient Health Questionnaire for Depression (PHQ-9)

https://www.apa.org/depression-guideline/patient-health-questionnaire.pdf

PHQ-2 are the first two questions of the PHQ-9 (see page 119)

Optional: Geriatric Depression Scale

http://geriatrictoolkit.missouri.edu/cog/GDS_SHORT_FORM.PDF (see page 122)



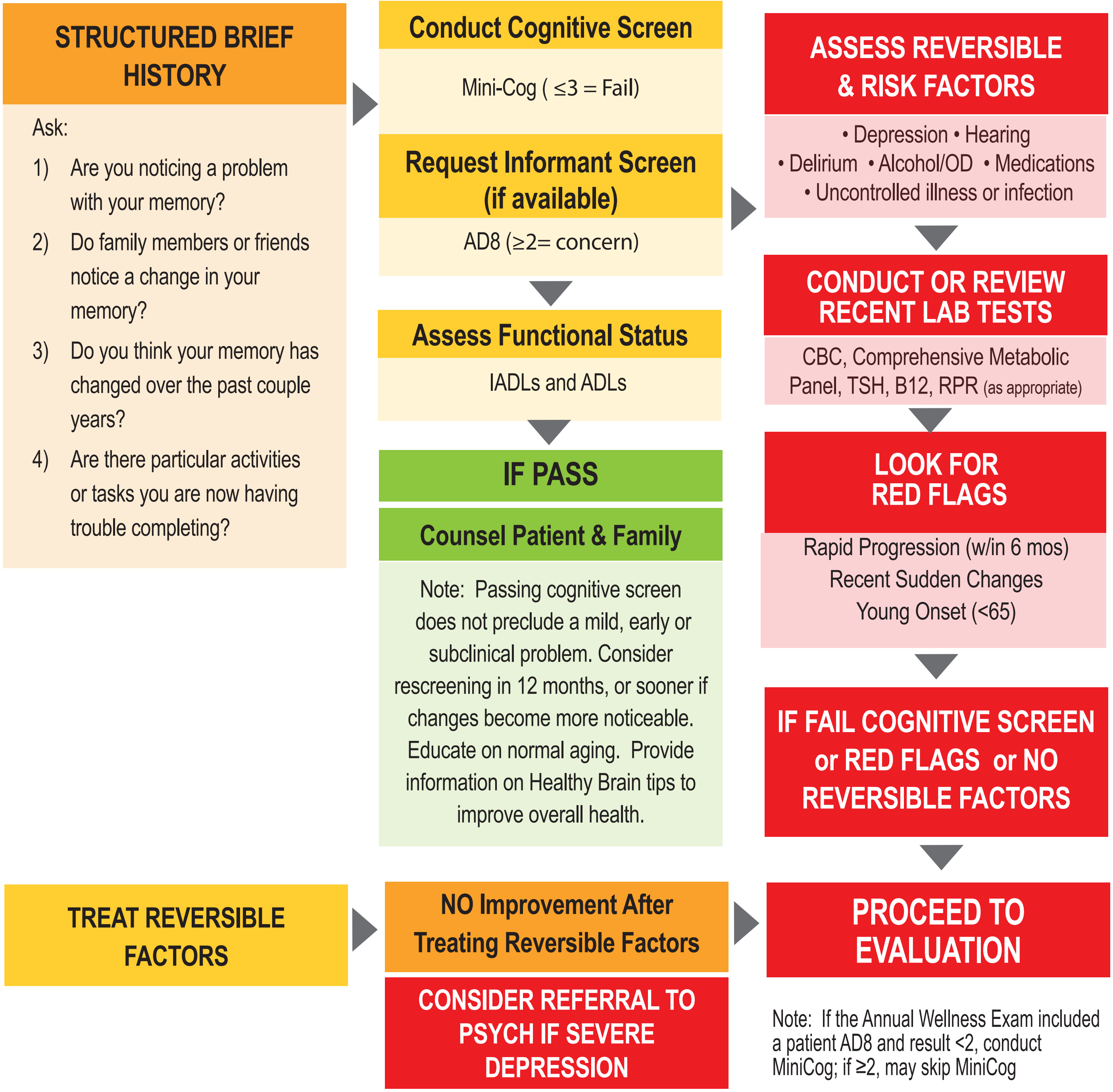
Alzheimer's Clinical Roundtable

Recommended Screening Algorithm for Adult Cognitive Impairment

NOTE: Cognitive screening may be a part of a regular annual physical exam.

SCREENING VISIT

Generally due to concerns about cognition or function, noted by Patient, Family Member or Physician, or may be included as part of an Annual Medicare or Medicaid (MediCal) Wellness Visit



STRUCTURED BRIEF HISTORY

Ask:

1) Are you noticing a problem with your memory?
2) Do family members or friends notice a change in your memory?
3) Do you think your memory has changed over the past couple years?
4) Are there particular activities or tasks you are now having trouble completing?

Conduct Cognitive Screen

Mini-Cog (≤3 = Fail)

Request Informant Screen (if available)

AD8 (≥2= concern)

Assess Functional Status

IADLs and ADLs

IF PASS

Counsel Patient & Family

Note: Passing cognitive screen does not preclude a mild, early or subclinical problem. Consider rescreening in 12 months, or sooner if changes become more noticeable. Educate on normal aging. Provide information on Healthy Brain tips to improve overall health.

ASSESS REVERSIBLE & RISK FACTORS

- Depression • Hearing
- Delirium • Alcohol/OD • Medications
- Uncontrolled illness or infection

CONDUCT OR REVIEW RECENT LAB TESTS

CBC, Comprehensive Metabolic Panel, TSH, B12, RPR (as appropriate)

LOOK FOR RED FLAGS

Rapid Progression (w/in 6 mos)
Recent Sudden Changes
Young Onset (<65)

IF FAIL COGNITIVE SCREEN or RED FLAGS or NO REVERSIBLE FACTORS

TREAT REVERSIBLE FACTORS

NO Improvement After Treating Reversible Factors

CONSIDER REFERRAL TO PSYCH IF SEVERE DEPRESSION

PROCEED TO EVALUATION

Note: If the Annual Wellness Exam included a patient AD8 and result <2, conduct MiniCog; if ≥2, may skip MiniCog

Labs/testing

The algorithm lists lab tests to be considered to determine if there may be treatable factors:

- CBC
- Comprehensive Metabolic Panel
- TSH
- Vitamin B12 (With exception of vitamin B12 deficiency, there is no convincing evidence for vitamin deficiency causing dementia)
- Consider screening for RPR when clinically appropriate.
- Patients with suspected dementia are at risk for nutritional disorders. When there is concern in that regard, checking vitamin levels as appropriate for general health maintenance may be considered.
- Patients sometimes self-treat with over-the-counter products. Frequently, the ingredients in over-the-counter products contain high doses of vitamins. As such, checking vitamin levels when appropriate to rule out vitamin toxicity may be considered.

Dementia Care Aware/MediCal Recommended Screening Instruments

In order for practitioners caring for an older adult who is insured through MediCal and is not Medicare eligible, and for the practitioner to utilize the MediCal billing code, the following instruments are required:

	Cognitive Screen Instruments	Functional Screen Instruments
Patient	MiniCog or GPCOG	IADL/ADL
Informant/Care Partner	AD8 or Short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)	Functional Activities Questionnaire (FAQ) or GPCOG Informant Interview

Functional Ability

ADLs	IADLs
Bathing	Using telephone
Dressing	Shopping
Toileting	Food preparation
Transferring	Housekeeping
Continence	Laundry
Feeding	Transportation
	Taking medications
	Handling finances

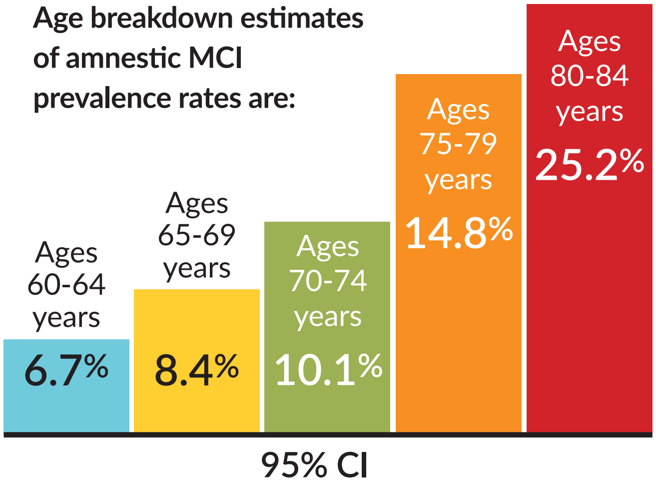
Screening for Dementia

Mild Cognitive Impairment (MCI), or Mild Neurocognitive Disorder, is defined as a change in cognitive abilities, noticed by the patient, family member or close friends, or the health provider, in which there is cognitive impairment in one or more domains (memory attention, executive function, language, visuospatial abilities) with minimal impairment of instrumental activities of daily living (IADLs) that does not cross the threshold for a dementia diagnosis. Although there is no absolute dividing line between MCI and mild dementia, the degree of impairment is used to make the judgment. Someone with MCI can compensate for many of their cognitive problems and can remain independent in many complex activities, sometimes with mild adjustments.

MCI can be the first cognitive expression of Alzheimer disease (AD), or may be secondary to other disease processes (i.e., other neurologic, neurodegenerative, systemic, or psychiatric disorders) that can cause cognitive deficits. While MCI can lead to major neurocognitive disorders in the future, MCI does not necessarily progress, and depending on the underlying cause(s), it can improve. Caveat: brief screening tests such as the MiniCog are less sensitive for detection of MCI than for dementia.

Mild Neurocognitive Disorder is a term developed by DSM-5 that overlaps with the description of MCI. There are different kinds of MCI. The following information is excerpted from a consensus statement by the American Academy of Neurology regarding MCI:

> *"Amnestic MCI (aMCI) is a syndrome in which memory dysfunction predominates; Nonamnestic MCI refers to impairment primarily in other cognitive domains (e.g., language, visuospatial, executive). The "narrow" definition of MCI includes amnestic, and the "broader" definition also includes nonamnestic MCI. The general prevalence rate for narrow criteria varied from 3.2% to 25% of individuals 65 years of age and older across studies conducted. The prevalence rate for the broader criteria varied between 13.4% and 42%."*


Age breakdown estimates of amnestic MCI prevalence rates are:

In individuals with MCI older than age 65 years followed for two years, the cumulative incidence for the development of dementia is 14.9%. Persons diagnosed with MCI may remain stable, return to neurologically intact, or progress to dementia (multiple Class I studies, 14.4%–55.6% reverting to normal).

Biomarkers are becoming highly relevant to rule in or rule out amyloid pathology in someone with MCI. At present, these are usually obtained by analysis of CSF or by an amyloid PET scan. However, blood-based biomarkers are showing high sensitivity and specificity to detect amyloid. Their place in primary care is still being studied.

The brain and cognitive abilities change with aging. For example, difficulty retrieving names or words, lapses of attention ('why did I go into that room,' 'what was I saying,' etc), and slight slowing of cognition are signs of normal brain aging. These should be differentiated from serious cognitive changes. This normal brain aging is not MCI.

Evaluation of Cognitive Decline and Dementia

Background

Alzheimer's disease (AD) is the most common cause of dementia in older individuals. Other common causes are vascular cognitive impairment, Dementia with Lewy Bodies (DLB), Fronto-Temporal Lobar Degeneration (FTLD) and later stage Parkinson's disease. Many other conditions may cause or contribute to dementia, including medically treatable conditions. In many patients with dementia, more than one pathology contributes, e.g., Alzheimer's accompanied by vascular changes.

Evaluation is more detailed and time-consuming than screening. The clinician performing an evaluation should have a thorough knowledge of diagnoses of cognitive disorders such as Alzheimer's disease and other types of dementia, and should also be comfortable disclosing a diagnosis of Alzheimer's disease or other dementia to patient and family. There are many guidelines for the evaluation of dementia. Recent guidelines for Alzheimer's disease, Mild Cognitive Impairment (MCI) due to AD, as well as prodromal AD emphasize biomarkers for amyloid and neurodegeneration in addition to clinical evaluation. These biomarkers can increase accuracy of diagnosis beyond clinical evaluation alone and are necessary to determine appropriate treatment options for people with MCI or mild dementia due to AD (called Early AD).

Diagnostic criteria also exist for vascular dementia, DLB, FTLD, and other disorders. For people suspected of having DLB, emerging biomarkers allow a rule in or rule out determination of a-Synuclein pathology.

An accurate diagnosis of cognitive impairment, dementia and its etiology can help to guide the patient and family regarding planning, accessing family and community resources, appropriate use of symptomatic treatment and the potential for disease-modifying anti-amyloid treatment.

Benefits of Assessing for MCI or Dementia

- *Assist with planning for the future*
- *Identify treatable or reversible factors (e.g., vascular risk, sleep, medications) and lifestyle interventions (e.g., physical activity, diet)*
- *Opportunities for early therapy initiation (e.g., with anti-amyloid immunotherapy) or for clinical trials*

An algorithm for diagnostic evaluation

An algorithm for diagnostic evaluation was created by a group of clinicians with expertise in Neurology, Geriatric Medicine and Psychiatry, representing different San Diego health care systems. They reviewed guidelines and studies of evaluation, as well as published diagnostic criteria. The goal was to develop an outline of the elements of evaluation of dementia or cognitive loss, to help to guide clinicians and improve the quality of care.

ALZHEIMER’S CLINICAL ROUNDTABLE

RECOMMENDED EVALUATION ALGORITHM

PATIENT REFERRED FOR EVALUATION OF ADULT COGNITIVE IMPAIRMENT

BASED ON RESULTS OF SCREENING PROTOCOL

DIAGNOSTIC WORKUP

Detailed History: History of risk factors (TIA, Stroke, cardiovascular risk). Assess family history of dementia, Parkinson's or ALS, Informant Interview (IQCODE, QDRS, AD8), Cognition, Function (IADLs) and/or Behavior Changes

Neurological exam

Mental Status Test: MoCA*, qMCI, MMSE*, or SLUMS *FEE FOR USE

Depression Screening: Geriatric Depression Scale 7 Item, PHQ-9 and/or Structured Questions

IF MENTAL STATUS EXAM NORMAL

Mental Status exam +/- normal and history or exam do not suggest gradual onset of MCI: Counsel patient: Consider rescreening in 6-12 months.

Provide Healthy Brain information

If concern re MCI consider Neuro-psychological testing

If Persistent Depression

Refer to psychiatrist, other specialists or treat as appropriate

IF FAIL EVALUATION INSTRUMENT /BORDERLINE OR POSSIBLE MCI

Proceed to Labs & Imaging

1. **Labs:** CBC, Comprehensive metabolic panel TSH, B12, RPR (if not done with screening)
2. **Imaging**: MRI (preferred; include SWI or GRE sequences, request volumetric MRI if available) or head CT (MRI required for MAB treatment)
3. **Neuropsychological testing:** (optional - consider for mild/unclear, atypical or early onset cases)

DIAGNOSIS

MCI or EARLY DEMENTIA

1. Discuss & disclose; counsel patient and family/Healthy Brain information
2. DevelopTreatment/ Management Plan; discussion of biomarker tests, disease modifying medications/ research studies
3. Access/provide resources including support groups

TYPICAL MODERATE / ADVANCED DEMENTIA

Probable Alzheimer’s Disease w/ or w/out cerebral vascular co-morbidity

1. Disclose; counsel patient and family
2. Develop Treatment/ Management Plan
3. Access/provide community resources

ATYPICAL CASES

Parkinsonian features, hallucinations, prominent aphasia, early onset, rapid progression, fluctuations, unexplained visual impairment, severe depression

Referral to neurologist, psychiatrist, or geriatrician recommended

Evaluation of Cognitive Decline and Dementia

Who should carry out an evaluation?

Physicians, Physician Assistants/Associates, Nurse Practitioners, or a clinical team member with adequate training can use the algorithm to help guide an evaluation. The clinician or team member should have a strong knowledge base concerning cognition, aging and different types of dementia, and also experience in how to disclose the diagnosis, develop a management plan, and make appropriate use of community resources.

For patients with unusual or uncommon disorders, referral to a subspecialty dementia clinic or practitioner is advisable. Patients with unusual clinical pictures, including progressive aphasia, progressive visual-perceptual impairment, apraxia, early movement disorder features, young onset of cognitive impairment (before age 65), rapidly progressive dementia, or presence of a strong family history of dementia are often best evaluated by a subspecialty clinic.

When to evaluate

The decision to evaluate could follow a screening assessment. In some situations, for example concerns about mild cognitive impairment, or cognitive problems that could affect work, driving or finances, an evaluation is appropriate.

The evaluation process

1. An evaluation typically will consist of at least one detailed visit to obtain the necessary elements of history, examination, cognitive assessment, and to determine appropriate laboratory testing, neuroimaging and other consultation or tests as appropriate. The examination would include the use of one of the recommended Mental Status Tests; it is recommended that the practitioner select one of the tests and use it consistently for all patients.
2. Obtaining collateral history from an informant to document cognitive, functional and behavioral symptoms is strongly recommended whenever possible. The history should explore risk factors, including family history of AD or other disorders, TIA or stroke, TBI, alcohol abuse, vascular risk factors (HTN, DM2), cardiac history, or systemic illnesses.
3. Discussion of the results of the evaluation, disclosure of the likely diagnosis, the prognosis, and an outline of treatment options, sources of information and resources is best left for a second visit.
4. Discussion of safety concerns including kitchen appliances, home safety, medications, finances (to avoid elder abuse scams), firearms and other weapons, and driving. Driving is the only safety issue where there is a legal requirement of the provider to report to another agency; in this case the DMV for their review and potential testing.
5. Referrals and additional testing as a result of the evaluation require specific clinical expertise. They may include:
    - Psychiatric assessment.
    - Neuropsychological testing.
    - Additional medical evaluation.
    - Genetic counseling.
    - Biomarker testing: Neuroimaging testing, e.g., MRI, or CT; in some instances FDG PET, blood tests for p-Tau217 are becoming available as diagnostic aids for Alzheimer's. If the patient is a candidate for anti-amyloid immunotherapy, a confirmatory test for amyoid pathology, such as CSF or amyloid PET, and MRI.

Recommended Evaluation Instruments

Informant surveys

Informant surveys may be given or even sent out to caregivers prior to the evaluation appointment. Reproducible copies are included in the back of this booklet.

Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)

https://www.alz.org/media/documents/short-form-informant-questionnaire-decline.pdf

https://rsph.anu.edu.au/research/tools-resources/informant-questionnaire-cognitive-decline-elderly

Quick Dementia Rating Survey (QDRS)

https://alz-journals.onlinelibrary.wiley.com/doi/10.1016/j.dadm.2015.03.003

Patient Evaluation Instruments

Some of these instruments require remuneration to the copyright holder. The clinician is advised to become knowledgeable and comfortable with one of these, and to use it consistently with patients.

The Montreal Cognitive Assessment (MOCA)

Public domain: www.mocatest.org/

Normal Range: 26 – 30, for people with < HS education, add 1 point to the total score

The MOCA is a cognitive test that briefly assesses executive/visuospatial function, memory, language, attention, calculation and orientation. Cut-off scores have been developed and it has been tested in the diagnosis of AD, DLB and PD-related disorders. Translated versions are available, in many languages, and there are three alternative versions in English.

Although the MOCA may be used as a stand-alone test, and has relatively high sensitivity for the diagnosis of dementia, it is less sensitive for MCI or mild dementia. In that setting, additional testing, either office-based if the clinician has appropriate knowledge or skills, or by a neuropsychologist, is strongly recommended.

Use of the MoCA currently requires registration at a website, viewing of instructions about how to administer the MoCA and payment of a fee to the copyright holders. MoCA also has a telehealth instrument available.

Quick Mild Cognitive Impairment (qMCI)

Public domain: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3633367/

Identifying mild cognitive impairment (MCI) is challenging. The qMCI was developed as an efficient screening test for MCI with sufficient sensitivity and specificity for use in busy clinical practice. The Qmci was shown more accurate than the ABCS 135, 6CIT, GPCOG, SMMSE and had similar sensitivity but greater specificity than the MoCA in differentiating MCI from normal.

St. Louis University Mental Status (SLUMS)

Public domain: https://www.slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/assessment-tools/mental-status-exam.php

Normal Range: 27–30; MCI: 21–26; Dementia: 1-20

30-point questionnaire that tests for orientation, memory, attention and executive function. Better at detecting mild neurocognitive disorder than MMSE.

The Mini-Mental State Exam (MMSE)

The Mini-Mental State Exam (MMSE) was originally developed as a general cognitive screening test. Since 2000, it has been licensed through Psychological Assessment Resources (PAR). There are a number of other instruments on their website as well, including the DRS-2, OACS, BPAD, and Cognistat 5.

https://cgatoolkit.ca/Uploads/ContentDocuments/MMSE.pdf

Cutoff scores on these instruments should be treated cautiously - beyond simply looking at the total score, it Is often helpful to review the areas where a patient loses points to try to identify a cognitive profile (e.g., Impairment of memory and orientation would point to an amnestic disorder).

Other cognitive instruments:

Rowland Universal Dementia Assessment Scale (RUDAS)

The **RUDAS** was developed for assessment that consider people with lower levels of literacy.

Public domain: https://www.dementia.org.au/resources/rowland-universal-dementia-assessment-scale-rudas

Measure/Assess IADLs

The Functional Activities Questionnaire (FAQ) is a validated instrument that assesses level of performance of 10 different complex (Instrumental) activities of daily living. It should be given as an Informant questionnaire.

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

Definitions of Specific Cognitive Impairment Types

As detailed earlier, the latest DSM-5 manual uses the term "Major Neurocognitive Disorder" for dementia and "Mild Neurocognitive Disorder" for mild cognitive impairment. This Guidelines booklet on Alzheimer's resources uses the more familiar terminology, as the newer terms have yet to be universally adopted.

Mild Cognitive Impairment

Mild deficit in one (single domain) or more than one (multi-domain) cognitive domains: memory, executive function, visuospatial, language, attention. Intact instrumental ADLs (IADLs) and basic ADLs do not meet criteria for dementia.

Alzheimer's Disease

Most common type of dementia (60–80% of cases). Gradual onset and progression of memory loss, disorientation, impaired judgment/problem solving, and language. Behavioral changes may include apathy/depression, and delusions. Social skills are typically preserved.

Dementia with Lewy Body Disease or Parkinson's Dementia

Second most common type of neurodegenerative dementia (up to 20% of cases). Hallmark symptoms include visual hallucinations, REM sleep disorder, parkinsonism, and significant fluctuations in cognition.

Fronto-Temporal Dementia

Third most common type of neurodegenerative dementia primarily affecting individuals in their 50s and 60s. Defined by EITHER marked changes in behavior/personality OR language variant (difficulty with speech production or loss of understanding of word meaning). More recently, the term Fronto-temporal Lobar Degeneration has been used to include behavioral variant FTD, Progressive Aphasia, and movement disorders with a prominent cognitive component, namely Corticobasal Syndrome (CBS) and Progressive Supranuclear Palsy (PSP)

Vascular Dementia

Although relatively rare in pure form (10% of cases), vascular changes often coexist with Alzheimer's disease, and mixed dementia (Alzheimer's plus vascular) or multiple etiology dementia is often found in older individuals. Symptoms often overlap with those of AD; history or physical exam findings may suggest stroke(s). T2 FLAIR MRI is helpful.

Normal Pressure Hydrocephalus

Normal pressure hydrocephalus (NPH) is a brain disorder in which excess cerebrospinal fluid (CSF) accumulates in the brain's ventricles, causing thinking and reasoning problems, difficulty walking, and loss of bladder control.

Assessing MCI

Clinicians should consider MCI and not assume that reported cognitive concerns are related to normal aging. Family members often provide important collateral history, e.g., regarding the patient sometimes forgetting information, having trouble in new and unfamiliar situations, having trouble with more complex aspects of work, managing money, driving, using a cellphone or a computer. Clinicians should know how to distinguish these symptoms from age-related cognitive changes such as difficulty with retrieving words or losing one's train of thought. In a significant number of cases, MCI is the earliest manifestation of forthcoming dementia.

Clinicians should not rely on a history of subjective memory concerns alone, and should use validated assessment tools as recommended in the screening section, including identification of reversible conditions or factors. For patients who perform at a borderline on screening, raising the question of MCI, clinicians should perform a more formal clinical assessment, with tools such as the MMSE, MoCA, SLUMS or qMCI, and assess for the presence of functional impairment related to cognition.

Going beyond office-based assessment, formal neuropsychological testing can be extremely helpful to sensitively assess cognition. Serial assessments over time can also help monitor for changes in cognitive status.

The laboratory workup for MCI is similar to that of dementia. Brain imaging can make a contribution in all cases of MCI, e.g., MRI can help to show vascular brain changes (e.g., significant white matter disease and lacunes or large-vessel infarction) or subtle atrophy patterns in cases of neurodegeneration. Now that monoclonal antibody (MAB) therapies have been FDA approved for the treatment of MCI/mild AD-dementia, an accurate clinical and biomarker-supported diagnosis of MCI due to AD is a standard of care. Leqembi (lecanemab) and donanemab (the former is covered by CMS/MediCare) are FDA approved.

Amyloid biomarkers include amyloid PET or CSF testing for Aβ42, t-Tau an p-Tau181. Plasma tests for p-Tau217 are emerging as triage tests to precede a confirmatory amyloid test or to use as a rule in/rule out test for a sizeable percentage of patients. Those who remain in a grey zone would need a confirmatory test. MRI should be obtained in people with MCI who might be appropriate for anti-amyloid immunotherapy to evaluate other pathologies, including microhemorrhages and vascular pathology burden (best assessed by including a GRE or SWAN sequence in the MRI protocol). Whether this is done by a subspecialty clinic that is prescribing Leqembi or by a clinician who is doing a diagnostic evaluation will depend on the skill and knowledge base of the diagnosing clinician.

Research

Interested patients may be directed to clinical research focused on long-term brain health, biomarker research, or other clinical trials to assess their condition over time. The participation of individuals with MCI in clinical research is crucial to finding the most effective treatments for early symptomatic stages of AD.

Biomarker Testing

Biomarkers can detect the presence of amyloid brain pathology (amyloid PET or CSF A-beta42 or CSF p-Tau 181/A-beta42); tau aggregation and pathology (Tau PET) or neurodegeneration (MRI quantitative atrophy measures, FDG PET detects regional patterns of impaired glucose metabolism, CSF neurofilament light reflects neurodegeneration).

There has been exciting progress in blood-based biomarkers in the past decade. Among various tests, measuring plasma P-tau217 stands out as having excellent predictive value for amyloid PET under clinical development/validation as screening tests to rule in or rule out amyloid pathology. Although none of these is FDA approved at present, there are strong supporting published data for several assays using antibodies or mass spectrometry, and at least four companies are offering these tests through freestanding laboratories that they have set up.

Plasma biomarkers such as P-tau217 could be used in the workup of patients with memory complaints and can reduce the number of patients who might require a CSF test or an amyloid PET scan for a definitive Alzheimer diagnosis. Guidelines for use are being developed, which do not suggest use of the blood tests as freestanding screening tests on their own. Recommendations indicate doing a clinical screening or evaluation before considering use of one of these tests. Certain medical conditions (e.g., impaired renal function) may affect the levels, and therefore interpretation of blood-based biomarkers. The blood biomarkers are not FDA approved as of publication date of these Guidelines.

At present, we recommend that unless a clinician has acquired enough knowledge about amyloid biomarkers and their interpretation, amyloid biomarker tests are best left to subspecialty clinics and providers. Biomarker testing is not recommended for people without significant symptoms, because the predictive value of a positive test for an asymptomatic person to develop MCI or dementia is uncertain, and there are no approved treatments for asymptomatic people with amyloid buildup in their brains. Research studies, including clinical trials, are being conducted in asymptomatic people who test positive for an amyloid biomarker.

Genetic testing

Genetic variants in the Apolipoprotein E (APOE) gene, called APOE e2, 3 and 4, affect the risk of developing late onset Alzheimer's Disease. People with one copy of APOE e4 have a two-to-three-fold higher lifetime risk of Alzheimer's than carriers of the e3/e3 genotype. People with two copies of e4 have a 6-10 fold higher lifetime risk of developing Alzheimer's. These risk estimates are derived from Caucasian populations and may be different among underrepresented minorities, e.g., African Americans, Latinos and Asians.

As part of a routine diagnostic workup, we do not recommend APOE gene testing because the results do not clearly point towards or against a diagnosis. People sometimes have APOE tested through 23andme or direct to consumer companies, or as part of cardiovascular panel tests.

APOE testing is required for a patient with early AD who is going to receive monoclonal antibody therapy, to provide information related to the risk of ARIA while receiving treatment. This testing and discussion may be best left to the specialist center that will be prescribing and overseeing the antibody treatment.

There are resources for patients to review should they consider obtaining APOE testing. (See RESOURCES) Rare families with autosomal dominant Alzheimer's with multiple affected family members and very early age at onset (30-50 years) may have gene mutations in APP, PSEN1 or PSEN2. Testing for this subset of patients should be preceded by genetic counseling and a specific disclosure process.

Efficacy

Clinical guidelines and criteria for Alzheimer's disease (AD) have high sensitivity, in excess of 80-90%, but lower specificity – i.e., they may sometimes misdiagnose AD when other etiologies are present. This is more likely at the stage of MCI than dementia.

Biomarkers such as amyloid testing in CSF or amyloid imaging have high specificity, i.e., if they are negative, AD is highly unlikely.

Clinical criteria for other disorders have been less thoroughly evaluated and were mainly assessed in tertiary referral settings. Sensitivity greater than 80% has been noted for FTD and 70-80% for DLB. It is now possible to test for abnormal forms of a-Synuclein that build up in DLB through either CSF testing using a seed amplification assay (offered by AMPRION, Inc as the SynTAP test) or through skin biopsy histology (offered by CND Diagnostics).

Vascular cognitive impairment (VCI) often accompanies AD, and many people with late life dementia show mixed pathology. Vascular risk factors and CT or MRI imaging help to evaluate the likelihood of VCI.

Advantages of MRI for Dementia Diagnosis

- *Can show overall and regional brain atrophy*
- *Highly sensitive for vascular pathology*
- *Can show other lesions*
- *Contrast typically not needed*
- *Required for MAB treatment*

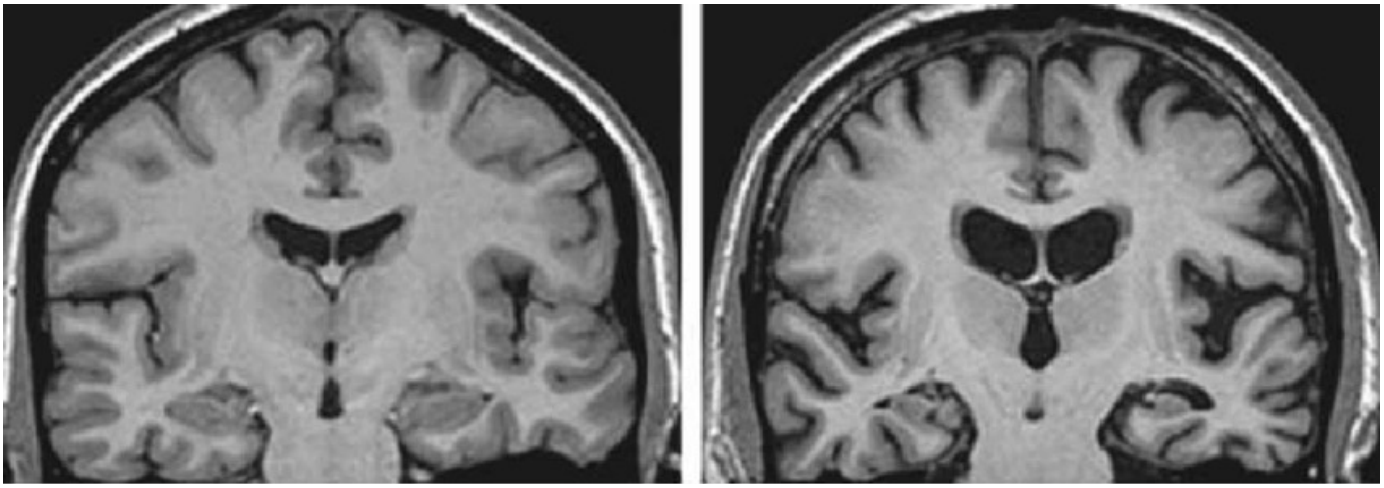
MRI vs CT for Dementia

Guidelines for the evaluation of dementia emphasize neuroimaging but do not specify head CT vs MRI. Head CT and MRI are comparable for ruling out disorders such as subdural hematoma and certain types of CNS tumors that are unusual causes of dementia. CT can also show rarefaction of white matter consistent with subcortical white matter disease due to CNS ischemia. However MRI is superior for demonstrating regional brain atrophy (e.g., in the hippocampus or parietal association cortex), which are suggestive of Alzheimer's. MRI can be combined with quantitative assessment of brain volumes to try to identify regional atrophy more precisely. MRI also can assess the CNS effects of vascular risk much more accurately, e.g., by evaluating white matter hyperintensities lacunes and micro-hemorrhage.

For Normal Pressure Hydrocephalus, certain classic measures can be done either on CT or MRI but are more precise on MRI, and additional signs can be detected. When treatment with a monoclonal antibody is planned, a baseline MRI that includes GRE or SWAN sequences is required in order to estimate the burden of microhemorrhages, which may determine eligibility for treatment.

Interested patients may be directed to clinical research focused on long-term brain health, biomarker research, or other clinical trials to assess their condition over time. The participation of individuals with MCI in clinical research is crucial to finding effective treatments for dementia.

Brain MRI in dementia



Normal Aging

Alzheimer's Disease

Volume loss in the hippocampus and temporal lobe, decreased cortical thickness, and enlargement of ventricles occur in Alzheimer's disease.

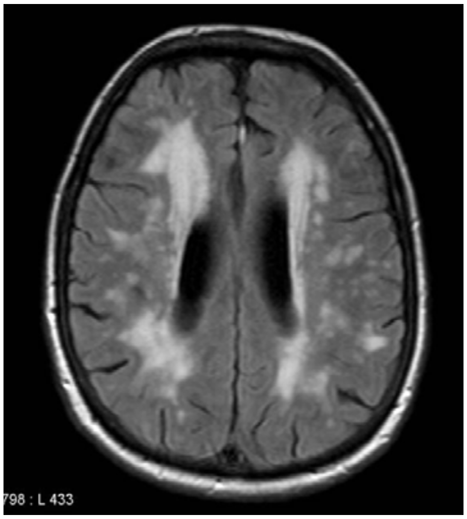
Signs of Normal Aging vs Mild Cognitive Impairment vs. Dementia

The chart below highlights how mild cognitive impairment differs from the changes seen in normal aging and dementia.*

	Normal Aging	Mild Cognitive Impairment	Dementia
Sometimes can't come up with names or words that are often recalled later	✓		
Losing things from time to time	✓		
Missing a monthly payment occasionally	✓	✓	
Difficulty coming up with words		✓	
Losing things often		✓	✓
Forgetting dates of important events		✓	✓
Trouble having a conversation and/or reading and writing			✓
Asking the same question or repeating the same story over and over		±	✓
Difficulty with basic daily activities			✓
Problems handling money and paying bills		±	✓
Becoming lost in familiar places			✓
Hallucinations, delusions, and paranoia			✓

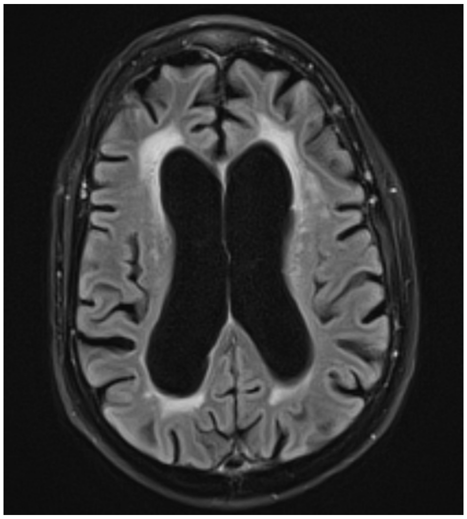
* This is not a complete list of all symptoms associated with these conditions, but it is designed to show how the symptoms differ.

Adapted from: NIH National Institute on Aging



Vascular

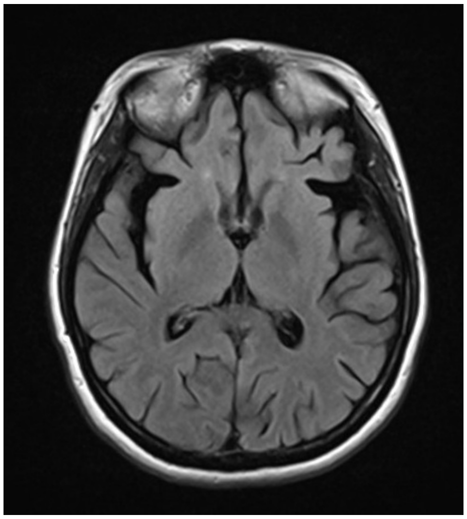
Case courtesy of Assoc Prof Frank Gaillard, https://radiopaedia.org/search?q=dementia&scope=all&lang=us



NPH

Case courtesy of Dr Mostafa El-Feky, Radiopaedia.org, rID: 75406

Online: Case courtesy of Dr Mostafa El-Feky, https://radiopaedia.org/search?q=dementia&scope=all&lang=us



FTD

Print: Case courtesy of Assoc Prof Frank Gaillard, Radiopaedia.org, rID: 50049

Online: Case courtesy of Assoc Prof Frank Gaillard, https://radiopaedia.org/search?q=dementia&scope=all&lang=us

Disclosing a Diagnosis

Once an evaluation is completed, the practitioner should be prepared to speak with the patient and caregiver or family members as a unit, and this should be done in person rather than in a virtual appointment. Often, the disclosure of a diagnosis is the maximum amount of information the patient can handle at that appointment, and the provider may want to schedule a longer, follow-up appointment to fully orient the patient and caregivers of important first steps.

The provider should assess and ask both the patient and caregiver if they feel ready to hear the results, and assess how they view the likelihood of a dementia diagnosis. How much research/reading have they already done? What has been their experience with others with dementia? What are their greatest fears?

The reasons for being able to make the diagnosis should be reviewed with the patient and caregivers/family. Once the diagnosis is stated, a pause is important to gauge the response. Launching into next steps too quickly may be overwhelming. Ask if this what they were expecting, or does it seem like a shock. Allow time for emotional responses and let tears or other emotions be expressed while maintaining compassionate eye contact or touch. This may be second nature for some clinicians but the pressure to cover the topics is always present!

Physicians may be reluctant to disclose a specific diagnosis of dementia and to mention Alzheimer's disease, as such a diagnosis may change the physician/patient relationship. Disclosure has been widely studied, and provided that it is done sensitively and with knowledge of the social and family dynamics, it is generally a helpful part of the process. Many families are relieved at obtaining closure regarding a diagnosis and explanation for the problems that they have noted. Disclosure should also include the review, assessment and discussion of medical, personal and social factors that may be impacted by dementia.

Initial Discussion and Disclosure May Cover:

- *The primary diagnosis.*
- *Contributing factors to the diagnosis (e.g., medical, neurological or psychiatric factors). Examples include depression, vascular risk factors, sleep disorders, medical comorbidity that may affect the brain, medications that may have cognitive side effects.*
- *Recommendations regarding questions such as work, driving, managing finances.*
- *Personal and home safety. This may include asking about firearms or other weapons if applicable, use of kitchen appliances, home safety, medications, finances (to avoid elder abuse scams) and driving. Driving is the only safety issue where there is a legal requirement of the provider to report to another agency; in this case the DMV for their review and potential testing.*

At the time of disclosure, impress upon the caregiver that the patient should be given extensive social support as he/she processes the information. This may take several days or longer. Inform the caregiver how to reach you during this critical period. Acknowledge that the discussion carries with it significant impact as the patient and caregivers attempt to normalize their reaction and link response to expected needs. If feasible, you may want to include other care professionals such as a social worker or psychologist to assist individuals and their caregivers to process the diagnosis. Assessing the family's coping resources and offering your medical system's and community resources will be important.

Ask, Tell, Ask. As patients and family members may have different needs for information about diagnosis, ask about and answer their questions, and prompt to assess their understanding of the information; offer educational and community resources.

Be careful not to overwhelm patient and family or give more information than they can digest at this emotional time. Encourage family not to leave individual alone for 2-3 days.

The most critical topics to cover at the next appointment:

- Medication options: Primary and proven treatment options; disclose those that are evidence based and sufficiently studied, and explain these, along with risks and benefits, as standards of practice.
- Driving – physician assessment of the patient's capacity to continue to drive, and when that should be re-evaluated. Physicians have a legal obligation to report patients with diminished capacity. (See resources for links to DMV). If uncomfortable making this disclosure, this would be an appropriate referral to a specialist.
- Finances and Legal Issues.
- How a healthy lifestyle can significantly benefit patient's long-term health.

Five Action Steps Family Caregivers Should Take

1) Establish legal responsibility and create legal documents that will be helpful to you and to your loved one.

2) Understand the diagnostic process, symptoms, and course of memory loss and dementia.

3) Care for yourself; a healthy, rested caregiver is a more effective caregiver.

4) Join a support group.

5) Plan for the future. Do research and know what lies ahead to plan accordingly. (see handouts at back of booklet to include with After Visit Summaries)

Topics for Early in the Disease Process

What to Talk About	How to Do It	Why
Medical Advance Care Planning	Ask the patient if they have selected a medical decision-maker and document the response in the EMR.	Ensure patient has a voice in their medical care regardless of how disease progresses, including minimizing unwanted burdensome care and maximizing wanted care.
	Establish with whom clinician can discuss patient care; document HIPAA form. Give patient and care partner a Health Care Advance Directive document to guide discussion and documentation.	Prior discussions with care partners and clinicians about choices can help reduce conflict and complicated grief among family and friends when patient loses capacity and decisions need to be made.
	File completed document in the EMR.	Ensure health systems can access Advance Directive and act accordingly.
Financial and Legal Advance Care Planning	Encourage patient to complete a Durable Power of Attorney designating an Agent to act on patient's behalf for all fiscal and legal decisions when loses capacity.	Prevent need for conservatorship, which can be a lengthy and expensive process that does not fulfill patient's wishes.
	Encourage patient and care partner/s to work with legal and financial advisors to execute trust/living will, etc to fulfill patient's wishes.	Working through these decisions early in the disease process empowers the patient and assures their wishes are preserved.
	Suggest family research eligibility for public assistance programs. Refer to community resources, social workers, public agencies.	Medicare and MediCal, along with County and State programs may provide significant financial benefits, as dementia care is very expensive long term, and a variety of services may be needed.

What to Talk About	How to Do It	Why
Caregiver Skills Training and Safety	Encourage care partners to educate themselves on disease process, effective communication, safety issues, etc. through online and print materials, classes.	A well-rested and prepared caregiver is able to provide the patient with the best care through this journey. Removing guns/ammunition important for family safety.
Patient and Caregiver Support	Encourage both patient and care partners to learn about community resources, join support groups and receive peer support.	Patients and caregivers benefit from the wisdom of others also on the journey.
	Discuss options for respite services and assistance with activities of daily living. Discuss that "it takes a village" and that care partners cannot do everything alone.	Caregivers must care for themselves and maintain those parts of their daily lives most important in order to be effective caregivers.
Long term care living arrangements	Encourage patient and family members to have frank discussions about future goals and expectations; what home modifications may be appropriate, what would patient not want their caregivers to do, i.e., incontinence, etc.	Having family discussions early in the disease process will help dissuade any guilt feelings later or conflicts among family members about the wishes of the individual with dementia.

Brochures covering many of these aspects of planning are available from the National Institute on Aging (NIA) and can be a helpful handout.

Initial Use of FDA Approved Medications for Cognitive Symptoms of Alheimer's

After a diagnosis and disclosure of Alzheimer's disease, many patients and caregivers may be looking for therapeutic options. **Cholinesterase inhibitors** have been extensively studied for symptomatic effects on cognition in Alzheimer's disease. Clinical trials and studies show significant but small benefits vs. placebo among individuals with mild through severe Alzheimer's. Overall, they may stabilize cognition or slow its progression but do not slow the progression of the underlying disease. The most common cholinesterase inhibitors are: donepezil (Aricept®), rivastigmine (Exelon®) available in transdermal patch form, and galantamine (Razadyne®).

These medications can be continued as long as no (or minimal) negative side effects occur. Different doses of cholinesterase inhibitors are available, and usual practice is to start a patient on a low dose and titrate to a higher dose as tolerated.

Approximately 23% of patients started on donepezil will experience some element of GI adverse effect, which is the most prominent negative outcome from the agent. If a patient wishes to continue acetylcholinesterase inhibitor therapy but cannot tolerate donepezil due to the GI effects, the practitioner can consider the rivastigmine patch, which bypasses first-pass metabolism and thereby has a lower GI adverse effect profile. If a patient experiences adverse effects, it is important to readdress therapy with the patient and/or their caregiver as any clinical adverse effect likely outweighs the statistical but not clinical benefit of the therapy. Additionally, if no benefit is shown from acetylcholinesterase inhibitors at optimal doses, it is recommended to discontinue the agent due to lack of effect. The American Geriatrics Society included this recommendation to stop acetylcholinesterase inhibitors if side effects are induced or lack of effect on cognitive tests is found in their *2014 Choosing Wisely* recommendations for the American Board of Internal Medicine's Choosing Wisely initiative.

Potential Side Effects of Both Type Medications

	Acetylcholinesterase Inhibitors	Memantine
GI (most common side effects)	Nausea, vomiting, diarrhea, abdominal pain, constipation, fecal incontinence, dyspepsia	Constipation, vomiting,
Cardiac	Bradycardia, hypotension, heart failure,	Hypertension, dyspnea, dizziness
Neurologic	Arthralgias, tremor, vertigo, gait disturbance, falls	
General	Anemia, Cough, rash, pruritis, conjunctivitis, blurred vision, UTI, flu-like symptoms	Fatigue, pain, somnolence, headache, cough,
Neuro-Psychiatric	Agitation, anxiety, wandering	Confusion, hallucinations, anxiety, depression, aggression

Memantine (Namenda®) has been shown to have small benefits on cognition and behavior in people with moderate to severe AD, either alone or added to a cholinesterase inhibitor. Memantine did not show benefit in mild AD. Memantine does not slow progress of the underlying disease. The agent has a more favorable adverse effect profile than the acetylcholinesterase inhibitors, and generally is well tolerated; however, as the clinical benefit is less clear, treatment decision should be based on the patient's preferences after a discussion of risks and benefits with the patient and/or their caregiver.

While there are combination pharmaceuticals available, e.g., Namzaric, which combines donepezil and memantine, monotherapy is likely as efficacious as combination therapy with fewer side effects and lower cost. It is possible to combine a cholinesterase inhibitor and memantine in patients with mild AD, but randomized clinical trials have not shown the efficacy of this combination.

There is FDA acceptable evidence that while these medications may alter several measures of dementia, many clinicians remain unsure of their benefits or impact on long term course. In addition to any benefits for function or behavior, prescribing medications can offer hope to the family at a time of great distress. Practitioners should discuss and weigh risks/side effects vs benefits with patients and caregivers, and discontinue use of these medications should side effects persist.

To date, no nutraceutical has been found to have clinical or statistical benefit for dementia. Non-pharmacologic interventions are likely to have an impact on AD, although this is harder to study and quantify.

Like many chronic conditions, healthy diet, physical activity, and social interaction have been proven to be the most effective therapies for Alzheimer's disease and related dementias. The Clinical Roundtable has created patient education tools that providers may include in the After Visit Summary on simple tips to improve brain health along with overall health. This is particularly important when a diagnosis of MCI is made, as only a proportion of MCI cases develop into full dementia, and overall health improvement has been shown to improve cognitive function in those with MCI. See the resources in the back of the booklet for the Healthy Body, Healthy Mind sheets, available in five languages on the website.

New Disease Modifying Medications

Monoclonal antibodies that target abnormal forms of amyloid and help to remove amyloid from the brain have undergone extensive clinical trials in relation to AD in the past decade. Some general observations have emerged:

1. Antibodies that target amyloid and remove it from the brain need to be given at high enough doses that they clear much or all of the amyloid detectable by PET scan over a relatively short period. Two antibodies, lecanemab and donanemab, that have completed phase 2 and recent phase 3 trials in MCI or mild dementia due to AD (Early AD), markedly reduced amyloid PET during 18 months of treatment.
2. Treatment is more likely to show clinical benefit vs placebo when started in patients with mild symptoms (therefore MCI or mild dementia – operationalized as MMSE scores of 22 or higher for lecanemab and 20 – 28 for donanemab).
3. Treatment is associated with slowing of clinical progression by about 25 – 35% vs placebo on standard clinical trial measures such as the CDR sum of boxes, the ADAScog and the ADCS-ADL (or related measures) over 18 months of treatment.
4. Treatment with anti-amyloid antibodies is associated with risks, the most common of which are visible on MRI, and are categorized as Amyloid Related Imaging Abnormality (ARIA):

A. intracranial bleeding may occur, thought due to antibodies binding to amyloid deposits in arterioles affected by amyloid angiopathy, or antibodies being cleared across vessels with amyloid angiopathy. This is most often asymptomatic and occurs during the first three to six months of treatment. Microhemorrhages can be detected on MRI by showing iron via GRE or SWAN sequences. Larger hemorrhages may occur and may result in symptoms. The MRI appearances are called ARIA-H.

B. Focal areas of inflammation may occur around blood vessels in the brain with or without associated hemorrhage. These are thought due to focal disruption of the blood-brain barrier and are associated with edema triggered by leakage through the vessel. These are called ARIA-E.

C. In clinical trials and clinical practice, obtaining a baseline MRI and interval MRIs during the first six months of treatment to monitor ARIA, and an MRI if a patient taking an anti-amyloid monoclonal antibody has symptoms such as sudden headache, seizure, or focal findings suggesting a stroke.

D. APOE e4 carriers have a dose-dependent effect of higher rates of ARIA when treated with an anti-amyloid antibody. APOE genotyping is recommended before prescribing lecanemab in order to discuss these risks with the patient and determine whether or not to prescribe the drug.

Lecanemab and donanemab received accelerated approval by the FDA for the treatment of MCI or mild dementia due to AD. In 2023, lecanemab received full approval and CMS (Medicare) coverage in the summer of 2023, and donanemab received FDA approval in June 2024. There are **guidelines about how to evaluate patients as candidates for lecanemab treatment (Leqembi).**

In outline these include:

- Diagnosis of MCI or Early AD
- Positive amyloid biomarker test (PET or CSF)
- Stable medically and not taking an anticoagulant medication such as Coumadin or a direct oral anticoagulant (DOAC) such as apixaban (Eliquis), dabigatran (Pradaxa), or rivaroxaban (Xarelto)
- MRI shows low or zero burden of microhemorrhages (up to 4 were allowed at baseline in the lecanemab trials)
- History of a stroke or seizure in the past 12 months
- Presence of a knowledgeable caregiver/informant/family member.

Other details are listed in a recent Guideline paper (Cummings, J., Apostolova, L., Rabinovici, G.D. *et al. Lecanemab: Appropriate Use Recommendations. J Prev Alzheimers Dis 10, 362–377 (2023). https://doi.org/10.14283/jpad.2023.30*

After initiating treatment, infusion reactions need to be monitored and treated as appropriate, and monitoring for ARIA with scheduled MRIs and educating the patient about symptoms that could indicate ARIA and warrant an ED visit. After ARIA develops, there are guidelines for when and for how long to withhold further infusions.

Management of Leqembi treatment is best done by a specialist and team with expertise and knowledge about Alzheimer's Disease, ARIA and about tracking changes in AD symptoms ad severity and in biomarkers over time.

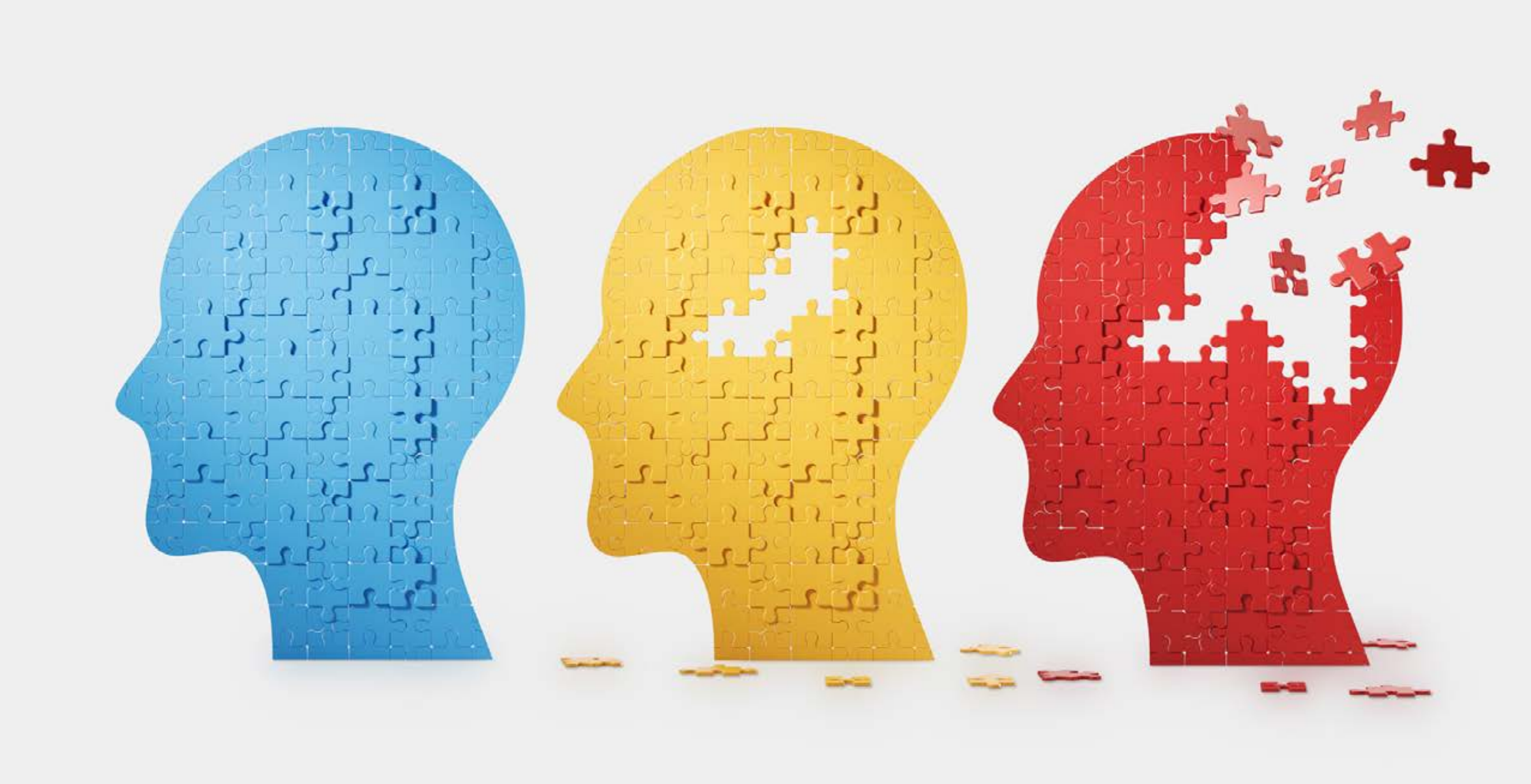
Nonpharmacologic treatments effective for patients diagnosed with MCI

Studies have shown that for patients with MCI, treatment with exercise training for six months is likely to improve cognitive measures (moderate confidence in the evidence based on 2 Class II studies). Individuals with MCI are encouraged to practice the same behaviors as individuals without MCI; eat a healthy diet, stop smoking, use alcohol in moderation, remain physically active, challenge their brain on a regular basis and maintain, and possibly expand, social connections.

Pharmacologic treatments for patients diagnosed with MCI

A number of studies have concluded that the use of cholinesterase inhibitors, memantine, vitamins, and other supplements were proven not to be effective for individuals with MCI. Further, the use of cholinesterase inhibitors and memantine are not FDA approved for MCI, and might be considered as off-label prescriptions. There are a number of sources of evidence to support this recommendation, e.g., the American Academy of Neurology (https://aan.com).

Recent success in anti-amyloid clinical trials has shown that treatment with anti-amyloid antibodies that are capable of clearing amyloid from the brain reasonably rapidly are associated with significant slowing of decline on cognitive and functional assessment. See section above for more information on Monoclonal Antibody therapies



Care Management through the Disease Stages

Living meaningfully with a diagnosis of dementia can be achieved, AND it requires planning for the different stages of disease progression. Planning involves conversations and education, accessing resources and supports, and receiving ongoing medical attention.

Family members and individuals with dementia may not often have had previous conversations about goals of care and treatment preferences, so it is important for the provider to encourage these discussions. Alzheimer's disease is a chronic, progressive, ultimately terminal illness. The time course is generally around 6–10 years from diagnosis to death, but can vary from 3–20 years.

- Common causes of death directly related to Alzheimer's disease are aspiration pneumonia and hypovolemic shock related to cessation of eating and drinking.
- Alzheimer's patients may also develop and die from infections other than aspiration pneumonia, including UTIs, community- or facility-acquired pneumonias, and infected pressure ulcers.
- They may also suffer strokes, myocardial infarction, arrhythmias, pulmonary emboli, and other common geriatric conditions.
- Patients may die of other causes (e.g., trauma) or comorbid (e.g., COPD) illnesses during the progression of their dementia.

Throughout the course of the disease, it is important for clinicians to show empathy and communicate with caregivers that the provider understands the gravity of the road they are traveling.

- This will take time to listen.
- If possible, allow for longer patient visits and schedule regular check-in appointments.
- It will be an opportunity to also assess caregiver stress and depression, and recommend separate appointments and even treatment for caregivers as appropriate.
- See Section on Caring for the Caregiver for more information.

Between diagnosis disclosure and end of life, there may be many years in which to educate patients and caregivers on the progress of the disease.

What to Discuss with Patients and Family Members, and When

Within a couple weeks	Within first two months	Ongoing at appointments
Identify primary decision maker, medical surrogate/agent (preferably under an advance directive, e.g. durable power of attorney for health care); document patient preference if they have capacity	Suggest family identify and list all important documents, including Advance Directives, passwords, etc.	Assess for behavioral symptoms, caregiver stress; introduce care options appropriate to family values, beliefs and budget
Discuss legal and financial issues for family to consider; encourage consultation with legal and financial professionals	Assist family to identify care support team and long-term preferences, if known, of individual with ADRD	Encourage using community resources and services, including support groups and respite
Discuss what the patient would like to see for their future while they have the capacity to make decisions	Introduce POLST form and choices for specific interventions: • CPR • Defibrillation • Intubation/Ventilation • Hospitalizations • Artificial nutrition (Enteral feeding tubes) • Selective treatments and surgeries	Discuss planning in case of illness of the caregiver Providers should remain on the alert if family members appear to be taking over all decision-making too soon
	A diagnosis of ADRD requires physician notification of the DMV	Discuss optimal communications
		Clinicians are mandated reporters for elder abuse and fiduciary abuse when suspected. Clinicians should have a low threshold to make reports to Adult Protective Services (APS) if there is any reasonable suspicion that abuse or neglect may be occurring

Advance Care Planning

Advance care planning is very important for patients with dementia, and should be undertaken as early as possible after diagnosis while the patient has capacity to make decisions about their own care (see page 26 regarding information to discuss at diagnosis). It is prudent not to bring up advance care planning simultaneously with sharing the initial diagnosis, as it may be too much information for the patient and caregiver to absorb. Patients who have already formulated advance health care directives may want to update them, and those who have not completed an AHCD, and who still have decision-making capacity, as with most patients in early stage dementia, should be strongly encouraged to execute such a document immediately. These documents should make it clear who the preferred designee(s) is(are) to make health care decisions on their behalf if and when the patient becomes incapacitated. If there is no designee, the form may still be important so that all providers know their wishes.

POLST has been available to seriously ill and frail Californians since 2009. POLST orders are portable across care settings and must be followed by health care professionals, including first responders. Failing to honor POLST orders carries potential for civil and regulatory exposure. While POLST forms are generally recommended for those in the last year or two of life, patients with early dementia who definitely do not want aggressive interventions may wish to complete these, and their physicians should assist in this process. Specific interventions to discuss include:

- CPR
- Defibrillation
- Intubation/Ventilation
- Hospitalization
- Artificial Nutrition (enteral tube feeding) and hydration
- Selective treatments (e.g., dialysis, transfusions, surgery)

Resources for making informed decisions can be found at:

- Coalition for Compassionate Care of California https://coalitionccc.org. Useful patient education decision aids are available that review CPR, Ventilators, Tube Feeding, Hydration. They are available in multiple languages, are written at very low health literacy levels, and can be extremely useful. Decision Aid Listing
- Resources indicating that tube feeding is contraindicated for persons with advanced dementia (AAHPM: 3.6.1._AAHPM_5_Things_-_Choosing_Wisely.pdf; AMDA: https://res.cloudinary.com/paltc/image/upload/v1666280559/docs/AMDA_Choosing_Wisely_Statements_10_xtww3e.pdf; AGS: https://www.healthinaging.org/tools-and-tips/tip-sheet-feeding-tubes-those-advanced-dementia)
- Caring Advocates My Way Cards (http://caringadvocates.org/card-sorting.php) To ascertain patient preferences through the use of cards.

Like all advance care planning discussions, these conversations are probably best undertaken by a primary care clinician who knows the patient well, but when there is family conflict or an unusually complex scenario, patients and families can be referred to palliative care specialists. However, these conversations can be deeply meaningful and usually well accepted and appreciated when undertaken by the primary care physician who knows the patient and family best. The CPT codes for advance care planning are discussed on page 76 or at: https://www.cms.gov/medicare-coverage-database/view/article.aspx?articleid=58664

Topics to discuss during advance care

CPR

It is important to note that CPR is rarely successful in the frail elderly; statistics show that it is ineffective 90 – 95% of the time for older adults, even lower when the arrest is unwitnessed. Further, almost all "successful" resuscitations with return of spontaneous circulation (ROSC) result in patients being intubated and ventilated. They also often suffer medical complications such as aspiration pneumonitis, and physical trauma such as rib and sternal fractures, or hepatic or splenic damage.

Tube Feeds

It is worth discussing tube feeding early on and actively discouraging consideration of a feeding tube when patients reach the stage of advanced dementia, despite family concerns about "starvation" and the tendency to associate food/nutrition with nurturing and love. In addition to the risks of aspiration, pneumonia and complications are directly related to the tube (such as intra-abdominal abscesses). There is good evidence from the American Geriatrics Society, the American Academy of Hospice & Palliative Medicine, and AMDA – The Society for Post-Acute and Long-Term Care Medicine, that feeding tubes are an inappropriate intervention in advanced dementia patients. Providers should check with their health system's policies and procedures. Despite best practices, there is evidence that feed tubes are still being offered and placed in this population. Feeding tubes are associated with higher rates of delirium and pressure ulcers and have not been demonstrated to prolong life. Thickened liquids and pureed diets, while frequently ordered, when dysphagia develops in dementia patients may not be well tolerated. Consider a palliative medicine referral if there are concerns about these issues.

Use of Ventilators

The use of ventilators for an individual with dementia could be very disorienting, uncomfortable, painful, and bewildering, and can prolong an unpleasant death. Individuals are generally heavily sedated, and it has been shown that ventilators generally do not improve prognosis in this population, although if the reason for respiratory failure is treatable (e.g., aspiration pneumonia), they may survive longer and be able to successfully wean from the ventilator.

At the end of life, patients with dementia and most other illnesses lose interest in food and fluids. It is part of a natural dying process, and dying from dehydration, while it has an unpleasant reputation in the public eye, is actually one of the more benign ways to die. In fact, often no medication for symptom relief (such as opioids or benzodiazepines) is necessary. Simple measures like moistening the inside of the mouth often suffice. Once all intake ceases, patients generally die in 7–14 days; these patients are usually on hospice. Reassuring patients and families that this process is natural and appears to be painless can be very helpful and appreciated.

The GEMS Brain Change Model

Care Management through the Disease Stages

Developed by Teepa Snow and based on the Allen Cognitive Scale, the model recognizes six different brain states. With dementia, while the progression, pattern, and changes may look very different for each type of dementia, the movement through the GEMS is somewhat predictable. The use of discussing dementia in terms of these GEMS may be easier for patients and caregivers to relate to than staging proposed by the Alzheimer's Association or other professional organizations.

Each of the GEMS identified by Ms. Snow includes information on what the individual with dementia is capable and interested in knowing, and what they may be experiencing. This information and details is available at www.teepasnow.com.

Non-Pharmacologic Management of

Gems	Basic Characteristics	Interests
Sapphire 	• Normal aging • May feel blue due to the changes of aging • No significant changes in cognition • Difficulty learning new things	• They like to choose • May need help or modifications to enjoy interests • Leaving a legacy, fulfilling promises, or making a difference
Diamond 	• Can do OLD habits and routines • Becomes more territorial OR less aware of boundaries • Likes the familiar and has difficulty with change • Tells the same stories, asks the same questions	• Things that make them feel competent and valued • What they enjoy and who they like • Where they feel comfortable but stimulated • What gives them a sense of control
Emerald 	• Gets lost in past life, past places, past roles • Gets emotional quickly • Loses important things and thinks someone stole them • Needs help, DOES NOT know it or like it	• Doing familiar tasks • Engaging with or helping others • Having tasks or a purpose • Does better with a friend than a boss
Amber 	• Need to have sensation (touch, look, feel, smell, or taste) • Private and quiet or public and noisy • Will get into things • Can't wait or put up with things that take time	• Things to mess with or explore • Textures, shapes, colors, movement • Verbal sounds that are familiar (music) • Tastes—usually more sweet or salty
Ruby 	• Fine motor skill is lost or stops in the mouth, eyes, fingers, and feet • Hard to stop and hard to get going • Limited visual awareness • One direction—forward only, can't back up safely	• Walking a routine path • Watching others, checking them out • Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap • Rhythmic movements and actions
Pearl 	• Not aware of the world around them (most of the time) • Hardly moves • Problems swallowing • Hard to get connected	• Pleasant and familiar sounds and voices • Warmth and comfort • Soft textures • Smooth and slow movement

Dementia

There is significant discussion in these Guidelines of pharmacologic treatment options. Evidence has proven, however, that non-pharmacologic interventions are often more helpful for both individuals with dementia and their care partners. What works to preserve cognitive capacity are the same strategies as for other chronic diseases: healthy diet, physical activity, social interactions, and brain-stimulating activities. The Clinical Roundtable developed a Healthy Brain Tool (available in multiple languages) to assist providers educate their patients on the strategies to improve overall health, including maintaining brain health. These tools can be uploaded to the EMR and used as an After Visit Summary attachment. The English version is included in these Guidelines and other languages are available at the website.

The Program of All-Inclusive Care for the Elderly (PACE) is a national program that serves over 20,000 older individuals with chronic disease in California alone. The community-based PACE centers coordinate and provide preventive, primary, acute and long-term care services along with socialization, meals and psychosocial supports. The model has proven to significantly reduce costs of care and keep frail seniors in their homes longer with high rates of satisfaction.

PACE covers the care patients would receive through Medicare and Medi-Cal if medically necessary. To be eligible, a person must be 55 years or older, be determined eligible at the nursing home level of care by the California Department of Health Care Services (DHCS), and be able to live safely in their home or community at the time of enrollment. A listing of San Diego-based PACE programs is included in the Resources for Caregivers sheet.

For those who may not be considered at the nursing home care level, other evidence and community-based interventions may provide essential elements of comprehensive care for dementia. Medicaid (MediCal) patients are able to access many of these services through their insurance provider with physician referral. Medicare is also assessing the value of providing these services through their Guiding an Improved Dementia Experience (GUIDE) innovation project, to be implemented at pilot locations around the country. The practices of the GUIDE model can be implemented by practitioners and health systems depending on their capacity and resources. Services to improve quality of life, reduce burden and stress on family caregivers, and prevent or delay long-term nursing home care include education and training, care navigation and an interdisciplinary care team, referrals to local community services, medication management, and respite care.

Medications to Avoid for Patients with Dementia

A list of medications used for a variety of purposes that should be avoided or used with caution for patients with dementia is included in the Beer's Criteria. Of particular note: anticholinergics should be avoided whenever possible, especially antihistamine OTC sleeping aids and meds for overactive bladder. Some medications have side-effects or can interact negatively with other medications. This can add to the symptoms patients are experiencing. Inform patients not to stop medications on their own, but to work with you to titrate them down to reduce negative reactions.

Avoiding Suboptimal Prescribing and Polypharmacy

Managing the care of an individual with dementia can be particularly difficult, as there may be a number of comorbid issues being addressed by a variety of subspecialists, requiring a number of prescription medications. This may result in behavioral issues (see section on Addressing Behavioral Issues for more information).

It is important to assess all medications prescribed, use the medicine most appropriate for an older patient and avoid:

- Polypharmacy (too many medications) and the prescribing cascade.
- Prescribing a medication from an essential category of medication that is not senior friendly.
- Prescribing a dose of an essential medication that is larger than needed.
- Prescribing a medication to be taken at a time of day that is not optimal (e.g. diuretics at bedtime).
- Not prescribing a needed medication (e.g. a pain medication).
- Long-term use of opiate pain medication in patients other than those with terminal cancer.

The American Geriatrics Society (AGS) Beers Criteria

The Beers List (https://agsjournals.onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.18372) is perhaps the most widely used set of consensus criteria for safe medication for older adults and updated regularly by the American Geriatrics Society. It lists potentially inappropriate medications (PIMS) that are typically best avoided by older adults in most circumstances or under specific situations, such as certain disease states.

The Beers Criteria are organized into five general categories:

1) Medications considered as potentially inappropriate,

2) Medications potentially inappropriate in patients with certain diseases or syndromes,

3) Medications to be used with caution,

4) Potentially inappropriate drug-drug interactions,

5) Medications whose dosages should be adjusted based on renal function.

The 2023 criteria incorporate exceptions to the criteria that the interprofessional expert panel deemed clinically appropriate and, as in recent past versions of the criteria, include rationales, recommendations, and ratings of both the quality of evidence (high, moderate, or low) and the strength of the recommendations (strong or weak).

- The strong recommendation for antidepressant medications that are highly anticholinergic, including all of the tricyclic antidepressants and paroxetine, is to avoid their use, and is based on high quality of evidence.
- For patients with dementia or cognitive impairment, four classes of medications are recommended to avoid: anticholinergic, antipsychotics when used chronically or persistently as needed, benzodiazepine, and “Z-drugs” (eszopiclone, zaleplon and zolpidem).
- Brexpiprazole (Rexulti) is the first drug to obtain FDA approval for the indication of dementia-related agitation. The 2023 Beers criteria used evidence published between 2017 and 2022, so information about brexpiprazole for dementia-related agitation was not available for review.
- For patients with a history of falls or fractures five categories of medications are listed as “avoid” including several classes of antidepressants. The criteria state that for selected classes of antidepressants the evidence for an association with falls is mixed, but newer evidence suggest that SNRIs, such as duloxetine and venlafaxine, may increase fall risk.
- Although most antipsychotics are considered inappropriate for patients who have Parkinson disease with psychosis, the guidelines recommend using pimavanserin (Nuplazid), quetiapine (Seroquel), and clozapine (Clozaril) cautiously.

- In the 2023 criteria there is a section on deprescribing which includes links to two potentially helpful resources.

Medication De-Prescribing

The geriatric mantra of de-prescribing should be initiated early and continued diligently, particularly for patients in a congregate living environment. When considering de-prescribing it is important to review on a routine basis the entirety of a patient's medication list. Each medication should be reviewed to answer the questions of: what is the drug's purpose, is the drug granting benefit that outweighs the risk, is the drug senior-friendly, is the drug dosed according to geriatric guidelines, are any drugs missing from the regimen that should be prescribed, and are there any drugs that can be consolidated to a single agent to reduce pill burden. De-prescribing includes a review of any over the counter medications or supplements.

Drugs that are high yield for review in patients with advanced dementia include:

- Anticholinergics (including common drugs for overactive bladder) promote delirium. It is advisable to use a tool such as the anticholinergic burden index (see table page 128) for assessing which medications have anticholinergic action and attempt to minimize the total number of these agents, substituting when possible for an alternate medication.
- Antihistamines (including many OTC sleep aids that contain diphenhydramine) promote delirium. These should be utilized with caution, if at all, in patients with dementia.
- Opioids, sedatives, and some classes of antidepressants increase the risk of falls.
- Blood pressure medications: The JNC-8 guidelines recommend a blood pressure target of less than 150/90 for the elderly so as to avoid hypotension and minimize falls. Certain blood pressure medications are on the Beer's list as ones to avoid in the elderly, most notably hydrochlorothiazide and clonidine.
- Consider stopping all non-essential drugs, especially those that require many years to show benefit. For instance, if an elderly patient with dementia is taking a baby aspirin or statin for primary prevention it is likely that neither of these medications' benefits outweigh their risks and should be stopped.
- Antipsychotics are dangerous and should be used as a last resort for extreme behavioral or psychotic symptoms (such as frightening hallucinations).
- Benzodiazepines tend to disinhibit behavior, sometimes exaggerating rather than alleviating anxiety or agitation. They should be avoided whenever possible.
- Cholinesterase inhibitors and memantine have their own side effects (especially nausea, anorexia and bradycardia for the cholinesterase inhibitors) which may become severe in patients with advanced AD. When the patient is already institutionalized, or they are progressing despite the medications, strong consideration should be given to discontinuing these drugs.

Certain vitamins and over the counter supplements can have adverse effect in the elderly. For instance, multivitamins with minerals contain iron which increases the risk of constipation, which if unrecognized can be a delirium contributing factor. The literature does not support the use of multivitamins in the elderly due to lack of any morbidity or mortality benefit, but rather a targeted supplementation with vitamins based on laboratory finding of specific vitamin deficiencies.

(Ann Intern Med. 2006;145(5):364; Arch Intern Med. 2011;171(18):1625).

No supplements for “cognitive enhancing” are recommended. To date evidence has not supported the use of supplements such as vitamin E, Prevagen, zinc; other agents have had no consistent evidence of benefit but risk of significant drug-drug interactions such as gingko biloba. When weighing the risks and benefits of homeopathic agents it is especially important in the elderly to consider how the agent will interact with prescribed pharmaceuticals.

A case in point is that of Percepta, which is a plant-based agent marketed as a “memory support.” The core component of Percepta is Cat’s Claw, which is an herb that is a potent inhibitor of CYP3A4 and hence can interact with many prescribed medications including anticoagulants, statins, HIV medications, and diuretics. Additionally Cat’s Claw has been shown to increase bleeding risk which could have a significant morbidity for older adults. As there has not been rigorous study of Cat’s Claw it is unclear if there is any benefit to this supplement, but the risks associated with it are substantial and hence a risk-benefit analysis would argue against its use.

More information on drugs that are potentially inappropriate in older patients is available on the Beers List through the American Geriatrics Society.

More information on supplements and dementia can be found at https://www.nccih.nih.gov/health/providers/digest/dietary-supplements-and-cognitive-function-dementia-and-alzheimers-disease-science

Transitions to Residential Care

Residential care is not the choice all caregivers make, yet providers may assess that the caregiver is unable to provide needed care or may be at risk for their own health due to caregiving. This assessment may be important to assuage guilt feelings of the caregivers.

Assistance with facility selection is available through the dementia organizations included on the Resource Listing. Once an individual with dementia is living in residential care, their primary care duties may be assigned to a palliative care provider or visiting physician. It may be important to communicate to the new provider your care plans and observations.

Referral for Palliative and Hospice Care

When/how to refer for palliative care

Palliative care can be obtained at any time along the course of any serious illness, including all types of dementia. A palliative care consultation should be considered anytime the primary care physician feels that a patient, caregiver and family might benefit from a team-based, holistic approach—whether due to issues with symptom control, conflicts over goals of care, existential or spiritual issues, or any other complex situation.

When/how to refer to hospice

Hospice can add an extra level of support for the caregiver, including social workers, faith workers and counseling services. The clinician may refer/write an order for hospice for a patient that you have anticipated has six months or less to live, and are hoping to improve the quality of life. The payment for hospice is through Medicare, VA, MediCal, or their insurance (if under 65) at no charge to patients. Referring sooner than later can provide additional resources and support for the patient and caregiver.

The Reisberg Functional Assessment Staging Scale (copyright 1984, Barry Reisberg, MD), known as the FAST Dementia Scale, is often used to determine eligibility for referral to hospice. The patient should have a rating equal to or greater than Stage 7 and should have specific comorbid or secondary conditions that adversely affect the patient’s expected survival. The FAST Dementia Scale can be found at https://www.compassus.com/healthcare-professionals/determining-eligibility/functional-assessment-staging-tool-fast-scale-for-dementia/ and on page 131.

There are many choices of hospice providers, both for profit and non-profit. Patients are not required to use the hospice affiliated with their health system.

Poor prognostic indicators for Alzheimer's patients and of a time that may signal appropriateness for a hospice referral include :

- *Significant weight loss (e.g., 10% in 6 months),*
- *Significant (stage 3-4) pressure ulcer development,*
- *Dysphagia,*
- *Recurrent upper UTIs or lower respiratory tract infections,*
- *Marked functional decline (e.g., becoming bedbound), and*
- *Becoming nonverbal*

Although cognitive impairment is the clinical hallmark of dementia, behavioral and psychological signs and symptoms of dementia (BPSD), which are also known as non-cognitive neuropsychiatric symptoms (NPS), are extremely common and are responsible for the majority of pain and suffering experienced by the individuals living with dementia and those who love and care for them. In addition, BPSD is a primary factor responsible for the medical and other costs associated with caring for individuals living with dementia. BPSD accounts for at least 30% percent of the cost of caring for community-dwelling individuals with dementia.

Research has found that BPSD is associated with:

1) Reduced quality of life for patients living with dementia,
2) Reduced quality of life for family members and caregivers,
3) Early nursing home placement,
4) Hospital admissions,
5) Avoidable morbidity and mortality,
6) Caregiver stress and depression,
7) Reduced caregiver employment income.

The assessment and treatment of BPSD is not simple. BPSD is the result of the interaction of numerous possible factors that are internal and external to the individual living with dementia, including the brain disease responsible for the dementia and the environment in which the individual with dementia is living.

A number of groups and organizations have developed and published excellent algorithms, treatment guidelines and other resources to help clinicians and family members accurately diagnose and treat BPSD, and many are included as references in this manuscript. The goal of this section is to succinctly summarize previously developed information with references so that the treating provider can easily obtain additional and more detailed information when necessary, and so that the provider knows when to seek consultation from a specialist in this area. Specifically, this guide contains an assessment and treatment algorithm, a number of guidelines for assessing and treating some of the most common forms of BPSD, and a form for caregivers to use when preparing to meet with a clinician in order to obtain help with BPSD.

DICE: Describe, Investigate, Create, Evaluate.

Helen Kales, MD, and her colleagues at the University of Michigan authored the DICE algorithm, which the Clinical Roundtable recommends. These guidelines emphasize the importance of creating an accurate description of the behaviors in the medical record, undertaking a systematic investigation of their cause(s), using the safest and most precisely targeted interventions possible, and periodically reassessing to determine if the interventions are working and if they are still needed.

DICE stands for Describe, Investigate, Create, and Evaluate. The algorithm summarized in the tables on pages 61-65 provide the practitioner with tools for convenient consultation in the middle of a busy day. This document also contains more detailed information on the use of the treatment options, as well as references and resources. There are many factors that may make the investigation of the etiology of BPSD and its treatment difficult. While most dementia and associated behavioral symptoms are screened, diagnosed and treated by the primary care provider, it is always advised to refer the patient to a geriatic internal medicine specialist, neurologist, psychiatrist, or geriatric psychiatrist if the primary care practitioner is unsure or uncomfortable with the evaluation or treatment.

DESCRIBE

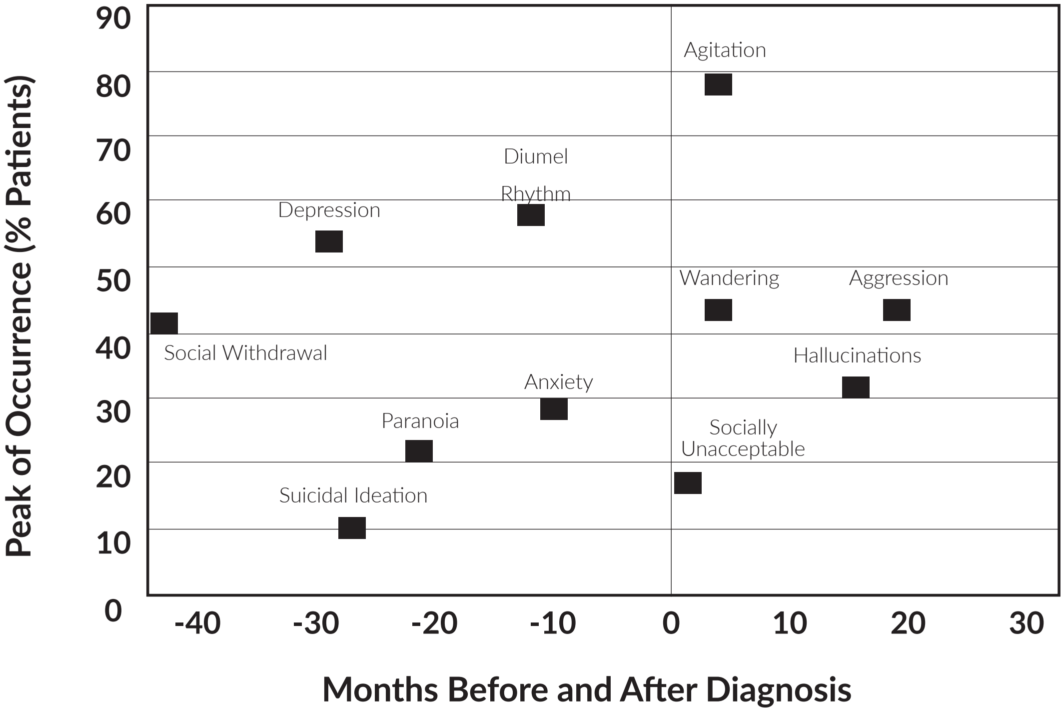
When an individual living with dementia develops behavioral symptoms, the clinician should guard against jumping to the conclusion that the symptoms are exclusively and intrinsically an expected outcome of the dementia illness. A somewhat liberal and yet compassionate and useful perspective is to view problem behavior or behaviors as a form of communication limited, perhaps, by the cognitive losses that are occurring as part of the dementia.

This perspective mandates that the clinician assume the stance of a scientist or private investigator and begin to systematically collect information that will ultimately lead to an understanding of the causes and associated best remedies of the behavior(s). This is, in essence, the underlying premise of the DICE approach. Although this approach may consume more time and other resources up front, in the long run the benefits in terms of improved quality of life for all involved and decreased healthcare expenditures, will far surpass these costs.

Common Behavioral Problems:

- Food Refusal
- Restlessness
- Combativeness
- Hypersexuality
- Depression
- ADL refusal
- Medication refusal
- Agitation
- Wandering
- Sleep disturbances
- Disinhibition
- Irritability
- Psychosis
- Social withdrawal
- Anxiety
- Aggression

Disease stages and symptoms. In patients living with Alzheimer's dementia, research has demonstrated that certain symptoms are most likely to occur at certain stages of the illness. Knowing this is very helpful because if a symptom like physical aggression occurs early in the course this strongly suggests that the symptom may be related to medical illness or some other psychiatric illness other than the dementia. Below is a graph depicting when specific symptoms of BPSD are most likely to occur over the course of the dementia illness.



Source: Jost BC, et al. *J Am Geriatr Soc*. 1996;44:1078-1081

INVESTIGATE

Critical to the effective management of behavioral issues or symptoms is the thorough investigation of the underlying causes of these behaviors. Consider these:

Key Points to Consider

1 *New or rapidly worsening behavioral symptoms in a patient with dementia should be considered a sign of an underlying medical illness until proven otherwise.*

2 *Assess whether a new or recurrent underlying medical factor may be involved.*

3 *Problem behaviors are often triggered by anticholinergic medications and suboptimal prescribing.*

4 *Obtain a careful history focused on potential environmental antecedents and any changes in the patient's medical status and medications.*

5 *Understanding the differences between the psychotic symptoms typically seen in patients with dementia versus the psychosis seen in other conditions will help refine the differential diagnosis.*

6 *The concept "psychobehavioral metaphor," described below, may help with selection of a class of medication with the highest probability of being helpful.*

7 *Another important factor to consider when choosing a medication category is whether the patient's BPSD includes emergent agitation. An algorithm for the treatment of emergent agitation is included below.*

8 *In spite of the FDA black box warnings, in certain situations a risk-to-benefit analysis may still favor the use of antipsychotic medications.*

9 *If insomnia appears to be the trigger for BPSD, a trial of melatonin might prove helpful. The use of melatonin is described below.*

10 *If initial treatment attempts are unsuccessful and/or the use of emerging but not well proven treatments are being considered (e.g. cannabinoids, dextromethorphan-quinidine, pimavanserin, or prazosin) then referral to a specialist such as a psychiatrist or geriatric psychiatrist, is strongly recommended.*

11 *The use of both pharmacological and behavioral strategies leads to the best results.*

12 *Remember that symptoms evolve over the stages of dementia and may decrease or disappear.*

Determining the Cause or Causes of Behavioral Symptoms in a Patient with Dementia

Potential Triggers of BPSD Include:

***Medical**: constipation, hypoglycemia, pain, sub-optimal prescribing, urinary tract infection.*

***Psychiatric**: anxiety, depression, disinhibition/impulsivity, mania, paranoia.*

***Psychological**: abandonment, anxiety, boredom, frustration, loneliness, TV violence.*

***Other**: fatigue, hunger, noise, movement restriction, thirst, suboptimal communication, uncorrected sensory deficits.*

Etiologic categories of the medical differential diagnosis include:

- Delirium
- Exacerbation of pre-existing medical illness
- Onset of new medical problem
- Medication toxicity (e.g. polypharmacy or suboptimal prescribing)
- Drug or alcohol intoxication or withdrawal
- Exacerbation of pre-existing psychiatric illness
- Onset of a new psychiatric illness

The Psychobehavioral Metaphor

Consider using the concept, psychobehavioral metaphor, first described by psychiatrist Pierre Tariot, MD, when attempting to discern the best fit common psychiatric syndrome occurring in a patient who is living with dementia. In essence, the concept invites the clinician to ask him or herself, "if I did not know that this patient had dementia, what common psychiatric syndrome or diagnosis would the signs and symptoms this patient has most resemble?"

For example, if the patient's BPSD symptoms include sadness/tearful episodes, and/or insomnia, and/or poor appetite and the remainder of the evaluation supports that these symptom(s) are occurring in the context of an episode of major depressive disorder, then the first medication trial to consider would be an antidepressant. A past history of depression or a family history of depression, would strengthen the rationale for an antidepressant trial. A concept closely related to the psychobehavioral metaphor which has been described by Lawlor and Bhriain (2001) has been called "BPSD clusters." These clusters include: Depression, Apathy, Aggression, Psychomotor Agitation, and Psychosis.

Possible psychiatric/psychological causes:

- Bipolar disorder, manic episode, new-onset or recurrent
- Bipolar disorder, hypo-manic episode, new-onset or recurrent
- Major depressive episode, new-onset or recurrent, with or without psychosis
- Panic disorder, new-onset or recurrent
- Panic attack
- Post-traumatic stress disorder
- Schizophrenia

Note: A patient whose PTSD symptoms have been treated successfully at an earlier stage of life may experience re-emergence of one or more of these symptoms as the progression of the dementia illness leads to the loss of previously learned insights and coping strategies.

If you or a specialist has prescribed a medication to treat BPSD, you should remain vigilant for the emergence of common and potentially dangerous side effects. A number of these potential side effects increase the risk of falling and include gait changes, orthostasis, sedation, and agitation.

Recommendations Regarding the Selection of a Medication to Treat BPSD

Education of caregivers and close monitoring by caregivers and the PCP is required when medications are used to treat BPSD. Though sometimes necessary, at least on a time-limited basis, psychiatric medications are associated with a spectrum of potentially problematic and/or dangerous side effects. Refer to the latest edition of the Beer's Criteria for more information on both potential signs of an emerging side effect and potential undesirable sequelae of these side effects.

The BPSD experienced by patients living with dementia may be divided into two categories based on the the PCP's assessment of whether or not the BPSD has caused the patient to be a danger to themselves or others. As outlined below, making this determination is critical because the initial treatment plan is different for these two presentations.

The Treatment of Emergent Agitation in Patients with BPSD

Agitation is a potential presentation of BPSD. The International Psychogeriatric Association (IPA) developed a consensus definition of agitation in patients with cognitive disorders (Cummings et al. 2015). This definition requires an observed behavior from at least one of three categories associated with evidence of emotional distress such as rapid changes in mood, irritability, or outbursts. The three categories of observed behavior with some of the specific examples provided by the IPA's definition are listed in the box below.

Behaviors Used to Define Agitation in Patients with Cognitive Disorders

Category of Behavior	Specific Examples
Excessive Motor Activity	Pacing, rocking, gesturing, repetitious mannerisms
Verbal Aggression	Yelling, screaming, shouting, using profanity
Physical Aggression	Grabbing, shoving, pushing, hitting, kicking, scratching, throwing objects, destroying property

When agitation endangers the patient or others, or when it seems highly likely to do so, it is considered "emergent agitation" and requires immediate intervention. Determining the underlying cause of the agitation is critical but the severity of the agitation may hamper or delay this effort. Emergent agitation is most often and best treated in an Emergency Department (ED) or inpatient hospital setting. When a PCP is notified that a community dwelling patient, living at home or in residential care, is experiencing emergent agitation, transfer to the nearest ED is strongly recommended. For patients already hospitalized, the failure of initial treatment efforts should trigger a psychiatric consultation and consideration of transfer to an inpatient psychiatric unit.

Behavioral interventions, such as decreasing environmental stimulation, verbalization of suspected unexpressed feelings, or direct contact with a loved one, may be helpful, but only rarely lead to complete and enduring resolution of emergent agitation. Whenever possible, behavioral interventions should be utilized with the understanding that medication management efforts will likely also be necessary, at least on a short-term basis. In addition to decreasing the likelihood of injury to the patient and others, the combined use of behavioral and medication treatments will facilitate the assessment of the etiology of the emergent agitation, the development of the differential diagnosis, and the application of the psycho-behavioral metaphor, if underlying medical illness is not identified as an etiologic factor or if optimal treatment of all medical conditions does not resolve the agitation. Examples of medical conditions whose successful treatment may relatively quickly resolve emergent agitation include fecal impaction, hypoxia, physical pain, and urinary retention.

Medical illnesses are often overlooked in older patients, especially those with psychiatric diagnoses or dementia prominently highlighted in their records!

The Use of Medications for Emergent Agitation

Oral medications should be used to treat BPSD whenever the patient is able and willing to take them. When the patient's ability to take oral medications is tenuous, like in the context of emergent agitation, psychiatric medications available in rapidly disintegrating form may be helpful. If the patient is unable or unwilling to take oral medication and the agitation continues to place the patient and/or others in danger, intramuscular medication (IM) is indicated.

As soon as the emergent agitation has improved to the point when the use of oral medication is possible, then the use of IM medications should be discontinued. The importance of close monitoring is especially important when IM medications are being used and, as previously stated, is best accomplished in an emergency department or an inpatient medical or psychiatric unit.

Antipsychotic medications, preferably second-generation antipsychotics such as aripiprazole, brexpiprazole, olanzapine, quetiapine or risperidone, are the preferred class of medications to treat emergent agitation. If the patient is unable or unwilling to take oral medication and is severely agitated or aggressive, then IM aripiprazole, olanzapine, or haloperidol (a first-generation antipsychotic) should be considered. The American Psychiatric Association Practice Guidelines (Reus et al 2016) recommends not using haloperidol as a first-line agent unless the patient is determined to have delirium.

Delirium is discussed in an upcoming section. The use of antipsychotics should continue only as long as necessary to resolve the emergent agitation, unless it is determined that persisting underlying psychotic symptoms, such as pre-existing conditions like schizophrenia or mood disorder with psychotic features, are responsible for the agitation.

With the exception of brexpiprazole, if indicated and in the absence of side effects, the initial dose can be increased every 30 to 60 minutes until the agitation resolves or is no longer dangerous or disruptive. The FDA approval of brexpiprazole for agitation in patients with dementia states that the initial dose of 0.5 mg should not be increased for 7 days. On day 8, if indicated, the dose can be increased to 1 mg. On day 15, if indicated, the dose can be increased to 2 mg which is the target dose, however, after 14 days, the dose can also be increased to 3 mg. Brexpiprazole should not be used on a prn basis for agitation in patients with dementia.

Medication	Oral Initial Dose (mg)	IM Initial Dose (mg)
Aripiprazole	2—5	1.875—7.5
Brexpiprazole	0.5	
Olanzapine	2.5—5	2.5—5
Quetiapine	25—50	
Risperidone	0.25—1	
Haloperidol		0.5—2

Pain may be a trigger for agitation, especially in non-verbal individuals. Consider assessing for pain in this circumstance.

If side effects emerge but the agitation continues to be disruptive or dangerous, consider using a different medication from the list to the left.

Recognizing Delirium

In 1959, Engel and Romano proposed that delirium be understood as a condition of Cerebral Insufficiency in line with the terminology used to describe medical conditions when other organs are no longer functioning adequately (e.g. cardiac insufficiency or renal insufficiency). One of the intended implications of the proposed terminology was to remind clinicians that delirium should be viewed as a medical problem. The signs and symptoms of delirium are the brain's way of shouting that one or more of its requirements for normal functioning is not being met (e.g. hypoxia, hypoglycemia, or hyponatremia). Research has found that as many as one-third of older adults who present for evaluation and treatment of new or worsening behavioral symptoms have these symptoms due to a medical problem that has not yet been accurately diagnosed and/or optimally treated (Woo et al. 2003) In many instances, the presence of these medical illnesses has resulted in the development of delirium.

Today, the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5),1 provides one of the most widely used criteria for defining delirium. The criteria for delirium are, in summary, a disturbance of attention and awareness, (i.e. a reduced ability to direct, focus, sustain or shift attention), and awareness associated with at least one additional change in cognition. The full DSM-5 criteria for delirium appear on the next page. Each of the five criteria are important, however, criteria A may be the most essential to detect and criteria E the most often not fully met (i.e. an underlying medical cause has not been fully ruled out).

Criteria for Delirium

according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5)

A. A disturbance in attention (i.e. reduced ability to direct, focus, sustain and shift attention) and awareness (reduced orientation to the environment).

B. The disturbance develops over a short period of time (usually hours to a few days), represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.

C. An additional disturbance in cognition (e.g. memory deficit, disorientation, language, visuospatial ability or perception).

D. The disturbances in Criteria A and C are not better explained by another pre-existing, established or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma.

E. There is evidence from the history, physical examination or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal (i.e. due to a drug of abuse or to a medication), or exposure to a toxin, or is due to multiple etiologies.

The recognition of the presence of delirium rests upon having a high index of suspicion. All of the following should be considered when assessing a patient for delirium:

- Have there been any recent medication changes?
- Does the patient look physically ill or physically uncomfortable?
- Are the patient's vital signs reasonable?
- Are the patient's vital signs around their usual baseline?
- Are the patient's lab values reasonable?
- Has the patient's mental status changed rather suddenly or dramatically?
- Is the patient suddenly behaving in ways that have never been characteristic for the patient?
- Is the patient's level of alertness and/or attention waxing and waning?

The conditions in which delirium may develop are diverse and numerous. In older adults living with dementia, a number of these are legend and include: constipation, medications (especially those which are anticholinergic), pain, and urinary tract infections. It is important to remember that dementia and depression, individually or in combination, may also be factors that contribute to and, as some might say, lower the threshold for, the development of delirium.

A common but complicated potential cause of delirium is that of urinary tract infection. It is often seen that when a delirium workup is undertaken a urinalysis will be performed and if abnormal, a diagnosis of UTI made resulting in antibiotics; however, it is important to consider not just the urinalysis, as we are increasingly recognizing an overdiagnosis of UTI based only on urinalysis results leading to poor antimicrobial stewardship. Behavioral agitation alone should not be sufficient to make the diagnosis of UTI.

To increase the accuracy of a UTI diagnosis, a patient should present with at least one lower urinary tract symptom, in addition to an abnormal UA. These symptoms may be difficult to assess in advanced dementia or delirium as the patient may not volunteer symptoms or describe symptoms accurately. Some historical factors and physical exam findings that may confirm the presence of an actual UTI include: staff notation of signs of pain with urination, increased agitation around toileting times, new incontinence of urine in an otherwise continent patient, hematuria, signs of ascending infection on exam such as CVA tenderness, systemic symptoms such as fever or chills, increased frequency of urination or signs of incomplete emptying on post-void residual.

It also is important to note that certain factors can confound a urinalysis, such as dehydration which often can result in a sterile pyuria leading to a positive leukocyte esterase. Additionally, patients may not be able to perform a truly clean catch for the urine sample which also can affect results of urinalysis. Hence before a diagnosis of UTI is made, beyond reviewing the urinalysis results, a thorough evaluation of the patient should be undertaken to be sure there is clinical evidence of a UTI.

Maintain Vigilance for "Stealth" Anticholinergic Medications: All sorts of medications can cause delirium but be especially watchful for those with anticholinergic properties and remember that the anticholinergic properties of some medications may be overlooked (e.g. digoxin, furosemide, warfarin). Refer to the most recent *Beer's Criteria* publication for more information.

Insomnia

Sleep problems in patients living with dementia and in caregivers of patients living with dementia have been and continue to be the subjects of a substantial and growing number of research studies and peer-reviewed journal articles. A complete review of these topics is beyond the scope of these guidelines. There is a broad consensus that sleep disturbances occur commonly in individuals living with dementia and that they are especially common in those living with Lewy body dementia. In addition, research suggests that sleep problems may be more common in individuals living in residential care settings than those living in their own homes. The frequency of sleep problems in residential care environments, including nursing homes, is believed to be higher, in part, because they are one of the common reasons that an individual living with dementia is moved to residential care, and, in part, due other factors such as diminished privacy, rooms which are not optimally darkened, and noise levels. In residential care, the frequency of sleep problems may be as high as 70% and for those living at home it may be around 20%.

Caregivers of patients living with dementia have also been found to report more sleep problems than those found in the general population. That this would be the case is not at all surprising given how relatively common sleep problems are seen in individuals living with dementia coupled with the obligation of caregivers to support and keep safe the individual for whom they are caring. In addition, caregivers experience other factors such as stress and depression illness which may be independent contributors to their sleep disturbance. Although better research is needed, some estimates of sleep problems in caregivers of patients living with dementia rise as high as 66%.

Given that most insomnia in all patients is secondary, not primary, searching for and correcting secondary causes of insomnia is essential. Examples of secondary causes of insomnia in patients living with dementia include: circadian rhythm changes, medication timing mistakes such as taking diuretic medication at bedtime with resulting nocturia, and partially treated or untreated pain. Thankfully the resolution of secondary causes and/or the adoption of sleep hygiene practices often resolves the problem with insomnia and obviates the need for medication.

The use of medication to treat insomnia in patients with dementia is challenging because the medications, which might seem reasonable in other clinical settings, all have especially worrisome side effect profiles in these patients. As a result, medications for insomnia in patients living with dementia are appropriate only when the insomnia is severe AND all other treatment options have failed. Diphenhydramine (Benadryl), and medications that contain diphenhydramine, like OTC cold and flu medications and OTC medications with names that include PM, are contraindicated in patients living with dementia due to their anticholinergic properties and high likelihood of causing problematic side effects.

It is important to ask caregivers if an OTC medication is already being used because the use of one of these medications could be causing delirium and making the insomnia worse, not better. It is also important to confirm that the caregiver has not been giving the patient with dementia alcohol, cannabis, or an insomnia medication that was prescribed for the caregiver. Sometimes these medications/substances have paradoxical effects which may be triggering or worsening the insomnia.

Unfortunately, a recent Cochrane Review (2020) concluded that there is very little evidence to guide the treatment of insomnia in patients living with dementia. There are no FDA approved medications for insomnia in patients with dementia. The most commonly used drugs are melatonin, z-hypnotics such as zolpidem, sedating antidepressants such as trazodone, and antipsychotics. For patients who have normal renal function, gabapentin may be helpful.

The treatment of insomnia in caregivers is also challenging for some of the same reasons as mentioned above regarding individuals living with dementia. In addition to caregivers, especially older caregivers, being vulnerable to their potential side effects, medicines prescribed for insomnia may interfere with the caregiver's ability to provide optimal care to the individual living with dementia. Additionally, sleep experts recommend FDA-approved medications for insomnia be used daily on a short-term basis (not more than three weeks) but the situational factors that may be responsible for the caregivers insomnia are usually not short-term.

For example, if given an insomnia medication at bedtime, the caregiver may sleep so deeply that they remain asleep when the patient with dementia awakens in the middle of the night. As noted in the above paragraph, secondary insomnia is much more common than primary insomnia and a search to identify possible contributing factors needs to be undertaken. Just as for patients, the application of behavioral interventions can be powerful and are much less dangerous.

Sleep Hygiene

(habits, behaviors, and environmental factors which are known to facilitate good sleep)

- *Avoid stimulants such as caffeine and nicotine*
- *Create a dark, quiet environment, however, if total darkness is upsetting, use night lights*
- *Engage in exercise during the day*
- *Establish and maintain a regular schedule including soothing activities before bedtime*
- *Limit naps during the day*
- *Make sure the bed is comfortable*
- *Participate in social activities*
- *Provide bright light exposure in the morning (natural or therapeutic levels of indoor light)*
- *Turn off the TV or other blue light emitting devices before bedtime*

Pain

Pain can be a major contributing factor to behavioral agitation, and adequate assessment for such can often lessen BPSD. At the same time, managing pain with agents that are not appropriate for seniors can lead to the opposite effect, worsening BPSD.

Assessing pain can be difficult in the patient with BPSD as often they are less able to verbalize symptoms. Hence careful attention to non-verbal signs of pain must be relied upon to ensure that pain if present is detected. Some examples of non-verbal signs of pain include signs such as facial grimacing, antalgic gait, rubbing at or favoring a joint affected by pain, or unexplained tearfulness. One sign that could be considered is timing of BPSD symptoms. If it is noted, for instance, that a patient grows more agitated at times of care requiring physical contact such as turning or moving the patient's arms/legs, pain should be considered as a possible source of the agitation. Identifying possible painful triggers can be accomplished by thorough discussion of the patient with a care team as often a single provider is unable to observe each interaction to determine the source.

When treating pain, it is important to remember that many agents are considered potentially inappropriate for seniors. For instance, it is advised to avoid opiates unless in extreme cases of acute pain such as in the case of traumatic injuries, as while they may ameliorate pain, they also can increase sedation which can induce delirium or add to cognitive confusion that may worsen BPSD. Additionally opiates increase constipation which if inadequately treated also may contribute to BPSD. Oral non-steroidal anti-inflammatory agents (NSAIDs) are also on the Beer's list as agents to be avoided in those over the age of 75 due to the risk of bleeding and nephrotoxicity that increases with age.

Use of topical NSAIDs like diclofenac gel for small to medium sized joints such as digits, wrists, elbows, ankles, and knees, can be a senior-friendly alternative to oral NSAIDs so as to address pain while lessening risk of systemic side effects that can potentially contribute to BPSD. For large joints such as hips, shoulders, and back, topical agents such as lidocaine patches are found to be more effective than topical NSAIDs. Scheduling topical analgesic agents, or in the patient without liver dysfunction, considering scheduling a baseline low dose Tylenol orally can be superior to having as needed (PRN) agents for pain in the patient with advanced dementia. A risk with as needed medications is them not being administered due to the patient not knowing they can, or not being able to, ask for the PRN agent.

Recognizing and Treating Depression

An episode of major depressive disorder in older individuals may not look the same as in younger patients. Remember that diagnosing an episode of major depressive disorder through the veil of dementia is difficult and it may be impossible to identify all of the signs and symptoms usually required to make a definite diagnosis. For example, a patient with dementia may have such severe aphasia that they are unable to answer questions about self-esteem or anhedonia, or the presence of rapid forgetting may prevent the patient from providing an accurate history of sleep or appetite.

Assessing and Treating Agitation

All agitation is not the same and, therefore, should not be treated the same.

In spite of the FDA black box warnings, antipsychotics may still be the best pharmacologic treatment option in patients with BPSD, especially in patients whose behavioral symptoms seem to be triggered by delusions or in patients who have a clear history of a psychiatric disorder that included psychotic symptoms and preceded the onset of dementia illness (e.g. a mood disorder with psychotic features or schizophrenia).

Common Delusions

Delusions are a common behavioral issue among individuals with dementia. Delusions associated with Alzheimer's dementia are simple and plausible. Delusions in patients living with dementia should be treated pharmacologically only when the delusions cause significant distress or endanger the patient. In the absence of these circumstances, only behavioral interventions should be provided. The presence of complex or bizarre delusions strongly suggests the presence of a pre-existing psychiatric disorder. The most frequent delusions associated with Alzheimer's are:

- Accusations of infidelity
- Persons or images from TV are real
- Fear of abandonment
- Accusations of theft of one's property
- Claims of impersonation (spouse is an imposter)
- Current residence is not one's home
- Misidentification of familiar persons

Whenever possible, medication changes (e.g. additions, discontinuations, dose amount adjustments, and changes in medication timing or frequencies), should occur one at a time and with sufficient time in between in order to more accurately evaluate the impact of the medication change prior to another medication change being made.

There are many factors that may make the investigation of the etiology of BPSD, and its subsequent treatment, difficult. The presence of one or more of these conditions requires the PCP to be flexible and to think outside the box.

These factors include but are not limited to:

- The patient is unwilling or unable to provide helpful history.
- A collateral historian is not readily available.
- The collateral historian, especially family caregivers who are exhausted by the demands of caregiving, have difficulty providing clear, concise, accurate historical information.
- The limited time that many healthcare systems allot for outpatient clinical appointments.
- The extra time and resources needed to properly examine a patient with BPSD. For example, severe constipation (obstipation) has been identified as a common trigger of BPSD and yet accurately diagnosing constipation in a patient living with dementia is more challenging for a variety of reasons, including the performance of a digital rectal examination.

When a patient or collateral historian is not willing or able to cooperate with history taking or the patient is unable to cooperate with a physical examination, the following may be helpful:

- Observing the patient from a distance (e.g. from across the room or via telehealth.)
- Enlisting additional personnel to assist with the examination in order to ensure patient and examiner comfort and safety.

The use of rating scales are often complex and cumbersome, but may be used to objectify symptoms over time. Most important is to assess and evaluate the frequency and severity of symptoms, and impact on the primary caregiver.

The importance of searching for medical triggers cannot be overemphasized. Published research including the work by Woo et al., have found that a significant subset of older individuals, including those who may be living with dementia, are experiencing the problem behaviors due to previously undiagnosed (and therefore untreated) medical problems or due to medical problems that have not been optimally treated.

CREATE a Care Management Plan

Disease Management: General Concepts

- *Define and document target symptoms.*
- *Identify and optimally treat all medical conditions.*
- *Identify and remove triggers (e.g. pain, noise, boredom, hunger…).*
- *Use all possible helpful tools.*
- *Depending on acuity of behavior, use behavioral interventions first.*
- *With one exception (brexpiprazole, discussed below), there are no FDA-approved treatments for behavioral disturbance with dementia.*
- *Combine behavioral and medication interventions.*
- *Use the psychobehavioral metaphor (defined in the algorithm chart on page 61 and in the text on page 45) to select initial class of medication.*

Behavioral and Environmental Management of BPSD

It is advised to develop behavioral intervention strategies with the family members and caregivers prior to utilization of pharmacological management. The algorithms included in this document offer a variety of treatment suggestions for use by caregivers. Educate and advise them of these essentials:

Create a safe, comfortable environment:

- Assess whether the amount of stimulation in the environment is optimal based on the patient's preferences and behaviors and then make the indicated adjustment.
- Assure adequate lighting and comfortable ambient temperature.
- Establish routines and provide structured activities.
- Explore using photographs or music to stimulate calming memories or prevent boredom.
- Provide an environment with a secured perimeter in which the patient can move about freely.
- Provide furniture with strong arm rests and seats at a comfortable height with firm cushions.
- Turn on bright lights in the home, or take the patient outdoors with appropriate solar protection, in late afternoon to avoid sundowning.

Improve suboptimal communication in order to achieve desired behavioral results. Examples of suboptimal communications include:

- Making more than one request at a time.
- Not allowing time for the person living with dementia to respond.
- Not assuming a comfortable, relaxed posture.
- Not identifying and verbalizing the patient's affect.
- Not maintaining eye contact.
- Not using more than one sensory modality.
- Not using simple, direct statements.
- Speaking too fast or with poor diction.

Redirection helps to improve communications, and helps the patient refocus in order to be calmer, cooperative, content, and safe. Physicians can refer caregivers to the Communication Tip Sheet in the back of this book.

See the Resources for Caregivers for additional information.

Care Refusal

The caregivers should be coached on dealing with difficult behaviors including the refusal of care. Many factors may be involved in these situations, including anger, anxiety, confusion, fear, occupational history (e.g. a career as a CEO), pre-existing personality characteristics (always being fiercely independent), and verbal or physical agitation or aggression due to delirium. The most common forms of care which are refused are bathing, eating, clinical appointments, and medications.

Caregivers should be encouraged to:

- Avoid arguments.
- Communicate that both the request and refusal is understood.
- Identify and verbalize the emotions which the patient is experiencing.
- Keep the emotional intensity of the interaction as low as possible.
- Remember who the patient was prior to the onset of dementia.
- Shift the focus to a pleasant experience and then reattempt later.

Refer the caregiver to resources to assist with these behaviors. See Resource Sheet.

Pharmacologic Management of BPSD

FDA approved use of cholinesterase inhibitors and memantine may have a role to play in the treatment of BPSD. They may also contribute to the development of BPSD. If a patient presents with BPSD and is currently taking a cognitive enhancer and/or memantine, efforts should be made to determine if there may be a temporal association between the initiation of treatment and the emergence of BPSD.

COMMON BEHAVIORAL SIDE EFFECTS of Current FDA Approved Medications

See section in Disclosing a Diagnosis regarding physiologic adverse effects of these medications.

Medication	Behavioral Side Effects
Cholinesterase Inhibitors	Agitation, Anxiety, Wandering
Mementine	Fatigue, Confusion, Hallucinations, Anxiety, Depression, Aggression

If a patient with BPSD is not yet taking a cognitive enhancer or memantine, then the addition of a cognitive enhancer or memantine should occur as one of the final steps in symptom management and only after the most pressing behavioral symptoms have been successfully addressed.

A cognitive enhancer or memantine should be added sequentially and only after it has been confirmed that the addition of the first medication has not caused problems. Although a combination medication containing both acetylcholine and memantine is available (Namzaric) and may facilitate adherence, this advantage may fade in the context of emerging or persisting BPSD when it is necessary to determine whether one or both of these medications is more harmful than helpful. See page 28 for more information on these medications.

Psychotropic Medication Management.

Before discussing the possible helpful pharmacological options for treating BPSD, it is important to remember that any medication prescribed for BPSD should be considered as second-line, unless the behavior is placing the patient or others in danger. A listing of categories of medications are presented on page 57. You may find that becoming especially familiar with one or two in each family is an efficient way to build confidence with their use.

Initial management of mild BPSD. It is important for clinicians involved with the assessment and treatment of BPSD to remember that with only rare exceptions, most types of dementia are progressive neurocognitive illnesses which means that the underlying disease process leads to ever increasing damage to the afflicted individual's brain. This reality sometimes leads to worsening behavioral challenges but sometimes leads to improvement in problem behaviors whenever the brain tissue centrally involved in triggering the behavior is damaged and no longer able to play a causal role in the behavior's occurrence.

Dementia illnesses are progressive which means that over time the brain of a person living with dementia is losing more and more neurons. The loss of these neurons leads to increasingly numerous and severe functional losses. It is possible that at some point the brain tissue responsible for the problem behaviors may no longer exist and, as a result, the problem behaviors will no longer occur. It is also possible that the disappearance of one or more triggering factors may result in elimination of the problem behavior(s). In order to determine if this has occurred and to confirm that ongoing treatment with psychotropic medication is necessary, with the exception of one category of psychotropic medication, tapering of the psychotropic medication is necessary.

Once a patient with BPSD has been stable on a psychotropic medication for 3-6 months, it is important to initiate a cautious, incremental reduction in the medication and to monitor the patient closely. If the problem behavior(s) does (do) not reappear after several weeks, then another reduction should occur. On the other hand, if at any point a reduction leads to the return of a problem behavior(s), then the patient should be returned to the dose at which the problem behavior remained in remission.

After another 3-6 months have passed during which time the patient's problem behavior(s) has (have) remained in remission, then another attempt at tapering the medication should be made. Underlying these efforts at dose reduction, or eventual discontinuation, is the awareness that these medications are associated with the possibility of very serious side effects such as increased fall risk, tar dive dyskinesia and increased risk of adverse cardiovascular events, which requires ongoing efforts to balance the risks versus benefits.

For antidepressants, however, incremental reduction may not be recommended. Given the relatively high likelihood of recurrent episodes of depression in this patient population and the relatively low risks associated with long-term use, in the absence of problematic side effects, continuation of antidepressant medication that proved helpful may be the optimal balance between risks and benefits.

Pharmacologic Treatment: General Principles

- *Avoid long-term use of opioid medications and attempt to taper and remove whenever possible.*
- *Behavioral symptoms vary according to stage of illness and may remit as the illness progresses.*
- *Check the timing of medication dose against other issues, i.e., diuretics at bedtime should be avoided.*
- *If not described here, refer to the PDR or comparable reference for information on introducing and titrating medication.*
- *Remember that older adults usually need lower dosages.*
- *Start low, go slow and determine lowest effective dose or,*
- *Start low, increase relatively swiftly and then be prepared for the need to back off in order to determine lowest effective dose.*
- *Use medications better tolerated by older adults (often these are renally excreted).*
- *Withdraw after an appropriate period and observe for relapse.*

Categories of Medications Which May be Helpful:

- Antipsychotics
- Antidepressants
- Anxiolytics
- Beta blockers
- Cholinesterase inhibitors
- Dextromethorphan-quinidine
- Melatonin
- Memantine
- Mood stabilizers
- Pain medications especially routine acetaminophen – consider topical agents

Antipsychotics Recently (May 2023), brexpiprazole (Rexulti) oral tablets received FDA Fast Track approval for the treatment of **agitation symptoms** associated with dementia due to Alzheimer's disease. Brexipiprazole retains the black box warning for medications in this class for older patients with dementia-related psychosis. The FDA approval was granted based on data showing that the potential benefits outweighed the potential risks of this medication when used for this indication. The absence of published research leaves unanswered the question of what, if any, advantages brexipiprazole offers compared to other medications in this class, apart from a potential reduction in malpractice liability.

Pimavanserin (Nuplazid) is an antipsychotic with FDA approval for the treatment of hallucinations and delusions associated with Parkinson disease psychosis. Evidence from the only published randomized clinical trial to date suggests that it may be effective and well-tolerated for patients with AD associated psychosis, however, more published trials are needed to confirm this.

Benzodiazepines are not recommended for short- or long-term use, except in palliative care settings. If necessary, short-acting, renally excreted agents are preferred, including lorazepam (Ativan®) or oxazepam (Serax®).

Melatonin The usual starting dose of melatonin is one 1 to 2mg slow-release tablet taken 30 minutes to 1 hour before bedtime. Older adults are more sensitive to melatonin and usually require lower doses. The use of melatonin in adults with dementia is not well-studied and patients with dementia may be especially sensitive to melatonin. Caution is required when used by patients living with dementia. The dose may gradually be increased to 2 to 3 tablets before bedtime, depending on how well it works and whether there are any side effects. Possible side effects include: daytime drowsiness, headache, stomachache, nausea, dizziness, irritability, restlessness, dry or itchy skin, strange dreams and night sweats. The maximum recommended dose is 6 mg once daily.

Trazodone (Desyrel®) There is no good data for the use of this medication based on Cochran Reports. Practitioners have found this medication may treat both acute agitation and prevent further episodes, and may be a good choice for insomnia. Dose range is 25 – 100 mg; complete response may take two to four weeks. Sedation is common, and priapism is very rare in older adults.

Antipsychotic Medications

Note: Except with being prescribed for primary psychiatric conditions which were present prior to the onset of a dementia illness, the use of long-acting injectable forms of anti-psychotic is not recommended.

Drug	Dose
Aripiprazole (Abilify)	6 forms including tablets (2, 5, 10, 15, 20, 30 mg), DiscMelt (10 and 15 mg), liquid 1 mg/ml, and IM (q4 wk & q8 wk)
Asenapine (Saphris)	2.5 mg, 5 mg and 10 mg sublingual; q12 hours
Brexpiprazole (Rexulti)	Tablets (0.25, 0.5 mg, 1, 2, 3, 4 mg) Titrate 2 wks, 1 wk, prior to daily dosage. Max 4 mg
Cariprazine (Vraylar)	Capsules (1.5, 3, 4.5 and 6 mg)
Clozapine (Clozaril)	Refer to psychiatrist
Iloperidone (Fanapt)	Tablets (1, 2, 4, 6, 8, 10, & 12 mg); q 12 hours
Lurasidone (Latuda)	Tablets (20, 40, 60, 80 mg)
Olanzapine (Zyprexa)	4 forms including tablets (2.5, 5, 7.5, 10, 15, 20 mg) Zydis (5, 10, 15 20 mg), IM, IM ER
Paliperidone (Invega)	4 forms, oral tablets: daily, monthly, quarterly & half-yearly; IM forms. Max = 12 mg, Renal = 3 mg. Max daily dose reduced based on CrCl; not used for patients w/CrCl<10 mL/min
Pimavanserin (Nuplazid)	Tablet 17 mg (FDA for Parkinson's disease psychosis)
Quetiapine (Seroquel)	Tabs (25, 50, 100, 200 mg) q 12 hours; Extended release tabs (50, 150, 200, 300, 400 mg)
Risperidone (Risperdal)	Tablets (0.25, 0.5, 1, 2, 3, 4 mg), liquid 1 mg/ml, Risperdal Consta IM (q 2 weeks)

Mood Stabilizing Medications

Drug	Dose
Divalproex (Depakote)	Sprinkles 125; , DR 125, 250 500 mg; ER 250 and 500 mg. Oral solution: 250 mg/5 ml. Starting dose = 125 to 250 mg. Dose is determined by clinical response and blood level of **total** valproic acid (50 to 100 µg/ml). When converting to ER, increase dose by 20%.
Lithium	Tablets, capsules, oral solution; and ER. 300 mg tabs. ER comes in 300 and 450s. Solution: 8 mEq/5 ml. Recommended trough serum range is 0.4 to 0.8 mmol/L. Starting dose = 300 mg.
Gabapentin (Neurontin)	Capsules 150, 300, 400 mg; Tablets 600 and 800. Starting dose 150 to 300 mg; Max dose = 3600 mg in a divided dose. Liquid 250mg/5 ml
Pregabalin (Lyrica)	Caps: 25 mg, 50 mg, 75 mg, 100 mg, 150 mg, 200 mg, 225 mg, and 300 mg. Oral Solution: 20 mg/mL.

Antidepressant Medications

Drug	Dose
Czitalopram (Celexa)	10, 20 and 40 mg tabs (20 and 40s are scored). Starting dose is 10 mg. Max dose = 40 mg. Doses above 40 mg not recommended due to QTc prolongation.
Escitalopram (Lexapro)	5, 10 and 20 mg (10 and 20s are scored). Starting dose is 5 mg. Max dose = 20.
Sertraline (Zoloft)	Tabs 25, 50 100 mg; liquid 20 mg/ml. Starting dose = 25 mg. Max dose = 200 mg.
Duloxetine (Cymbalta)	20, 30, 60 mg tabs. Starting dose 20 mg. Max dose = 60 mg.
Mirtazapine (Remeron) RemeronSOLTAB	7.5, 15, 30 and 45 mg tabs. Starting dose 7.5 mg Max dose = 45mg Orally disintegrating tab; 15, 30, 45 mg tabs

Note: These are generally considered the best choices for older adults but other factors like previous treatment history or family history may influence your choice. If you prescribed two antidepressant medications for a particular patient without success, then a referral to a psychiatrist is recommended.

The risks of the interventions provided, and the speed of their implementation should be in direct proportion to the pain and dangerousness of the behaviors. Sometimes, the use of less precise medication interventions is needed initially in order to facilitate the investigation for underlying causes.

Factors to consider in the creation of a care plan include:

Health system traditions, regulations and policies:

- Will the patient's insurance plan pay for services that would often help reduce the frequency and intensity of BPSD? What might the financial impact be for the family? Adult day healthcare programs that specialize in the care of patients living with dementia are often not affordable for many individuals living with dementia in spite of their proven benefits. Benefits may include increasing the quality of life of individuals living with dementia, reducing rates of illness and burn out in family caregivers, reducing the rates of BPSD by providing meaningful and enjoyable activities for patients and the delaying or even prevention of placement in residential care.
- The emphasis on keeping the duration of hospitalizations as brief as possible may sometimes tempt clinicians to make too any changes in care at the same time which may makes it difficult to know precisely which intervention was responsible for improvement or, possibly, in worsening of the behaviors.
- The lack of supply of appropriate healthcare facilities that are designed to care for older patients who have concurrent medical and psychiatric problems.

Shortage of Clinicians.

Given the huge mismatch between the projected number of individuals who will be afflicted with dementia and the number of clinicians who have completed specialized training programs to prepare them to efficiently and safely diagnose and treat BPSD, most of this work will be undertaken by clinicians who will need resources like this manuscript in order to provide the care that these patients need.

In general, if the application of the information in these Guidelines does not result in acceptable clinical outcomes, then making a referral to a board-certified neurologist, geriatric internist, general psychiatrist or geriatric psychiatrist is recommended. In particular, if you are considering the use of any of the above medications listed under the category of “Other Medications That May Prove Helpful,” then a consultation with or a referral to a neurologist, geriatric internist, general psychiatrist or geriatric psychiatrist is highly recommended.

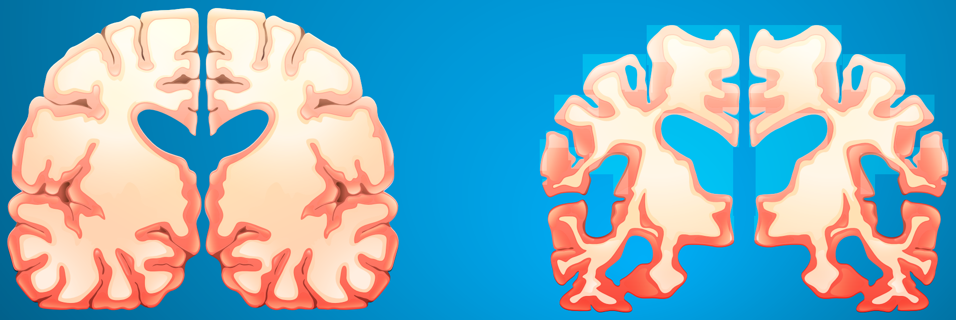
EVALUATE (Re-Evaluate)

It is important to review whether the interventions employed and implemented by caregivers have been safe and effective. An initial evaluation should be done within two to three weeks, and modifications made as needed. The practitioners should continue to look for possible underlying causes of behavioral factors.

If the patient is stable for three to six months on psychotropic medication, initiate a cautious incremental reduction, and monitor the patient closely. If symptoms reappear after the psychotropic dose reduction, then restore the dose to the level at which no symptoms were observed and wait another three to six months before re-attempting a dose reduction. If symptoms do not re-emerge after about four weeks, then make another reduction. If a variety of interventions are not effective, or if the patient or caregiver is in danger, consider referral to a neurologist, geriatric internist, general psychiatrist or geriatric psychiatrist.

During the last stage of dementia illness, referral to palliative care is often helpful. Psychiatric medication reduction may be possible. For more information, please see the section on Palliative and Hospice Care

Progression of Alzheimer’s Disease



Healthy Brain

Severe Alzheimer’s Disease

DICE APPROACH TO BEHAVIORAL AND PSYCHOLOGICAL SIGNS AND SYMPTOMS OF DEMENTIA

DESCRIBE	**Caregiver describes behavioral factors:** • Social & physical environment • Patient perspective • Degree of distress to patient and caregiver **Look for:** • Antecedents • Patterns • Context • Co-occurring events
INVESTIGATE (ASSESS)	**Investigate possible causes of behavior:** • Medication side effects • Pain • Functional limitations • Medical conditions • Psychiatric comorbidity • Severity of cog impairment • Degree of executive dysfunction • Poor sleep • Sensory changes • Emotional triggers: ie.,fear, abandonment • Lack of physical activity • Suboptimal exposure to bright light
CREATE (TREATMENT)	**Provider, caregivers, clinical team collaborate to create and implement a treatment plan** **Address physical problems and medical issues first** **Employ behavioral interventions** • Provide caregiver interventions • Enhance communication • Create meaningful activities • Simplify tasks **Ensure that the environment is safe** Increase or decrease the amount of stimulation in the environment If behavioral interventions not effective/partially effective, employ pharmacological management, selecting a class of psychotropic medication based on psychobehavioral "Assume/Assess/Align" model, as below **ASSUME patient does not have dementia** **ASSESS psychiatric signs and symptoms** **ALIGN symptoms to best fit psychiatric syndrome** eg., major depression, paranoid psychosis, mania, etc.
EVALUATE (AND RE-EVALUATE)	**Evaluate whether "CREATE" interventions implemented by caregiver(s) have been safe/effective** • Make modifications as needed and continue to look for possible underlying causes • Re-evaluate periodically • If intervention not effective or if patient or caregiver are in danger, consider referring to neurologist or psychiatrist

THE ALZHEIMER'S PROJECT

DICE APPROACH FOR BEHAVIORAL AND PHARMACOLOGIC TREATMENT OF DEPRESSION

DESCRIBE	Symptoms overlap with behavioral symptoms of dementia. Depressed mood may not be evident in older patients with major depression. Consider the following in older patients: anxiety, insomnia, anorexia, irritability, anger/hostility, insecurity, paranoia, etc.	**Presenting symptoms:** Depressed mood, tearfulness, anxiety, anhedonia, anorexia, weight loss, insomnia, hypersomnia, irritability, pessimism, suicidal ideation, somatic preoccupation, decreased concentration, psychomotor slowing, social isolation, psychosis.
INVESTIGATE (ASSESS)	- **Evaluate** underlying medical causes including medication side effects; work-up significant cognitive impairment/dementia. - **Do not assume** cognitive impairment is solely due to depression. - **Evaluate for the following:** social/family support, past psychiatric and substance abuse history, family mental health history.	
CREATE (TREATMENT)	**Educate** - patient and family; provide psychosocial interventions to support both patient and caregivers. **Medication** - Antidepressant medication should be started at low dose and increased slowly. Preferred antidepressant in older adults include certraline, citalopram, escitalopram	**Psychiatric consultation** - consider in context of severe depression, failure to thrive, psychosis, suicidal ideation, history of major psychiatric illness (eg. bipolar disorder, schizophrenia, past suicidal attempts, severe agitation, etc.)
EVALUATE (AND RE-EVALUATE)	**Gather information** - from caregivers and patient; use rating scales to track response to treatment. **Medication response** - Evaluate for side effects of medication within 2 weeks and efficacy within 3-4 weeks. **Evaluate for consultation** - Worsening symptoms or adverse effects of treatment (worsening cognitive symptoms, increased agitation, worsening insomnia, new suicidal ideation, etc.) should lead to psychiatric consultation.	

DICE APPROACH FOR BEHAVIORAL AND PHARMACOLOGIC TREATMENT OF AGITATION & AGGRESSION

DESCRIBE

Verbal Agitation
- Aggressive vs Non-Aggressive

Physical Agitation
- Aggressive vs Non-Aggressive

INVESTIGATE (ASSESS)

Agitation Type	Exhibits As	Potential Underlying Cause
Verbal Non-aggressive	Loud Screaming or Moaning, Requests for Help	Depression, Anxiety, Boredom
Verbal Aggressive	Threats, Name Calling	Paranoia
Physical Non-Aggressive	Pacing, Repetitive Pounding	Disinhibition, Boredom, Need for Attention, Companionship
Physical Aggressive	Hitting/Kicking/Pushing	Pain disorder or physical discomfort associated with movement, or constipation

CREATE (TREATMENT)

Address physical problems and/or utilize behavioral modifications. For behavioral specific resources:

www.alz.org/care

The 36 Hour Day by Nancy L. Mace & Peter V. Rabins

Ensure environment is safe with appropriate stimulation

If treatment of physical problems and/or behavioral modifications do not control behaviors consider pharmacologic treatment — Examples:
- Irritability/depression - antidepressant
- Fear/paranoia - antipsychotic
- Disinhibition/embarrassment - mood stabilizer
- Movement/pain - analgesic

EVALUATE (AND RE-EVALUATE)

***If patient stable 3-6 months, and psychotropic medication has been required, initiate a cautious incremental reduction and monitor patient closely**
- If symptoms are not fully resolved, look for other underlying causes
- If intervention not effective or if patient or caregiver are in danger, consider referring to neurologist or psychiatrist

THE ALZHEIMER'S PROJECT

DICE APPROACH FOR ASSESSMENT AND TREATMENT OF SLEEP PROBLEMS

DESCRIBE	Sundowning Daytime Sleeping Sleep Fragmentation	Initial Insomnia Middle Insomnia
INVESTIGATE (ASSESS)	Pain Osteoarthritis Sleep Apnea or Orthopnea	Boredom Poor Sleep Hygiene Suboptimal Prescribing
CREATE (TREATMENT)	Educate on good sleep hygiene practices **Correct any potential medical problems** If strict application of sleep hygiene practices and successful treatment of all medical co-morbidities has not resolved the insomnia problem, consider insomnia as potential symptons of a psychiatric disorder and apply the psychobehavioral methaphor. If insomnia appears to be related to temporary/situational factors, consider use of very low dose FDA approved medication for insomnia.*	
EVALUATE (AND RE-EVALUATE)	***If patient stable 3-6 months, and psychotropic medication has been required, initiate a cautious incremental reduction and monitor patient closely** • If symptoms are not fully resolved, look for other underlying causes • If intervention not effective or if patient or caregiver are in danger, consider referring to geriatric neurologist or psychiatrist	

DICE APPROACH FOR WANDERING

DESCRIBE	**Wandering** May occur in indoor residential or commercial environments as well as outdoor areas with or without secured perimeter
INVESTIGATE (ASSESS)	**Look for patterns, time of day/Sundowning** **Common triggers include:** • Boredom • Lack of physical activity • Searching for familiar/home • Dietary factors: sugar/caffeine • Medical factors: pain/constipation • Psychiatric issues: anxiety/mania
CREATE (TREATMENT)	**EMPLOY APPROPRIATE BEHAVIORAL AND SAFETY STRATEGIES. IF BEHAVIORAL INTERVENTIONS DO NOT RESOLVE BEHAVIORS: MEDICATION MAY BE NEEDED** Mania - may need pharmacologic treatment: anti psychotics or mood stabilizers*
EVALUATE (AND RE-EVALUATE)	**If wandering persists, look for other underlying causes** • *If patient stable 3-6 months, and psychotropic medication has been required, initiate a cautious incremental reduction and monitor patient closely • If intervention not effective or if patient or caregiver are in danger, consider referring to neurologist or psychiatrist

When treating individuals with dementia, the clinician is really treating both the patient and the family members who are primarily responsible for the individual's care. Therefore, it is important to identify key signals that the caregivers may need more assessment, support, and both medical and psychological treatment. It is good to know who the caregivers are, what are the impacts of caregiving, and what steps can be used to support caregivers.

Caring for Dementia Means Caring for the Care Partner

The best care can be provided by caregivers who are rested, and who take the time for self-care, similar to the analogy that on a plane, "put your own oxygen mask on first." The patient's continued health and well-being depends on a family caregiver. That person must be willing and able to handle the patient's complex health, financial, legal, and social needs. With care for an individual with dementia, the job can continue for months, or more commonly years.

Who Are the Caregivers?

According to the 2023 Alzheimer's Disease Facts and Figures report (alz.org/facts) there were over 1.374 million caregivers in California alone in 2022. Unpaid caregivers are providing an increasing proportion of the care needed, **providing 1.864 billion hours of unpaid care, valued at more than $44 billion each year.**

The report details the demographics of family caregivers:

- 67% women, providing 21 hours or more per week; 33% are daughters,
- 25% are "sandwich generation" women,
- 30% age 65 or older,
- 60% are married or living with a partner or in a long-term relationship,
- 66% live with the person with dementia,
- Over 50% are providing assistance to a parent or in-law,
- 66% are White, 10% Black, 8% Hispanic, 5% Asian American nationally.

Female caregivers may experience slightly higher levels of burden, impaired mood, depression and impaired health than caregivers who are men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, assume more caregiving tasks, and care for someone with more cognitive, functional and/or behavioral problems. Of dementia caregivers who indicated a need for individual counseling or respite care, the large majority were women (individual counseling, 85%, and respite care, 84%).

Racial disparities of Alzheimer's disease and related dementias (ADRD) mirror the disparities of other chronic diseases including hypertension, diabetes, and COPD. Older Black and Hispanic Americans are disproportionately more likely than older White Americans to have Alzheimer's or other dementias.

Data indicates AD prevalence rates compared to caregivers among racial/ethnic adults 65 years of age and older at:

Ethnicity/Race	Persons with Dementia	Caregivers
Black	18.6%	10%
Hispanic	14%	8%
White	10%	66%
Asian/Pacific Islander	8%	5%

While the prevalence of the disease and caregivers by ethnicity are not parallel, the data collection does not differentiate full time vs part time caregiving. A higher proportion of lower-income individuals and people of color are cared for at home rather than in congregate settings. The Alzheimer's Association study shows that Black caregivers are more likely to provide more than 40 hours of care per week (54.3% versus 38.6%) and 69% less likely to use respite services when compared with White caregivers. Hispanic, Black, and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use, and greater depression when compared with White caregivers.

Three of the main reasons caregivers provide assistance to a person with ADRD are: (1) the desire to keep a family member or friend at home (65%), (2) proximity to the person with dementia (48%), and (3) the caregiver's perceived obligation to the person with dementia (38%). Caregivers often indicate love and a sense of duty and obligation when describing what motivates them to assume care responsibilities for a relative or friend living with dementia. As those afflicted with dementia can live with the disease for four to 20 years, the slow, insidious and uncertain progression of the disease can take a substantial toll on caregivers.

Black caregivers are more likely than White caregivers to report positive aspects of caregiving. The report found that Black dementia caregivers indicate slightly higher psychological well-being than White dementia caregivers. Hispanic dementia caregivers, however, reported slightly lower physical well-being than White dementia caregivers. Support from family and friends is associated with better self-rated health for Black dementia caregivers, but not for White or Hispanic caregivers. A more positive perceived relationship between the caregiver and person with dementia was associated with better self-rated health among Black and White caregivers.

Health and Economic Impacts of Alzheimer's Caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the moderate to severe stages of Alzheimer's dementia experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer's manage these issues. The personality and behavior of a person with Alzheimer's are often affected as well, and these changes are among the most challenging for family caregivers. Individuals with ADRD also require increasing levels of supervision and personal care as the disease progresses. As the person with dementia's symptoms worsen, caregivers can experience increased emotional stress and depression; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services for themselves and people living with dementia.

Caregiver Emotional and Social Well-Being

The intimacy, shared experiences and memories that are often part of the relationship between a caregiver and person living with dementia may be threatened due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of ADRD. Almost half of caregivers of people with dementia indicated that providing help to someone with cognitive impairment was very rewarding. Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, they also frequently report higher levels of stress. It is important to stress to caregivers the importance of self-care to meet their own emotional and social needs. (see Caregiver Tip sheet)

Burden and Stress

- Twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties as caregivers of people without dementia.
- 59% of family caregivers rated the emotional stress of caregiving as high or very high.
- Spousal dementia caregivers are more likely than non-spousal caregivers to experience increased burden over time, particularly when the loved one experiences behavioral changes and decreased functional ability.
- Caregivers of people with ADRD were twice as likely as caregivers of individuals without dementia (22% compared with 11%) to report that completing medical/nursing-related tasks (for example, injections, tube feedings and catheter/colostomy care) was difficult.
- Dementia caregivers often lack the information or resources necessary to manage complex medication regimens.
- More than half of women with children under age 18 felt that caregiving for someone with dementia was more challenging than caring for children.
- 59% of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful.
- 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.

Depression and Mental Health

Caregivers of people with dementia were significantly (30% to 40%) more likely to experience depression and anxiety than non-caregivers.

- Dementia caregivers also indicate more depressive symptoms than non-dementia caregivers.
- Caregivers of spouses with dementia had two-and-a-half times higher odds of having depression than caregivers of people with dementia who were not spouses.
- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).
- Increased depressive symptoms among caregivers over time are linked to more frequent doctor visits, increased outpatient tests and procedures, and greater use of over-the-counter and prescription medications.

Caregiver Physical Health and Health Conditions

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications.

- The distress associated with caregiving has been shown to negatively influence the quality of family caregivers' sleep, and caregivers are estimated to lose between 2.4 hours and 3.5 hours of sleep a week.
- Many caregivers may contend with health challenges of their own.
- Caregivers indicate lower health-related quality of life than non-caregivers and are more likely than non-caregivers or other caregivers to report that their health is fair or poor.
- Dementia caregivers who provided care to spouses were much more likely (41% increased odds) than other spousal caregivers of similar age to become increasingly frail during the time between becoming a caregiver and their spouse's death.

- On a positive note, caregiving tasks may have the positive effect of keeping older caregivers more physically active than non-caregivers.

Mortality

Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings:

- Caregivers who perceive higher strain due to care responsibilities were at higher risk for death than caregivers who perceive little or no strain.
- There is the possibility that individuals who assume dementia care roles do so in part because their initial health allows them to do so.
- 18% of spousal caregivers die before their partners with dementia.

Appropriate Interventions Through Stages of the Disease

The goal of interventions is to improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Some also aim to delay admission of the person with dementia to long-term care facilities by providing caregivers with skills and resources (emotional, social, psychological and/or technological) to continue helping their relatives or friends at home. Specific approaches used in various interventions include:

- Psychoeducational approaches – caregivers learning about disease and caregiving,
- Assistance/education on dementia-related symptoms,
- Case management,
- Support groups and other social supports,
- Respite,
- Counseling,
- Self-care – exercise, personal care, nutrition,
- Consideration of medication.

If caregiver needs are unmet, chances are much higher that your patient's needs will be unmet as well. Community resources, as well as resources available through the provider's health system should be recommended. See the Resource listing at end of the booklet.

Caring for the Caregiver

Steps to Support Caregivers

1. *Understand the multitude of impacts borne by caregivers.*
2. *Include caregivers as a member of the care team by identifying who they are, including them in appointments and conversations with the patient, and documenting their presence at visits and contact information in the patient's medical record.*
3. *Utilize a care team approach with social workers, nurse practitioners and other members of your office staff. Make referrals to palliative care teams as appropriate.*
4. *Assess and address the caregiver's physical and mental health, well-being, capacity and willingness to be a caregiver, and any unmet needs.*
5. *Be familiar with care options, system supports and community resources, and address caregiver needs via referral to appropriate services, including medical consultation, disease education resources, and online and community resources.*
6. *Create care plans for both patient and caregiver that are matched to their needs and reflect goals of care and advance care planning.*
7. *Train caregivers on behaviors as a form of communication, particularly as the patient's ability to communicate verbally diminishes.*
8. *Add information to EHR to track progress and to make use of appropriate billing codes (see page 74)*

Assessing Family Caregivers

As a health care professional, you assess patients all the time. But you may not routinely assess a patient's family caregiver, especially if the caregiver is a patient of another clinician. When treating individuals with dementia, the clinician should be treating both the patient and the family members who are primarily responsible for the individual's care. Therefore, it is important to identify key signals that the caregivers may need more assessment, support, and both medical and psychological treatment. The primary care physician is encouraged to utilize the clinical team to conduct caregiver assessments.

Caregiver assessment is a tool to help identify strengths and limitations and to develop a realistic plan for the next stage of care. The goal is twofold: (1) to ensure that the patient's health and well-being are maintained and enhanced; and (2) to ensure that the caregiver's capacities and needs are considered and addressed in a care plan, and that the caregiver's capacities and needs are not exceeded by the patient's condition.

Next Step in Care (https://uhfnyc.org/publications/publication/home-alone-revisited/) has created a guide as an introduction to caregiver assessment in hospitals, nursing homes, and home health agencies. Although these settings are different, the guide gives some basic information and suggestions. These are the questions addressed:

- Who is a family caregiver?
- What is caregiver assessment and why is it important?
- Who should do it, when, and how?
- What should it cover?
- How should the assessment be used?

As a first step in caregiver assessment, it is essential to determine who provides and/or manages that care. Even when there is a designated family member who receives medical updates and communicates to the rest of the family, that person may not provide the hands-on care. One way to identify the main family caregiver is to ask the patient, if he or she can respond, "Who helps you at home?" or "Whom do you rely on most for help at home?" If the patient cannot respond, then ask the family member who seems to be most involved if he or she lives with the patient and provides care at home. Instead of asking, "Are you a caregiver?" it is better to ask, "What do you do at home for your family member? Do you do this all the time? Is there anyone who helps you?"

What is the caregiver assessment?

According to the National Center on Caregiving at Family Caregiver Alliance, Caregiver Assessment is the process of gathering information to identify problems, needs, resources and strengths of the family caregiver aligned with the caregiver's perspective and culture. The assessment is focused on the caregiver rather than the individual with dementia and seeks to maintain the caregiver's own health and well-being.

For family caregivers, an assessment is a chance to talk about their own lives for perhaps the first time in any encounter with the patient's health care team. They can express concerns about their own abilities to provide certain kinds of care, and the realities of their own situations. In health care settings, assessments will necessarily be brief but they can raise questions that the family caregiver can discuss further with others and can suggest types of resources that may be available and helpful. Some clinicians may be reluctant to ask questions about the kinds of help that a caregiver may need, because they cannot fill those gaps, but referral to community resources can be very helpful. But most caregivers are grateful for any suggestions and for the attention being paid to them.

Who should do a caregiver assessment, when, and how?

The primary care physician is encouraged to utilize the clinical team to conduct caregiver assessments. If a social worker is available to the practice, that person may be best suited. If the patient qualifies for home health care services, the home health agency can provide a social work evaluation in the home. A nurse, nurse practitioner, or the rooming staff medical assistant may be able to initiate the assessment.

There are a number of self-assessment tools (see Instruments at end of section) that may be sent to the caregiver to complete prior to the patient's appointment, and bring to the appointment, similar to the use of the informant survey (AD8) to assess changes in behaviors in the individual with dementia. More important than the professional status of the assessors are their attitudes and ability to relate to the caregiver in a nonjudgmental and thoughtful way.

Assessments should be introduced as – and should be – a way to acknowledge the family caregiver's perspective, not as a test and certainly not as a guilt-inducing technique. The assessor should have good communication skills, including the ability to listen attentively, probe for clarifications, and respect diversity in all its many forms. If the caregiver does not speak English, the assessment should be done by a trained interpreter.

If possible, the assessment should be completed outside the presence of the individual with dementia, as the caregiver may not feel comfortable talking about their own needs or issues in front of their loved one. Potentially a clinical staff member could perform the assessment while the clinician is examining the patient. If upon a cursory assessment the clinician notes significant signs of stress, anxiety or depression, it would be helpful to request a separate appointment with the caregiver to provide adequate time for assessment and treatment or make a dedicated referral to the caregiver's primary care physician with direct communication to that practitioner.

What should the assessment cover?

There are a variety of caregiver assessment tools available; most, however, were developed for use in community-based agencies, not in health care settings. Using those assessment tools as a framework, some basic questions should include:

- The caregiver's background, including age, education, employment, other family responsibilities, living arrangements.
- The caregiver's perception of the care recipient's health and functional status.
- Length of time the caregiver has been providing care; if this is a new event, what the caregiver worries most about in providing care.
- Values and preferences about caregiving ("do it all myself,"; "can't deal with needles or incontinence,"; "I can't take Mom to my home because there just isn't room for another person").
- Caregiver's health status, including any limitations relevant to caregiving.
- Impact of caregiving on emotional status, finances, other family members.
- Knowledge, skills, and abilities to perform necessary caregiving tasks.
- Support systems available to reduce social isolation.
- Resources used or interested in accessing.

The Zarit Burden Interview (ZBI-12) is included in these Guidelines and may be helpful in assessing caregiver burden and stress.

How should the assessment be used?

In introducing the assessment process to the family caregiver, the assessor should clarify the goals of the assessment and make it clear that all information (unless specified by the caregiver) will be shared with the health care team in order to develop a care plan. Caregivers should understand that a summary of the assessment may be documented in the medical record and perhaps shared with other healthcare professionals. Thus, if there is information that the caregiver does not want shared, this should be made clear to the person conducting the assessment. Family caregivers should be assured that the assessment will not be shared with the patient or other family members, unless the caregiver authorizes release of the information. Also, the caregiver should be informed that the assessor is a mandated reporter of suspected elder abuse or neglect, and in the event there is such a suspicion, confidentiality cannot be maintained.

The assessor should also summarize the conversation, so that the family caregiver feels that their concerns have been heard. The assessor can emphasize the positives first, and then list the areas where some questions have been raised and suggest a process for following up. The family caregiver can also be given a copy of one of the Self-Assessment tools for future use.

In addition to providing information in a systematic way, assessments recognize the importance of family caregivers as direct care providers and managers, and affords them the opportunity to self-identify as a caregiver and take stock of their strengths, limitations, and needs. To be effective, however, caregiver assessments must be undertaken by professionals with good communication and relationship-building skills.

There are also caregiver-information handouts available at https://ChampionsforHealth.org/alzheimers you may want to have on hand for family caregivers. Many of the dementia-specific organizations also provide valuable resources to improve the quality of life of caregivers.

Medicare and MediCal have separate guidelines for billing and reimbursement. This information is meant only to provide an overview. Please consult with your carriers for confirmation.

Medicare Billing

Medicare Annual Wellness Visit

For the Medicare Annual Wellness Visits, the codes are the following:

G0438 Annual wellness visit; includes a personalized prevention plan of service, Initial visit.

G0439 Annual wellness visit; includes a personalized prevention plan of service, subsequent visit.

When you furnish a significant, separately identifiable, medically necessary Evaluation and Management (E/M) service along with the AWV, Medicare may pay for the additional service. Report the additional Current Procedural Terminology (CPT) code with modifier -25. That portion of the visit must be medically necessary to treat the beneficiary's illness or injury, or to improve the functioning of a malformed body member.

Cognitive Examination

Medicare established a code in 2018 for services aimed at improving detection, diagnosis, and care planning and coordination for patients with Alzheimer's disease and related dementias. CPT code 99483, which supersedes the older code G0505, provides reimbursement to physicians and other eligible billing practitioners for a comprehensive clinical visit that results in a written care plan.

Code 99483 requires an independent historian; a multidimensional assessment that includes cognition, function, and safety; evaluation of neuropsychiatric and behavioral symptoms; review and reconciliation of medications; and assessment of the needs of the patient's caregiver. Eligible practitioners must provide documentation that supports a moderate-to-high level of complexity in medical decision making, as defined by E/M guidelines (with application as appropriate of the usual "incident-to" rules, consistent with other E/M services). The provider must also document the detailed care plan developed as a result of each required element covered by 99483. Typically, 50 minutes are spent face to face with the patient and/or family or caregiver.

The nine assessment elements of 99483 can be evaluated within the care planning visit or in one or more visits that precede it, using appropriate billing codes (most often an E/M code). Patients with complex medical, behavioral, psychosocial and/or caregiving needs may require a series of assessment visits, while those with well-defined or less complex problems may be fully assessed during the care plan visit. Results of assessments conducted prior to the care plan visit are allowed in care planning documentation provided they remain valid or are updated with any changes at the time of care planning. A single physician or other qualified health care professional should not report 99483 more than once every 180 days. (See the CPT manual for full details, and the Care Plan Template developed by PeerView Primary Care in the resource section of these Guidelines.)

Ongoing Care Management

For Medicare care management bill the regular E&M codes:

99203-99205 (New patient)

99212-99215 (Established patients)

For any additional time spent with the patient during an E&M visit you can bill a prolonged code. 99417 (For commercial payers) – Prolonged office or other outpatient evaluation and management services beyond the minimum required time of the primary procedure which has been selected using total time, requiring total time with or without direct patient contact beyond the usual service, on the date of the primary service, each 15 minutes of total time. G2212 (For Medicare billing).

Medicare Chronic Care Management: Healthcare providers, including physicians, nurse practitioners, physician assistants, and clinical nurse specialists, can bill Medicare for providing chronic care management services to individuals with two or more chronic conditions that are expected to last at least 12 months. These services include activities such as creating or updating a comprehensive care plan, coordinating care with other healthcare providers, monitoring patient health remotely, providing medication management, and offering support for lifestyle changes.

By reimbursing healthcare providers for CCM services, Medicare aims to incentivize the provision of ongoing care management for patients with chronic conditions, ultimately improving health outcomes and reducing healthcare costs associated with preventable complications and hospitalizations.

CPT code 99490 may be billed once per calendar month, and requires at least 20 minutes of clinical staff time spent providing CCM services within that period. CPT code 99439 may be billed for each additional 20 minutes of clinical staff time spent providing CCM services within that period. See your billing specialist for use of other related codes.

Advance Care Planning

CPT 99497: Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate.

CPT 99498: Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes. (List separately in addition to code for primary procedure)

You must report a diagnosis code when submitting a claim for ACP as an optional element of an AWV. Since you are not required to document a specific diagnosis code for ACP as an optional element of an AWV, you may choose any diagnosis code consistent with a beneficiary's exam.

Medicare waives both the coinsurance and the Medicare Part B deductible for ACP when it is:

- Provided on the same day as the covered AWV,
- Furnished by the same provider as the covered AWV,
- Billed with modifier -33 (Preventive Service),
- Billed on the same claim as the AWV.

The deductible and coinsurance for ACP are waived only once per year, when it is billed with the AWV. If the AWV billed with ACP is denied for exceeding the once per year limit, the deductible and coinsurance will be applied to the ACP.

NOTE: The deductible and coinsurance apply when ACP is provided outside the covered AWV.

Supportive Services

Medicare is initiating a multi-year innovation demonstration project (GUIDE) to offer similar social support services for MediCal beneficiaries. Providers should check with their healthcare system/administration to see if they are or will be participating in this program.

MediCal Billing

Annual Cognitive Health Assessment

Effective July 1, 2022, an annual Cognitive Health Assessment (CHA) for Medi-Cal beneficiaries who are 65 years of age or older is a covered benefit if the beneficiary is otherwise ineligible for a similar assessment as part of an annual wellness visit under the Medicare Program. This assessment should be a component of an Evaluation and Management (E&M) visit. When a CHA is performed during an E&M visit, bill an additional claim line using CPT-4 code 1494F Cognition assessed and reviewed.

Medi-Cal providers must complete training as specified and approved by the Department of Health Care Services (DHCS), and use validated tools recommended by DHCS (https://dementiacareaware.org). The CHA should include cognitive and functional screen tests for both patient and an informant, e.g., a Mini-Cog or GPCOG, AND ADL/IADL for patient, along with an AD-8 or IQCODE, AND a GPCOG Informant Interview or FAQ for the Informant. To bill under this code, practitioners must: document the screening tools used, provide verification that the results were reviewed by the provider, the results and interpretation, other details discussed, and the documentation of a care partner in the electronic medical record.

MediCal CalAIM Care Management

Healthcare providers and systems contracting with MediCal managed care insurers may be able to access services for their patients through the CalAIM Community Supports for Social Drivers of Health, including care navigation, housing services, recuperative care, caregiver respite, medically supportive food, and other services. Providers should check with the insurers on how to access these services.

Enhanced Care Management (ECM): ECM is a statewide MediCal Managed Care Plan (MCP) benefit to support comprehensive care management for members with complex needs. The vision is to coordinate all care for eligible members across the physical, behavioral and dental health delivery systems. ECM is interdisciplinary, person-centered, and provided primarily through in-person interactions. It is the highest tier of care management for MediCal Managed Care Plan members. Rules regarding services, community supports and billing are currently undergoing changes. It is recommended to refer to your MediCal billing specialist.

Resources and References

General Informational Resources

Alzheimer's Association http://alz.org

Alzheimer's San Diego http://alzsd.org

Alzheimer's Disease Education and Referral (ADEAR) https://www.nia.nih.gov/alzheimers

Alzheimer's Drug Discovery Foundation (ADDF) information about risk factors. https://www.alzdiscovery.org

California Alzheimer's Disease Centers Assessment of Cognitive Complaints Toolkit https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/CDPH%20Document%20Library/Alzheimers'%20Disease%20Program/ACCT-AD%20Toolkit%2012%2027%2018.pdf

Gerontological Society of America, KAER Toolit: 4-Step Process to Detecting Cognitive Impairment and Earlier Diagnosis of Dementia. https://www.geron.org/Resources/Brain-Health-and-Dementia

American Academy of Neurology https://aan.com

Lewy Body Dementia Association http://www.LBDA.org

Association for Fronto-Temporal Degeneration (AFTD) http://www.theaftd.org

Clinical trials ADRD:

ClinicalTrials.gov

https://clinicaltrials.gov/ct2/results?cond=dementia&term=&cntry=&state=&city=&dist=

Alzheimer Association TrialMatch https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials

Screening & Evaluation Instruments

Mini-Cog: https://mini-cog.com/download-the-mini-cog-instrument/

Mini-Cog other languages: https://mini-cog.com/mini-cog-in-other-languages/

MOCA In English and other languages: https://www.mocatest.org

PHQ-9 in English and other languages: https://www.apa.org/depression-guideline/patient-health-questionnaire.pdf

qMCI: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3633367/

Comparison of the Quick Mild Cognitive Impairment (Qmci) screen to the Montreal Cognitive Assessment (MoCA) in an Australian geriatrics clinic - PubMed https://pubmed.ncbi.nlm.nih.gov/27427212/

SLUMS Examination in English and other languages: https://www.elderguru.com/download-the-slums-dementia-alzheimers-test-exam/

https://www.elderguru.com/slums-dementia-test-available-in-various-languages/

AD 8: https://alz.org/media/documents/ad8-dementia-screening.pdf

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Identification of IADLs vs ADLs

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Driving with Dementia

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Elder Abuse

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End of Life Planning and Care

www.prepareforyourcare.org

www.caringadvocates.org

www.coalitionccc.org

https://theconversationproject.org

Advanced Care Planning Worksheets for Patients and family members
https://www.nia.nih.gov/health/advance-care-planning/advance-care-planning-worksheetsGraphic element


Meine Vergangenheit nicht vergessen !!!

Mini-Cog™

Instructions for Administration & Scoring

ID: ____________ Date: ____________________

Step 1: Three Word Registration

Look directly at person and say, "Please listen carefully. I am going to say three words that I want you to repeat back to me now and try to remember. The words are [select a list of words from the versions below]. Please say them for me now." If the person is unable to repeat the words after three attempts, move on to Step 2 (clock drawing).

The following and other word lists have been used in one or more clinical studies.[1-3] For repeated administrations, use of an alternative word list is recommended.

Version 1	**Version 2**	**Version 3**	**Version 4**	**Version 5**	**Version 6**
Banana	Leader	Village	River	Captain	Daughter
Sunrise	Season	Kitchen	Nation	Garden	Heaven
Chair	Table	Baby	Finger	Picture	Mountain

Step 2: Clock Drawing

Say: "Next, I want you to draw a clock for me. First, put in all of the numbers where they go." When that is completed, say: "Now, set the hands to 10 past 11."

Use preprinted circle (see next page) for this exercise. Repeat instructions as needed as this is not a memory test. Move to Step 3 if the clock is not complete within three minutes.

Step 3: Three Word Recall

Ask the person to recall the three words you stated in Step 1. Say: "What were the three words I asked you to remember?" Record the word list version number and the person's answers below.

Word List Version: _____ Person's Answers: ________________ ________________ ________________

Scoring

Word Recall: _____ (0-3 points)	1 point for each word spontaneously recalled without cueing.
Clock Draw: _____ (0 or 2 points)	Normal clock = 2 points. A normal clock has all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
Total Score: _____ (0-5 points)	Total score = Word Recall score + Clock Draw score. A cut point of <3 on the Mini-Cog™ has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

v. 01.19.16

Clock Drawing

ID: ______________ Date: ________________________

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Mini-Cog©

Instrucciones para la aplicación y conteo de puntos

Nombre del cliente: ______ No. de cliente: ______ Terapeuta: ______

Paso N.º 1: Registro de tres palabras

Mire directamente a la persona y dígale, "Escuche con cuidado. Voy a decir tres palabras que quiero que usted repita ahora y trate de recordar. Las palabras son [seleccione una lista de palabras de las versiones que aparecen a continuación]. "Ahora repita las palabras." Si la persona no es capaz de repetir las palabras después de tres intentos, continúe al Paso N.º 2 (Dibujo de reloj).

La siguiente lista de palabras y otras más se han utilizado en varios estudios clínicos. .1-3 Si planea aplicar la prueba repetidamente, se recomienda el uso de una lista alternativa de palabras.

Versión 1	Versión 2	Versión 3	Versión 4	Versión 5	Versión 6
Plátano	Líder	Pueblo	Río	Capitán	Hija
Amanecer	Temporada	Cocina	Nación	Jardín	Cielo
Silla	Mesa	Bebé	Dedo	Retrato	Montaña

Paso N.º 2: Dibujo de reloj

Diga: "Ahora, quiero que me dibuje un reloj. Primero, coloque los números donde van". Una vez que el cliente haya terminado, diga: "Ahora, ponga las manecillas del reloj en la posición que indiquen las 11:10".

Use la página con el círculo impreso (vea la siguiente página) para este ejercicio. Repita las instrucciones según sea necesario ya que esto no es una prueba de memoria. Continúe al Paso N.º 3 si el cliente no lo ha completado en tres minutos.

Paso N.º 3: Memoria de tres palabras

Pídale a la persona que repita las tres palabras que usted dijo en el Paso N.º 1. Diga: "¿Cuáles fueron las tres palabras que le pedí que recordara?" Registre el número de versión de lista de palabras y las respuestas de la persona a continuación.

Versión de lista de palabras: ______ Respuestas de la persona: ______ ______ ______

Puntaje

Memoria de palabras : ___ (0-3 puntos)	1 punto por cada palabra que recuerde espontáneamente sin pistas.
Dibujo de reloj: ___ (0-2 puntos)	Reloj normal= 2 puntos. Un reloj normal tiene todos los números colocados en la secuencia y posición aproximadamente correctas (p. ej., 12, 3, 6, 9 están en posiciones de anclaje y 2 (11:10). Longitud de la manecilla no se cuenta en el puntaje. Si la persona no es capaz de dibujar un reloj o se rehúsa (anormal) = 0 puntos.
Puntaje total: ___ (0-5 puntos)	Puntaje total = Puntaja de Memoria de palabras + Puntaje de Dibujo de reloj. Se ha establecido un valor de corte de < 3 en la Mini-Cog™ para la detección de demencia, pero muchas personas con deterioro cognitivo clínicamente significativo tendrán una puntuación más alta. Cuando se desea una mayor sensibilidad, se recomienda usar un valor de corte de < 4, ya que podría indicar la necesidad de evaluaciones adicionales para determinar el estado cognitivo.

AD8 Dementia Screening Interview

Patient ID#:__________
CS ID#:___________
Date:___________

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	**YES, A change**	**NO, No change**	**N/A, Don't know**
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. **Daily** problems with thinking and/or memory			
TOTAL AD8 SCORE			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

The AD8 Administration and Scoring Guidelines

A spontaneous self-correction is allowed for all responses without counting as an error.

The questions are given to the respondent on a clipboard for self–administration or can be read aloud to the respondent either in person or over the phone. It is preferable to administer the AD8 to an informant, if available. If an informant is not available, the AD8 may be administered to the patient.

When administered to an informant, specifically ask the respondent to rate change in the patient.

When administered to the patient, specifically ask the patient to rate changes in his/her ability for each of the items, ***without*** attributing causality.

If read aloud to the respondent, it is important for the clinician to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems). There should be a one second delay between individual items.

No timeframe for change is required.

The final score is a sum of the number items marked “Yes, A change”.

Interpretation of the AD8 (Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564)

A screening test in itself is insufficient to diagnose a dementing disorder. The AD8 is, however, quite sensitive to detecting early cognitive changes associated many common dementing illness including Alzheimer disease, vascular dementia, Lewy body dementia and frontotemporal dementia.

Scores in the impaired range (see below) indicate a need for further assessment. Scores in the “normal” range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

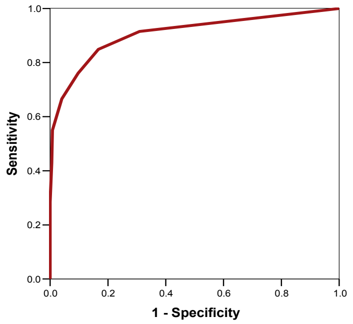
Based on clinical research findings from 995 individuals included in the development and validation samples, the following cut points are provided:

- 0 – 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

Administered to either the informant (preferable) or the patient, the AD8 has the following properties:

- Sensitivity > 84%
- Specificity > 80%
- Positive Predictive Value > 85%
- Negative Predictive Value > 70%
- Area under the Curve: 0.908; 95%CI: 0.888-0.925

Reciever Operator Characteristics (ROC) curve for AD8



Permission Statement

AD8 Dementia Screening Interview

Patient ID#:__________
CS ID#:___________
Date:____________

Recuerde: "sÍ. Hay cambios." signica que ha habido un cambio en los últimos años debido a problemas cognitivos (pensamiento y memoria).	**SÍ.** **Hay cambios** 1 punto	**NO.** **No hay cambios** 0 punto	**No aplicable.** **No sé.**
1. Problemas de juicio (ejemplo: compra regalos inadecuados, ha sido estafado/a, toma malas decisiones en lo económico)			
2. Menor interés en realizar actividades o sus pasatiempos			
3. Repite las preguntas, historias			
4. Tiene dificultad para aprender a usar instrumentos tecno- lógicos, electrodomésticos (como el control remoto TV, computador, microondas, video grabadora)			
5. Olvida el mes o año			
6. Tiene dificultad en el manejo de asuntos financieros complejos (pagar las cuentas, llevar la chequera, pago de impuestos)			
7. Tiene dificultad para acordarse de los compromisos (citas al doctor etc.)			
8. Problema persistente de memoria y pensamiento (no ocasional)			
TOTAL AD8 SCORE			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

Patient Name:______________________ **Date:**_____________
Patient ID #_________________________

LAWTON - BRODY
INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)

Scoring: For each category, circle the item description that most closely resembles the client's highest functional level (either 0 or 1).

A. Ability to Use Telephone		**E. Laundry**	
1. Operates telephone on own initiative-looks up and dials numbers, etc. 2. Dials a few well-known numbers 3. Answers telephone but does not dial 4. Does not use telephone at all	1 1 1 0	1. Does personal laundry completely 2. Launders small items-rinses stockings, etc. 3. All laundry must be done by others	1 1 0
B. Shopping		**F. Mode of Transportation**	
1. Takes care of all shopping needs independently 2. Shops independently for small purchases 3. Needs to be accompanied on any shopping trip 4. Completely unable to shop	1 0 0 0	1. Travels independently on public transportation or drives own car 2. Arranges own travel via taxi, but does not otherwise use public transportation 3. Travels on public transportation when accompanied by another 4. Travel limited to taxi or automobile with assistance of another 5. Does not travel at all	1 1 1 0 0
C. Food Preparation		**G. Responsibility for Own Medications**	
1. Plans, prepares and serves adequate meals independently 2. Prepares adequate meals if supplied with ingredients 3. Heats, serves and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet 4. Needs to have meals prepared and served	1 0 0 0	1. Is responsible for taking medication in correct dosages at correct time 2. Takes responsibility if medication is prepared in advance in separate dosage 3. Is not capable of dispensing own medication	1 0 0
D. Housekeeping		**H. Ability to Handle Finances**	
1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") 2. Performs light daily tasks such as dish washing, bed making 3. Performs light daily tasks but cannot maintain acceptable level of cleanliness 4. Needs help with all home maintenance tasks 5. Does not participate in any housekeeping tasks	1 1 1 1 0	1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income 2. Manages day-to-day purchases, but needs help with banking, major purchases, etc. 3. Incapable of handling money	1 1 0
Score		**Score**	
Total score__________________ A summary score ranges from 0 (low function, dependent) to 8 (high function, independent) for women and 0 through 5 for men to avoid potential gender bias.			

Source: *try this:* Best Practices in Nursing Care to Older Adults, The Hartford Institute for Geriatric Nursing, New York University, College of Nursing, www.hartfordign.org.

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Editor-in-Chief: Sherry A. Greenberg, PhD, RN, GNP-BC
New York University Rory Meyers College of Nursing

Use of the Functional Activities Questionnaire in Older Adults with Dementia

By: Ann M. Mayo, DNSc, RN, FAAN
Hahn School of Nursing & Health Science, University of San Diego

WHY: Dementia is a neurodegenerative disease where functional ability in individuals with dementia (IWD) declines over time. The majority of care costs in IWD are directly attributed to functional disability (Hurd, 2013). Compromised functional ability is unsafe for IWD, anxiety provoking for families and costly to health care organizations. Valid and reliable clinical information about functional ability can be used to individualize care and design safe and supportive environments thereby promoting the highest level of independence for individuals with dementia. Therefore, an effective and efficient method for measuring functional ability is important.

BEST TOOL: The Functional Activities Questionnaire (FAQ) measures instrumental activities of daily living (IADLs), such as preparing balanced meals and managing personal finances. Since functional changes are noted earlier in the dementia process with IADLs that require a higher cognitive ability compared to basic activities of daily living (ADLs) (Hall, 2011; Peres et al., 2008), this tool is useful to monitor these functional changes over time. The FAQ may be used to differentiate those with mild cognitive impairment and mild Alzheimer's disease. To further exemplify the importance and utilization of the FAQ, thousands of research participants across the United States are administered the FAQ annually as part of the National Alzheimer's Coordinating Center (NACC) longitudinal research study taking place in 29 National Institute on Aging-funded Alzheimer's Disease Centers (Weintraub et al., 2009).

TARGET POPULATION: Older adults with normal cognition, mild cognitive impairment, as well as mild, moderate, and advanced dementia (Weintraub et al., 2009). The FAQ is appropriate for clinical settings, such as acute and primary care, rehabilitation, assisted living, and home settings, as well as for research.

VALIDITY AND RELIABILITY: In IWD the FAQ is a consistently accurate instrument with good sensitivity (85%) to identify an individual's functional impairment. The FAQ demonstrates high reliability (exceeding 0.90). Tests of validity have been performed on the FAQ establishing it as an instrument for the bedside and research because it can discriminate among different functional levels of individuals, predict neurological exam ratings and mental status scores such as the Folstein Mini-Mental Status Examination (MMSE) and demonstrate sensitivity to change (Assis, 2014; Malek-Ahmadi, 2015; Pfeffer, 1982).

STRENGTHS AND LIMITATIONS: The FAQ is efficient to administer to older adults giving consistent results across different professionals and settings including primary care settings, as well as with different forms of dementia (Mayo, 2013; Tabert et al., 2002). As with other instruments that measure functional activities using indirect approaches, there may be over or under estimation of abilities because of the lack of direct observations.

FOLLOW-UP: Continued monitoring of IADLs in IWD is important to ensure environmental adaptations keeping these individuals safe. The measurement of IADLs is also important for advancing science. Therefore, the FAQ is an important measure for clinicians and researchers.

MORE ON THE TOPIC:

Best practice information on care of older adults: http://consultgeri.org/.

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Functional Activities Questionnaire

Administration

Ask informant to rate patient's ability using the following scoring system:

- Dependent = 3
- Requires assistance = 2
- Has difficulty but does by self = 1
- Normal = 0
- Never did [the activity] but could do now = 0
- Never did and would have difficulty now = 1

1.	Writing checks, paying bills, balancing checkbook	
2.	Assembling tax records, business affairs, or papers	
3.	Shopping alone for clothes, household necessities, or groceries	
4.	Playing a game of skill, working on a hobby	
5.	Heating water, making a cup of coffee, turning off stove after use	
6.	Preparing a balanced meal	
7.	Keeping track of current events	
8.	Paying attention to, understanding, discussing TV, book, magazine	
9.	Remembering appointments, family occasions, holidays, medications	
10.	Traveling out of neighborhood, driving, arranging to take buses	
	TOTAL SCORE:	

Evaluation

Sum scores (range 0-30). Cut-point of 9 (dependent in 3 or more activities) is recommended to indicate impaired function and possible cognitive impairment.

Pfeffer, R.I., Kurosaki, T.T., Harrah, C.H. Jr., Chance, J.M., & Filos, S. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology, 37*(3), 323-329. Reprinted with permission of Oxford University Press.

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CLINICAL NURSING WEBSITE **www.ConsultGeriRN.org**

Patient name:____________________________ **Date:** ______________

GPCOG Screening Test

Step 1: Patient Examination

Unless specified, each question should only be asked once

Name and Address for subsequent recall test

1. "*I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington.*" (Allow a maximum of 4 attempts).

Time Orientation

	Correct	**Incorrect**
2. *What is the date?* (exact only)	☐	☐

Clock Drawing – use blank page

3. *Please mark in all the numbers to indicate the hours of a clock* (correct spacing required)	☐	☐
4. *Please mark in hands to show 10 minutes past eleven o'clock* (11.10)	☐	☐

Information

5. *Can you tell me something that happened in the news recently?* (Recently = in the last week. If a general answer is given, eg "war", "lot of rain", ask for details. Only specific answer scores).	☐	☐

Recall

6. *What was the name and address I asked you to remember*

John	☐	☐
Brown	☐	☐
42	☐	☐
West (St)	☐	☐
Kensington	☐	☐

(*To get a total score, add the number of items answered correctly*
Total correct (score out of 9) **/9**

If patient scores 9, no significant cognitive impairment and further testing not necessary.
If patient scores 5-8, more information required. Proceed with Step 2, informant section.
If patient scores 0-4, cognitive impairment is indicated. Conduct standard investigations.

Brodaty et al, *JAGS* 2002; 50:530-534

GPCOG
Informant Interview

Date: ____________

Informant's name: ___________________________________

Informant's relationship to patient, i.e. informant is the patient's: ____________

These six questions ask how the patient is compared to when s/he was well, say 5 – 10 years ago

Compared to a few years ago:

	Yes	No	Don't Know	N/A
▪ Does the patient have more trouble remembering things that have happened recently than s/he used to?	☐	☐	☐	
▪ Does he or she have more trouble recalling conversations a few days later?	☐	☐	☐	
▪ When speaking, does the patient have more difficulty in finding the right word or tend to use the wrong words more often?	☐	☐	☐	
▪ Is the patient less able to manage money and financial affairs (e.g. paying bills, budgeting)?	☐	☐	☐	☐
▪ Is the patient less able to manage his or her medication independently?	☐	☐	☐	☐
▪ Does the patient need more assistance with transport (either private or public)? (If the patient has difficulties due only to physical problems, e.g bad leg, tick 'no')	☐	☐	☐	☐

(*To get a total score, add the number of items answered 'no', 'don't know' or 'N/A'*)

Total score (out of 6) ☐

If patient scores 0-3, cognitive impairment is indicated. Conduct standard investigations.

Brodaty et al, *JAGS* 2002; 50:530-534

Montreal Cognitive Assessment (MoCA)
Version 8.1

Administration and Scoring Instructions

The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. The MoCA may be administered by anyone who understands and follows the instructions, however, only a health professional with expertise in the cognitive field may interpret the results. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal.

All instructions may be repeated once. Spanish language instructions are included here.

1. Alternating Trail Making:

Administration: The examiner instructs the subject: "Please draw a line going from a number to a letter in ascending order. Begin here [point to (l)] and draw a line from 1 then to A then to 2 and so on. End here [point to (E)]."

Spanish

El examinador da las instrucciones siguientes: "Me gustaria que dibujara una linea alternando entre cifras y letras, respetando el orden numerico y el orden alfabetico. Comience aqui (sefiale el 1) y dibuje una linea desde el 1 hacia la letra A y, a continuaci6n, de la A hacia el 2 y asi sucesivamente. Termine aqui (sefiale la E)".

Scoring: One point is allocated if the subject successfully draws the following pattern:
1- A- 2- B- 3- C- 4- D- 5- E, without drawing any lines that cross. Any error that is not immediately self-corrected (meaning corrected before moving on to the Cube task) earns a score of O. A point is not allocated if the subject draws a line to connect the end (E) to the beginning (1).

2. Visuoconstructional Skills (Cube):

Administration: The examiner gives the following instructions, pointing to the cube:
"Copy this drawing as accurately as you can."

Spanish

El examinador da las instrucciones siguientes, sefialando el cubo: *"Me gustaria que copiara este dibujo de la manera mas precisa posible."*

Scoring: One point is allocated for a correctly executed drawing.
- Drawing must be three-dimensional.
- All lines are drawn.
- All lines meet with little or no space.
- No line is added.
- Lines are relatively parallel and their length is similar (rectangular prisms are accepted).
- The cube's orientation in space must be preserved.

A point is not assigned if any of the above criteria is not met.

3. Visuoconstructional Skills (Clock):

Administration: The examiner must ensure that the subject does not look at his/her watch while performing the task and that no clocks are in sight. The examiner indicates the appropriate space and gives the following instructions: *"Draw a clock. Put in all the numbers and set the time to 10 past 11."*

Spanish
El examinador debe asegurarse de que la persona no mira el reloj mientras realiza la tarea y de que no hay ningun reloj a la vista. El examinador sefiala el espacio adecuado y da las instrucciones siguientes: *"Dibuje un reloj. Incluya todos las numeros y dibujelo seiialando las 11 y 10 minutos"*.

Scoring: One point is allocated for each of the following three criteria:

- Contour (1 pt.): the clock contour must be drawn (either a circle or a square). Only minor distortions are acceptable (e.g., slight imperfection on closing the circle). If the numbers are arranged in a circular manner but the contour is not drawn the contour is scored as incorrect.
- Numbers (1 pt.): all clock numbers must be present with no additional numbers. Numbers must be in the correct order, upright and placed in the approximate quadrants on the clock face. Roman numerals are acceptable. The numbers must be arranged in a circular manner (even if the contour is a square). All numbers must either be placed inside or outside the clock contour. If the subject places some numbers inside the clock contour and some outside the clock contour, (s)he does not receive a point for Numbers.
- Hands (1 pt.): there must be two hands jointly indicating the correct time. The hour hand must be clearly shorter than the minute hand. Hands must be centered within the clock face with their junction close to the clock center.

4. Naming:

Administration: Beginning on the left, the examiner points to each figure and says: *"Tell me the name of this animal."*

Spanish
El examinador sefiala cada dibujo, empezando por la izquierda, y dice: *"Digame el nombre de este animal."*

Scoring: One point is given for each of the following responses: (1) lion (2) rhinoceros or rhino (3) camel or dromedary.

5. Memory:

Administration: The examiner reads a list of five words at a rate of one per second, giving the following instructions: *"This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them."* The examiner marks a check in the allocated space for each word the subject produces on this first trial. The examiner may not correct the subject if (s)he recalls a deformed word or a word that sounds like the target word. When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, the examiner reads the list a second time with the following instructions: *"I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time."* The examiner puts a check in the allocated space for each word the subject recalls on the second trial. At the end of the second trial, the examiner informs the subject that (s)he will be asked to recall these words again by saying: *"I will ask you to recall those words again at the end of the test."*

Spanish
El examinador lee una lista de cinco palabras a un ritmo de una palabra por segundo, tras dar las siguientes instrucciones: *"Esta es una prueba de memoria. Le voy a leer una lista de palabras que debe recordar. Escuche con atenci6n. Cuando acabe, digame todas las palabras que pueda recordar. No importa el orden en el que me las diga"*. El examinador debera marcar con una cruz, en el espacio reservado a dicho efecto, todas las palabras que el paciente repita en este primer intento. El examinador no debe corregir al paciente si este recuerda mal una palabra o dice una palabra que se parece a la correcta. Cuando el paciente diga que ya ha terminado (se haya acordado de todas las palabras) o cuando no pueda acordarse de mas palabras, el examinador volvera a leer la lista de palabras tras dar las instrucciones siguientes: *"Ahora le voy a leer la misma lista de palabras una vez mas. Intente acordarse de! mayor numero posible de palabras, incluyendo las que repiti6 en la primera ronda"*. El examinador marca con una cruz, en el espacio reservado a dicho efecto, todas las palabras que el paciente repita en el segundo intento.
Al final del segundo intento, el examinador informara al paciente de que debe recordar estas palabras diciendo: *"Le volvere a preguntar estas palabras al final de la prueba"*.

Scoring: No points are given for Trials One and Two.

6. **Attention:**

Forward Digit Span: Administration: The examiner gives the following instructions: *"I am going to say some numbers and when I am through, repeat them to me exactly as I said them."* The examiner reads the five number sequence at a rate of one digit per second.

Spanish
El examinador dara las siguientes instrucciones: *"Le voy a leer una serie de numeros y, cuando haya terminado, debera repetirlos en el mismo orden en el que yo las he dicho".* El examinador lee una secuencia de cinco numeros a un ritmo de uno por segundo.

Backward Digit Span: Administration: The examiner gives the following instructions: *"Now I am going to say some more numbers, but when I am through you must repeat them to me in the backward order."* The examiner reads the three number sequence at a rate of one digit per second. If the subject repeats the sequence in the forward order, the examiner may not ask the subject to repeat the sequence in backward order at this point.

Spanish
El examinador dara las siguientes instrucciones: *"Le voy a leer otra serie de numeros y, cuando haya terminado, debera repetirlos hacia atras".* El examinador leera la secuencia de tres numeros a un ritrno de uno por segundo. Si el paciente repite la secuencia hacia delante, el examinador no podra pedirle en ese mismo momenta que repita la secuencia hacia atras.

Scoring: One point is allocated for each sequence correctly repeated (N.B.: the correct response for the backward trial is 2-4-7).

Vigilance: Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instructions: *"I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If I say a different letter, do not tap your hand."*

Spanish
"Vay a leerle una serie de letras. Cada vez que diga la letra 'A ', de un golpecito con la mano. Cuando diga una letra que no sea la A, no de ningun golpecito".

Scoring: One point is allocated if there is zero to one error (an error is a tap on a wrong letter or a failure to tap on letter A).

Serial 7s: Administration: The examiner gives the following instructions: *"Now, I will ask you to count by subtracting 7 from 100, and then, keep subtracting 7 from your answer until I tell you to stop."* The subject must perform a mental calculation, therefore, (s)he may not use his/her fingers nor a pencil and paper to execute the task. The examiner may not repeat the subject's answers. If the subject asks what her/his last given answer was or what number (s)he must subtract from his/her answer, the examiner responds by repeating the instructions if not already done so.

Spanish
"Ahora me gustaria que restara 7 de 100 y que continuara restando 7 a la cifra de su respuesta anterior hasta que le pida que pare".

Scoring: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correct subtraction, 2 points for two or three correct subtractions, and 3 points if the subject successfully makes four or five correct subtractions. Each subtraction is evaluated independently; that is, if the subject responds with an incorrect number but continues to correctly subtract 7 from it, each correct subtraction is counted. For example, a subject may respond "92 - 85 - 78 - 71 - 64" where the "92" is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the task would be given a score of 3.

7. **Sentence repetition:**

Administration: The examiner gives the following instructions: *"I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]:* ***I only know that John is the one to help today.****"* Following the response, say: *"Now I am going to read you another sentence. Repeat it after me, exactly as I say it [pause]:* ***The cat always hid under the couch when dogs were in***

the room."

Spanish
"Ahora le voy a leer una frase. Repitala exactamente cuando yo termine [pausa]: ***Solo se que le toca a Juan ayudar hoy"****.* Despues de la respuesta, diga: *"Ahora voy a leerle otrafrase. Repitala exactamente cuando yo termine [pausa]:* ***El gato siempre se esconde debajo del sofit cuando hay perros en la habitacion.****"*

Scoring: One point is allocated for each sentence correctly repeated. Repetitions must be exact. Be alert for omissions (e.g., omitting "only"), substitutions/additions (e.g., substituting "only" for "always"), grammar errors/altering plurals (e.g. "hides" for "hid"), etc.

8. **Verbal fluency:**

Administration: The examiner gives the following instructions: *"Now, I want you to tell me as many words as you can think of that begin with the letter F. I will tell you to stop after one minute. Proper nouns, numbers, and different forms of a verb are not permitted. Are you ready? [Pause] [Time for 60 sec.] Stop."* If the subject names two consecutive words that begin with another letter of the alphabet, the examiner repeats the target letter if the instructions have not yet been repeated.

Spanish
El examinador dara las instrucciones siguientes: *"Ahora, diga el mayor numero posible de palabras que comiencen par la letra F. Le pedire que pare al minuto. No se permiten nombres, numeros y las formas conjugadas de un verbo. ;,Esta preparado? [Pausa] [Tiempo 60 seg.] Pare".* Si el paciente nombra dos palabras seguidas que empiezan con otra letra del abecedario, debera repetirle la letra correcta si aun no le ha repetido las instrucciones.

Scoring: One point is allocated if the subject generates 11 words or more in 60 seconds. The examiner records the subject's responses in the margins or on the back of the test sheet.

9. **Abstraction:**

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: *"I will give you two words and I would like you to tell me to what category they belong to [pause]: an orange and a banana."* If the subject responds correctly the examiner replies: *"Yes, both items are part of the category Fruits."* If the subject answers in a concrete manner, the examiner gives one additional prompt: *"Tell me another category to which these items belong to."* If the subject does not give the appropriate response (fruits), the examiner says: *"Yes, and they also both belong to the category Fruits."* No additional instructions or clarifications are given. After the practice trial, the examiner says: *"Now, a train and a bicycle."* Following the response, the examiner administers the second trial by saying: *"Now, a ruler and a watch."* A prompt (one for the entire abstraction section) may be given if none was used during the example.

Spanish
El examinador pedira al paciente que le explique que tienen en comun cada pareja de palabras, ilustrandolo con el ejemplo siguiente: *"Le dire dos palabras y me gustaria que usted me dijera a que categoria pertenecen [pausa]: una naranja y un platano"* Si el paciente da la respuesta correcta, el examinador debera decir:*"Si, las dos pertenecen a esta categoria de frutas."* Si el paciente responde de una manera concreta, el examinador debera ofrecerle una pista adicional: *"Digame otra categoria a la que tambien puedan pertenecer estas cosas."* Si el paciente no da la respuesta correcta (frutas), el examinador debera decir: *"Si y las dos pertenecen tambien a la categoria de frutas."* No de otras instrucciones o explicaciones. Tras el primer intento de prueba, el examinador debera decir: *"Ahora, un tren y una bicicleta."* Tras la respuesta, el examinador administrara el segundo intento diciendo: *"Ahora, una regla y un reloj."* Podra ofrecerse una pista (una sola para todo el apartado de abstracci6n) si nose ha dado ninguna en el primer ejemplo

Scoring: Only the last two pairs are scored. One point is given for each pair correctly answered. The following responses are acceptable:

- train-bicycle = means of transportation, means of traveling, you take trips in both
- ruler-watch = measuring instruments, used to measure

The following responses are **not** acceptable:

- train-bicycle = they have wheels
- ruler-watch = they have numbers

10. Delayed recall:

Administration: The examiner gives the following instructions: *"I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember."* The examiner makes a check mark(✔) for each of the words correctly recalled spontaneously without any cues, in the allocated space.

Spanish
El examinador dara las siguientes instrucciones: *"Antes le he leido una serie de palabras y le he pedido que las recordase. Digame ahora todas las palabras de las que se acuerde."* El examinador marca con una cruz las palabras que el paciente recuerde sin necesidad de pistas en el espacio reservado a dicho efecto.

Memory index score (MIS):

Administration: Following the delayed free recall trial, the examiner provides a category (semantic) cue for each word the subject was unable to recall. Example: *"I will give you some hints to see if it helps you remember the words, the first word was a body part."* If the subject is unable to recall the word with the category cue, the examiner provides him/her with a multiple choice cue. Example: *"Which of the following words do you think it was, NOSE, FACE, or HAND?"* All non-recalled words are prompted in this manner. The examiner identifies the words the subject was able to recall with the help of a cue (category or multiple-choice) by placing a check mark(✔) in the appropriate space. The cues for each word are presented below:

Target Word	Category Cue	Multiple Choice
FACE	body part	nose, face, hand (shoulder, leg)
VELVET	type of fabric	denim, velvet, cotton (nylon, silk)
CHURCH	type of building	church, school, hospital (library, store)
DAISY	type of flower	rose, daisy, tulip (lily, daffodil)
RED	color	red, blue, green (yellow, purple)

* The words in parentheses are to be used if the subject mentions one or two of the multiple choice responses during the category cuing.

Scoring: To determine the MIS (which is a sub-score), the examiner attributes points according to the type of recall (see table below). The use of cues provides clinical information on the nature of the memory deficits. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.

MIS scoring				**Total**
Number of words recalled spontaneously	…	multiplied by	3	…
Number of words recalled with a category cue	…	multiplied by	2	…
Number of words recalled with a multiple choice cue	…	multiplied by	1	…
	Total MIS (add all points)			**______/15**

Scoring: **One point is allocated for each word recalled freely without any cues.**

11. Orientation:

Administration: The examiner gives the following instructions: "Tell me today's date." If the subject does not give a complete answer, the examiner prompts accordingly by saying: "Tell me the [year, month, exact date, and day of the week}. "Then the examiner says: "Now, tell me the name of this place, and which city it is in."

Spanish
El examinador dara las siguientes instrucciones: *"Digame en que fecha estamos hoy."* Si el paciente ofrece una respuesta incompleta, el examinador le apuntara de forma oportuna diciendo: *"Digame [el ano, el mes, la feeha exacta y el dia de la semana}"*. A continuaci6n, el examinador dira: *"Ahora, digame c6mo se llama este lugar y en que localidad nos encontramos"*.

Scoring: One point is allocated for each item correctly answered. The date and place (name of hospital, clinic, office) must be exact. No points are allocated if the subject makes an error of one day for the day and date.

TOTAL SCORE: Sum all subscores listed on the right-hand side. Add one point for subject who has 12 years or fewer of formal education, for a possible maximum of 30 points. A final total score of 26 and above is considered normal.

Please refer to the MoCA website at www.mocatest.org for more information on the MoCA.

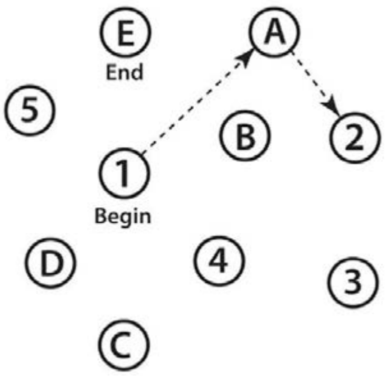
MONTREAL COGNITIVE ASSESSMENT (MOCA®)

Version 8.1 English

Name:
Education:
Sex:
Date of birth:
DATE:

POINTS

VISUOSPATIAL / EXECUTIVE



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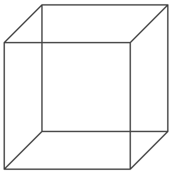


Copy cube

[ ]

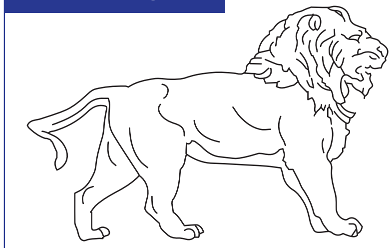
Draw CLOCK (Ten past eleven)

(3 points)

[ ] Contour   [ ] Numbers   [ ] Hands

__/5

NAMING



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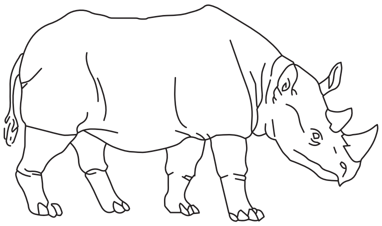

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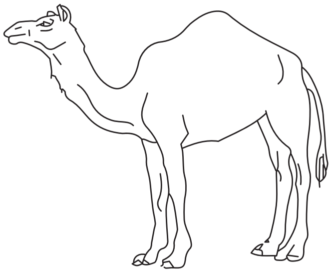


[ ]

__/3

MEMORY

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1ST TRIAL					
2ND TRIAL					

NO POINTS

ATTENTION

Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order. [ ] 2 1 8 5 4

Subject has to repeat them in the backward order. [ ] 7 4 2

__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Serial 7 subtraction starting at 100. [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts,** 2 or 3 correct: **2 pts,** 1 correct: **1 pt,** 0 correct: **0**

__/3

LANGUAGE

Repeat: I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ]

__/2

Fluency: Name maximum number of words in one minute that begin with the letter F. [ ] _____ (N ≥ 11 words)

__/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler

__/2

DELAYED RECALL	(MIS)		FACE	VELVET	CHURCH	DAISY	RED	
	X3	Has to recall words WITH NO CUE	[ ]	[ ]	[ ]	[ ]	[ ]	Points for UNCUED recall only
Memory Index Score (MIS)	X2	Category cue						MIS = ____/15
	X1	Multiple choice cue						

__/5

ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

www.mocatest.org

Administered by: ______________________________

Training and Certification are required to ensure accuracy

MIS: /15

(Normal ≥ 26/30)

Add 1 point if ≤ 12 yr edu

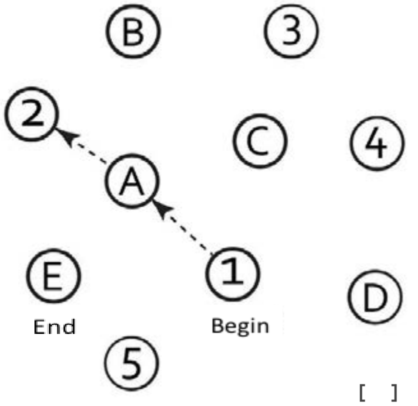
TOTAL __/30

MONTREAL COGNITIVE ASSESSMENT (MoCA®)

Version 8.2 English

Name:
Education:
Sex:
Date of birth :
DATE :

VISUOSPATIAL / EXECUTIVE



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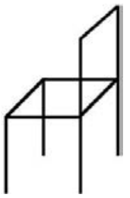
Copy chair



[ ]

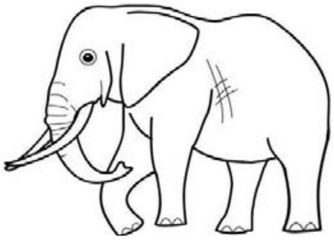
Draw CLOCK (Ten past nine)
(3 points)

[ ] **Contour** [ ] **Numbers** [ ] **Hands**

POINTS __/5

NAMING

[ ]



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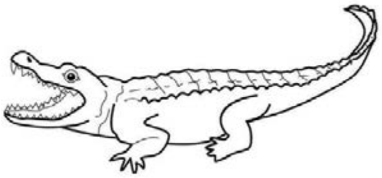

[ ]

__/3

MEMORY

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	HAND	NYLON	PARK	CARROT	YELLOW
1st TRIAL					
2nd TRIAL					

NO POINTS

ATTENTION

Read list of digits (1 digit / sec.).

Subject has to repeat them in the forward order. [ ] **8 1 5 2 4**

Subject has to repeat them in the backward order. [ ] **2 4 7**

__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.

[ ] **F B A C M N A A J K L B A F A K D E A A A J A M O F A A B**

__/1

Serial 7 subtraction starting at 70. [ ] 63 [ ] 56 [ ] 49 [ ] 42 [ ] 35

4 or 5 correct subtractions: **3 pts,** 2 or 3 correct: **2 pts,** 1 correct: **1 pt,** 0 correct: **0 pt**

__/3

LANGUAGE

Repeat: The robber of the gray car was stopped by the police. [ ]
The student went back to school without his books and pencils. [ ]

__/2

Language Fluency. Name maximum number of words in one minute that begin with the letter S. [ ] ______ (N ≥ 11 words)

__/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] bed - table [ ] letter - telephone

__/2

DELAYED RECALL

DELAYED RECALL	(MIS) X3	Has to recall words WITH NO CUE	HAND [ ]	NYLON [ ]	PARK [ ]	CARROT [ ]	YELLOW [ ]	Points for UNCUED recall only
Memory Index Score (MIS)	X2	Category cue						MIS = ____/15
	X1	Multiple choice cue						

__/5

ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

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www.mocatest.org

MIS: / 15

(Normal ≥ 26/30)

Add 1 point if ≤ 12 yr education

TOTAL __ /30

Administered by: ___________________________

Training and Certification are required to ensure accuracy.

MONTREAL COGNITIVE ASSESSMENT (MOCA®) (EVALUACIÓN COGNITIVA MONTREAL)

Versión 8.1 Spanis(Spain)

Nombre:

Nivel de estudios:

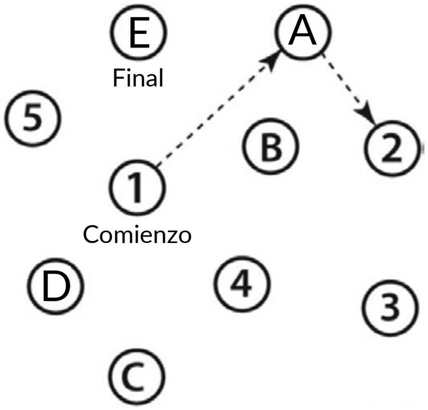
Sexo:

Fecha de nacimiento:

FECHA:

PUNTOS

VISUOESPACIAL/EJECUTIVA



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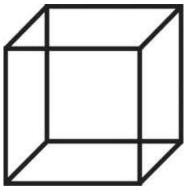
Copiar el cubo



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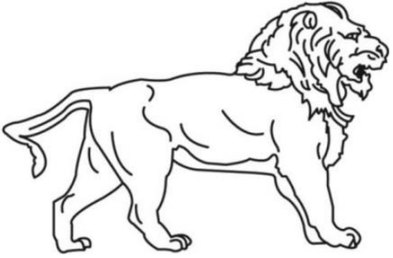
Dibujar un RELOJ (Once y diez) (3 puntos)

[ ] Contorno [ ] Números [ ] Agujas

__/5

IDENTIFICACIÓN



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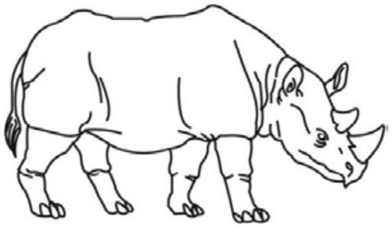

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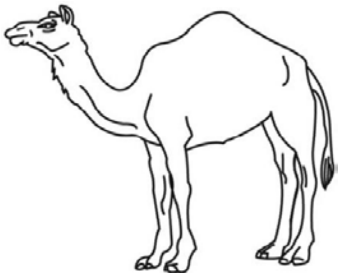

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__/3

MEMORIA

Lea la lista de palabras, el paciente debe repetirlas. Haga dos intentos. Recuérdeselas 5 minutos más tarde.

	ROSTRO	SEDA	TEMPLO	CLAVEL	ROJO
1er INTENTO					
2° INTENTO					

NINGÚN PUNTO

ATENCIÓN

Lea la serie de números (1 número/seg.) El paciente debe repetirlos en el mismo orden. [ ] 2 1 8 5 4

El paciente debe repetirlos en orden inverso [ ] 7 4 2

__/2

Lea la serie de letras. El paciente debe dar un golpecito con la mano cada vez que se diga la letra A. No se asignan puntos si ≥ 2 errores.

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Restar de 7 en 7 empezando desde 100. [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 o 5 restas correctas: **3 puntos** 2 o 3 restas correctas: **2 puntos** 1 resta correcta: **1 punto** 0 restas correctas: **0 puntos**

__/3

LENGUAJE

Repetir: Solo sé que le toca a Juan ayudar hoy. [ ]
El gato siempre se esconde debajo del sofá cuando hay perros en la habitación. [ ]

__/2

Fluidez del lenguaje. Decir el mayor número posible de palabras que comiencen por la letra "F" en 1 minuto. [ ] ____ (N ≥ 11 palabras)

__/1

ABSTRACCIÓN

Semejanza entre p. ej. plátano - naranja = fruta [ ] tren-bicicleta [ ] reloj-regla

__/2

RECUERDO DIFERIDO

(MIS)	Debe recordar las palabras	ROSTRO	SEDA	TEMPLO	CLAVEL	ROJO	Puntos por recuerdos SIN PISTAS únicamente
X3	SIN DARLE PISTAS	[ ]	[ ]	[ ]	[ ]	[ ]	
X2	Pista de categoría						
X1	Pista de elección múltiple						MIS = ____ / 15

Puntuación de la escala de memoria (MIS)

__/5

ORIENTACIÓN

[ ] Fecha [ ] Mes [ ] Año [ ] Día de la semana [ ] Lugar [ ] Localidad

__/6

www.mocatest.org

MIS: /15

(Normal ≥ 26/30)

Administrado por:____________________________

Se requiere formación y certificado para garantizar la exactitud.

Añadir 1 punto si tiene ≤ 12 años de estudios

TOTAL __/30

MOCA - Spain/Spanish - Version of 19 Feb 2018 - Mapi.
ID061021 / MOCA8.1-Test_AU1.0_ spa-ES .doc

VAMC
SLUMS Examination

Questions about this assessment tool? E-mail aging@slu.edu.

Name________________________ Age ________________________

Is patient alert?________________________ Level of education ________________________

__/1 ❶ **1. What day of the week is it?**

__/1 ❶ **2. What is the year?**

__/1 ❶ **3. What state are we in?**

4. Please remember these five objects. I will ask you what they are later.

Apple Pen Tie House Car

5. You have $100 and you go to the store and buy a dozen apples for $3 and a tricycle for $20.

❶ **How much did you spend?**

__/3 ❷ **How much do you have left?**

6. Please name as many animals as you can in one minute.

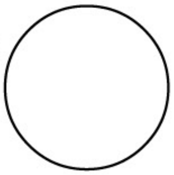
__/3 ⓿ 0-4 animals ❶ 5-9 animals ❷ 10-14 animals ❸ 15+ animals

__/5 **7. What were the five objects I asked you to remember?** 1 point for each one correct.

8. I am going to give you a series of numbers and I would like you to give them to me backwards. For example, if I say 42, you would say 24.

__/2 ⓿ 87 ❶ 649 ❶ 8537

9. This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.



❷ Hour markers okay

__/4 ❷ Time correct

__/2 ❶ **10. Please place an X in the triangle.**

❶ **Which of the above figures is largest?**

11. I am going to tell you a story. Please listen carefully because afterwards, I'm going to ask you some questions about it.

Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.

❷ **What was the female's name?**

❷ **What work did she do?**

__/8 ❷ **When did she go back to work?**

❷ **What state did she live in?**

_______ **TOTAL SCORE**

Department of Veterans Affairs

SAINT LOUIS UNIVERSITY

SCORING

HIGH SCHOOL EDUCATION		LESS THAN HIGH SCHOOL EDUCATION
27-30	**Normal**	25-30
21-26	**MNCD***	20-24
1-20	**Dementia**	1-19

* Mild Neurocognitive Disorder

SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. Am J Geriatr Psychiatry 14:900-910, 2006.

VAMC
SLUMS Examination

Name: ____________________________ **ID:** _____________ **Age:** _________________________

Educ: ____________________________ **Alert?** _____________ **Date Given:** _________________________

____/1 ❶ **1. Qué día de la semana es hoy?** __________

____/1 ❶ **2. En qué año estamos?** __________

____/1 ❶ **3. En qué estado estamos?** __________

4. Por favor, recuerde los cinco objetos que le voy a nombrar. Mas tarde, le preguntaré nuevamente por ellos.

Manzana Lapiz Corbata Perro Casa

____/3 **5. Usted tiene ciento dolares, y en la tienda compra una docena de manzanas por tres dolares y una bicicleta por veinte dolares.**

❶ **Cuánto dinero gastó?** __________

❷ **Cuánto dinero le queda?** __________

____/3 **6. Por favor en un minuto nombre todos los animales que pueda.**

⓿ 0-4 animals ❶ 5-9 animals ❷ 10-14 animals ❸ 15+ animals

____/5 **7. Cuáles fueron los 5 objetos que le dije que recordara?**

Manzana Lapiz Corbata Perro Casa

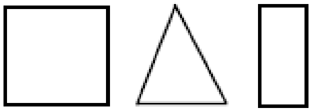
____/2 **8. Voy a decirle una serie de números. Me gustaría que usted me los dijera al revés. Por ejemplo, si yo digo 42, usted debe decir 24.**

⓿ **87** ❶ **649** ❶ **8537**

____/4 **9. Este círculo representa un reloj. Por favor escriba los números de las horas y las manecillas señalando las once menos diez.**

❷ Hour markers correct?

❷ Time correct?



____/2 ❶ **10a. Por favor, señale el triángulo con una equis.**

❶ **10b. Cuál de estas figuras es la mas grande?**

____/8 **11. Voy a contarle una historia. Por favor, escuche cuidadosamente, porque al terminar le voy a hacer unas preguntas sobre esta historia.**

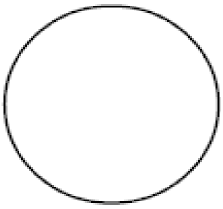
María era una abogada muy exitosa y ganaba mucho dinero en la compañía donde trabajaba. Ella conoció a Carlos, un hombre muy apuesto, y, al cabo del tiempo, se casaron, tuvieron 3 hijos y vivían en Chicago. Ella dejo de trabajar para criar a sus hijos, y cuando estos fueron adolescentes ella volvió al trabajo. Ella y Carlos vivieron felices por siempre.

❷ **Cuál era el nombre de la mujer?** ❷ **Cuando volvió a trabaja?**

❷ **Que profesión tenía ella?** ❷ **En que estado vivía?**

_______ **Total Score**

HS Educ		**No HS Educ**
27 - 30	**Normal**	25 - 30
21 - 26	**MNCD**	20 - 24
1 - 20	**Dementia**	1 - 19



The Quick Mild Cognitive Impairment (Qmci) Screen

Quick *Mild Cognitive Impairment* screen (*Qmci*)

Name: DOB: Gender: Years in Education: Date: Time:

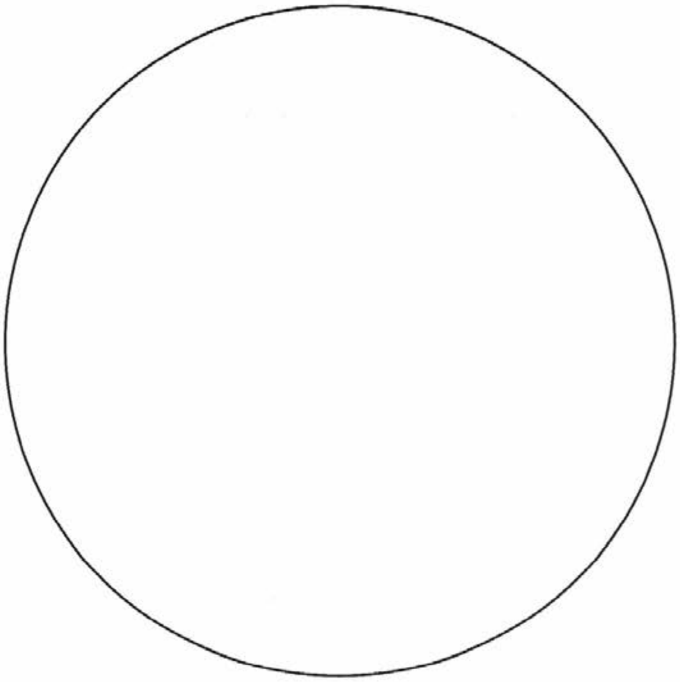
1. Orientation **To begin ask 5 questions.** ✎ One minute. ✎ Give **2 points for correct answer,** 1 if attempted but incorrect, 0 if no attempt.	**What country is it?** ___ **/ 2** **What year is it?** ___ **/ 2** **What month is it?** ___ **/ 2** **What is todays date?** ___ **/ 2** **What day of the week is it?** ___ **/ 2**	**Score** **__/ 10**
2. Word Registration To begin say… **"I am going to say 5 words. After I have said these 5 words, repeat them back to me. Are you ready?"** ✎ 30 seconds. ✎ Give **1 point per word** repeated, in any order, no hints.	**Dog Rain Butter Love Door** Alternate word groups include… **Cat Dark Pepper Fear Bed** **Rat Heat Bread Round Chair**	**Score** **__/ 5**
3. Clock Drawing **"Use the circle provided over page to draw a clock face, set the time to 'ten past eleven'."** ✎ One minute approximately. ✎ Give 1 mark for each number, 1 for each hand & 1 for the pivot correctly placed or close to their ideal location. Loose 1 mark for each number duplicated or greater than 12, e.g, 15 or 45, i.e. errors.	**Score:** Numbers Correct + ______/ 12 Errors - ______ Hands + ______/ 2 Pivot + ______/ 1 **Total + ______/ 15**	**Score** **__/ 15**
4. Delayed Recall **"A few minutes ago I named five words. Name as many of those words as you can remember."** ✎ 30 seconds. ✎ Recall in any order, within 30 seconds, giving **4 points per word,** no hints.	**Dog Rain Butter Love Door** Alternate word groups include… **Cat Dark Pepper Fear Bed** **Rat Heat Bread Round Chair**	**Score** **__/ 20**
5. Verbal Fluency **"Name as many animals as you can in one minute. Ready? Go."** ✎ One minute. ✎ Give half a point per animal named; to a maximum of 40. Accept all 'creatures' including birds, fish, insects etc. Do NOT count suffixes twice, e.g. mouse/mice but allow points for similar names calf, cow, bull.	Alternative forms include: ***fruit & veg*** or ***towns & cities.*** **Score 0.5 x number of animals =** List here, in 'shorthand' if required:	**Score** **__/ 20**

	Story 1		Alternative version 1		Alternative version 2		
6. Logical Memory **"I am going to read you ONE short story. After I have finished reading it completely, I want you to tell me as much of the story as you can. OK?"** ✎ 30 seconds. ✎ Give 2 points per highlighted word, recalled exactly, immediately within 30 seconds, in any order, no hints. Two alternatives are provided.	The **red**	It was a **hot**	The **brown**	It was a **cold**	The **white**	It was a **warm**	**Score**
	fox	**May**	**dog**	**October**	**hen**	**September**	
	ran across the	**morning.**	**ran across**	**day.**	**walked across**	**afternoon.**	
	ploughed	**Fragrant**	the **metal**	**Ripe**	the **concrete**	**Dry**	
	field.	**blossoms**	**bridge.**	**apples**	**road.**	**leaves**	
	It was **chased** by	were **forming** on	It was **hunting**	were **hanging** on	It was **followed** by	were **blowing** in	
	a **brown**	the **bushes.**	a **white**	the **trees.**	a **black**	the **wind.**	
	dog.		**Rabbit.**		**cat.**		**__/ 30**

Qmci **Total score** *___**/ 100**

*adjust score for age & education (see over).

Administered by:________________



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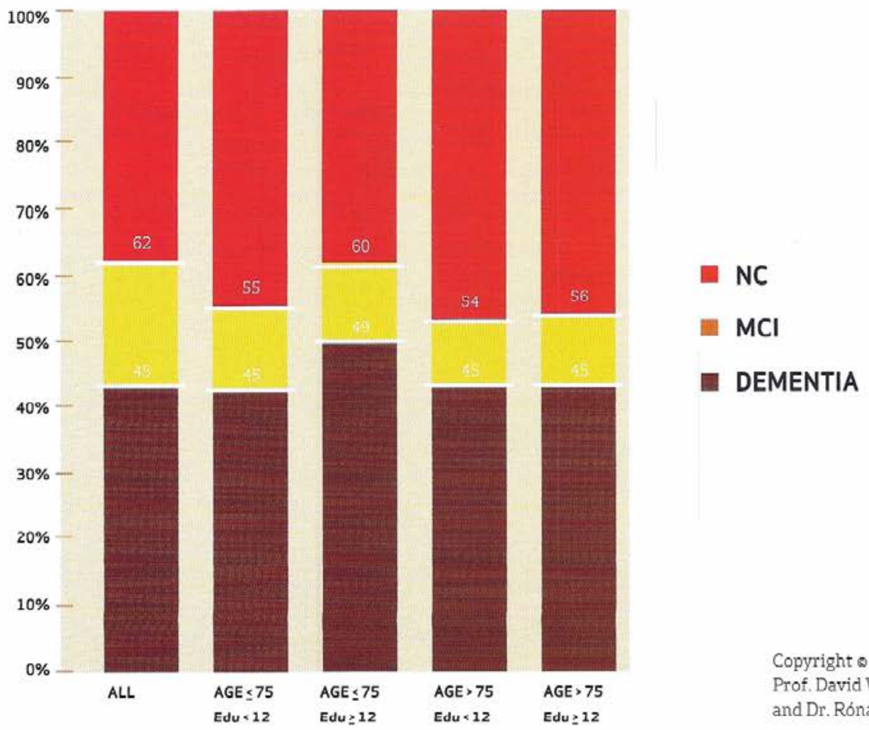


FOLD HERE

1. Orientation

Scoring

2 points for the correct answer, 1 point for wrong answers, and 0 points for no answer or a conceptually unrelated answer (see details below).

Timing

Maximum of 10 seconds for each answer.

Instructions and Scoring Guide

Year	If the person gives the correct year score 2 points, the incorrect year score 1 point, and 0 points if no year is given.
Country	Score 2 points for correct country, 1 point for incorrect country, and 0 if no country is named.
Month	Score 2 points for the correct month or for the previous or following month if within two days of the change of the month (for example, if the date is September 30th, score the full 2 points if person answers October. Similarly, if the date is October 2nd, score 2 points if person says September). Score 1 point if the month is incorrect and 0 if no month is named.
Date	Score 2 points for exact date or ± one day, 1 point for any other date, 0 if no date is named.
Day of week	2 points for correct day, 1 point for incorrect day, 0 if no day named.

To begin say...

"I'd like to ask you some questions and give you some problems to solve. Would that be OK?"

What country is this? __________

What year is this? __________

What month is this? __________

What is today's date? __________

What day of the week is this? __________

Score __________ / 10

2. Word Registration

Instructions and Scoring Guide

Scoring

Score 1 point for each word recalled after the first reading. If subject recalls all five, repeat the five items once and then go on to clock drawing. If subject does not repeat all 5, repeat the 5 items and ask the subject to repeat them. Do this until the subject correctly recalls all 5 items or for a maximum of 3 trials. Do not score for trials 2 and 3. These trials are to help the person learn in preparation for the delayed recall task.

Timing

Say the words very deliberately, one per second. Allow 10 seconds for the recall.

To begin say…

"I am going to say 5 words. After I have said these 5 words, repeat them back to me. Are you ready?"

Dog rain butter love door

Score __________ / 5

When finished, say… **"Remember these words because I'll ask you to recall them later."**

Alternate word groups include…

cat	**dark**	**pepper**	**fear**	**bed**
rat	**heat**	**bread**	**round**	**chair**

3. Clock Drawing

Instructions and Scoring Guide

Scoring

Place the circle of the transparent scoring template over the circle of the patient's completed clock. Rotate the template circle so that the "12" s align. Score 1 point each if the 1, 2, 4, 5, 7, 8, 10, and 11 are in the correct quadrants. Score 1 point each if the 12, 3, 6, and 9 touch their quadrant lines. Subtract one point for each number repeated or for numbers above 12. (Should the patient not have drawn a "12" align the template with the 3, 6, or 9.)

Score the placement of hands according to the tips and pivot. Give 1 point for each hand between the dashed lines. Score 1 point for hands connecting at the pivot.

Timing

One minute.

To begin…

Give the sheet of paper with the pre-drawn circle and a pencil to the patient. Say **"Now put in the numbers like the face of a clock."** Then say **"Set the hands to show ten past eleven." Place the numbers and hands as carefully as you can."**

You may prompt at each stage…"**put in the numbers…. put the time as ten past eleven**".

Score:	Numbers	Correct	+ ______/ 12
		Errors	- ______
	Hands		+ ______/ 2
	Pivot		+ ______/ 1
	Total		**+ _______/ 15**

4. Delayed Recall

Instructions and Scoring Guide

Scoring

Score 4 points for each word recalled. Subjects may recall words in any order.

Timing

10 seconds.

To begin say…

A few minutes ago I named five words. Name as many of those words as you can remember.

dog	**rain**	**butter**	**love**	**door**

Score ___________ / 20

Alternate word groups include…

cat	**dark**	**pepper**	**fear**	**bed**
rat	**heat**	**bread**	**round**	**chair**

5. Verbal Fluency

Instructions and Scoring Guide

Scoring.

Give ½ point for each correct word recalled to a maximum of 40 words. Round up the final score. Do not count words with different suffixes twice (e.g. fish / fishes, mouse / mice, etc.). Accept alternate species (e.g. blue jay, robin, sparrow, duck, etc.). Alternate forms include fruits and vegetables, cities and towns.

Timing.

60 seconds. Write down each word the patient says. (You may need to develop some kind of “shorthand” for the speedier patients, such as writing the first 3 letters of each word and then completing them later.)

To begin say…

“Name as many *animals* as you can in one minute. Ready? Go.”

Score ___________ / 20

6. Logical Memory

Instructions and Scoring Guide

Scoring.

Give 2 points for each correct word item recalled verbatim. All bolded words within each section must be recalled for score 2 points. Otherwise score 0. Recall may be in any order.

Timing.
30 seconds. Check off each word unit recalled.

To begin say…

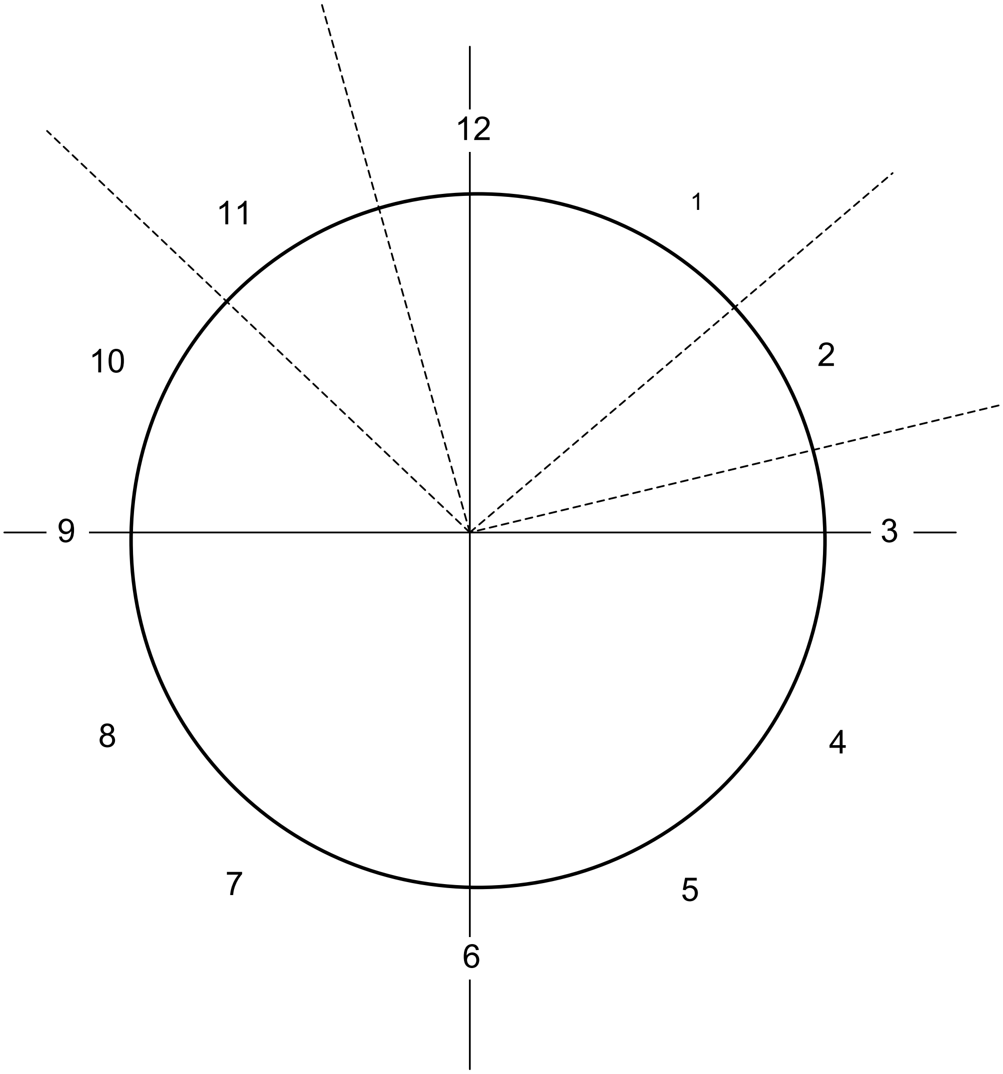
"I am going to read you a short story. After I have finished reading I want you to tell me as much of the story as you can. OK?" [patient signifies agreement, then begin reading the paragraph at about 1 second for each word unit] **"The red… fox… ran across........... the bushes."**

6. Logical Memory			
The **red**	The **brown**	The **white**	2 / 0
fox	**dog**	**hen**	2 / 0
ran across	**ran across**	**walked across**	2 / 0
the **ploughed**	the **metal**	the **concrete**	2 / 0
field.	**bridge**.	**road**.	2 / 0
It was **chased** by	It was **hunting**	It was **followed** by	2 / 0
a **brown**	a **white**	a **black**	2 / 0
dog.	**rabbit**.	**cat**.	2 / 0
It was a **hot**	It was a **cold**	It was a **warm**	2 / 0
May	**October**	**September**	2 / 0
morning.	**day**.	**afternoon**.	2 / 0
Fragrant	**Ripe**	**Dry**	2 / 0
blossoms	**apples**	**leaves**	2 / 0
were **forming** on	were **hanging** on	were **blowing** in	2 / 0
the **bushes**.	the **trees**.	the **wind**.	2 / 0

Score __________ / 30

Qmci Total Score _____________ / 100

The Clock Transparency Scoring Template



Scoring
Place this scoring template over the completed clock with the template's "12 o'clock" line placed over the subject's 12. Adjust the template to maximize the score for the numbers and hands. The total score is 15. Record scores on the score sheet as follows:

Numbers

- For the numbers 12, 3, 6, and 9 score one (1) point if they touch their respective lines, zero (0) point if missed, and zero (0) if the number is omitted.
- For the numbers 1, 2, 4, 5, 7, 8, 10, and 11 score one (1) point for each number in the correct quadrant, zero (0) point if the number is outside the quadrant, and zero (0) if the number is omitted.
- **Subtract one point for each number repeated or more than 12.**

Hands

- Score the placement of the entire hand. If the hands are drawn within range, score one (1) point for each hand; if the hands are drawn outside the hatched line or are omitted score zero (0); Give one (1) point if the hands join at the pivot.

The QDRS, Quick Dementia Rating System

1. Memory and recall _____C

0 No obvious memory loss or inconsistent forgetfulness that does not interfere with function in everyday activities

0.5 Consistent mild forgetfulness or partial recollection of events that may interfere with performing everyday activities; repeats questions/statements, misplaces items, forgets appointments

1 Mild to moderate memory loss; more noticeable for recent events; interferes with performing everyday activities

2 Moderate to severe memory loss; only highly learned information remembered; new information rapidly forgotten

3 Severe memory loss, almost impossible to recall new information; long-term memory may be affected

2. Orientation _____C

0 Fully oriented to person, place, and time nearly all the time

0.5 Slight difficulty in keeping track of time; may forget day or date more frequently than in the past

1 Mild to moderate difficulty in keeping track of time and sequence of events; forgets month or year; oriented to familiar places but gets confused outside familiar areas; gets lost or wanders

2 Moderate to severe difficulty, usually disoriented to time and place (familiar and unfamiliar); frequently dwells in past

3 Only oriented to their name, although may recognize family members

3. Decision making and problem-solving abilities _____C

0 Solves everyday problems without difficulty; handles personal business and financial matters well; decision-making abilities consistent with past performance

0.5 Slight impairment or takes longer to solve problems; trouble with abstract concepts; decisions still sound

1 Moderate difficulty with handling problems and making decisions; defers many decisions to others; social judgment and behavior may be slightly impaired; loss of insight

2 Severely impaired in handling problems, making only simple personal decisions; social judgment and behavior often impaired; lacks insight

3 Unable to make decisions or solve problems; others make nearly all decisions for patient

4. Activities outside the home _____B

0 Independent in function at the usual level of performance in profession, shopping, community and religious activities, volunteering, or social groups

0.5 Slight impairment in these activities compared with previous performance; slight change in driving skills; still able to handle emergency situations

1 Unable to function independently but still may attend and be engaged; appears “normal” to others; notable changes in driving skills; concern about ability to handle emergency situations

2 No pretense of independent function outside the home; appears well enough to be taken to activities outside the family home but generally needs to be accompanied

3 No independent function or activities; appear too ill to be taken to activities outside the home

5. Function at home and hobby activities _____B

0 Chores at home, hobbies and personal interests are well maintained compared with past performance

0.5 Slight impairment or less interest in these activities; trouble operating appliances (particularly new purchases)

1 Mild but definite impairment in home and hobby function; more difficult chores or tasks abandoned; more complicated hobbies and interests
given up

2 Only simple chores preserved, very restricted interest in hobbies which are poorly maintained

3 No meaningful function in household chores or with prior hobbies

6. Toileting and personal hygiene _____B

0 Fully capable of self-care (dressing, grooming, washing, bathing, toileting)
0.5 Slight changes in abilities and attention to these activities
1 Needs prompting to complete these activities but may still complete independently
2 Requires some assistance in dressing, hygiene, keeping of personal items; occasionally incontinent
3 Requires significant help with personal care and hygiene; frequent incontinence

7. Behavior and personality changes _____B

0 Socially appropriate behavior in public and private; no changes in personality
0.5 Questionable or very mild changes in behavior, personality, emotional control, appropriateness of choices
1 Mild changes in behavior or personality
2 Moderate behavior or personality changes, affects interactions with others; may be avoided by friends, neighbors, or distant relatives
3 Severe behavior or personality changes; making interactions with others often unpleasant or avoided

8. Language _____C

0 No language difficulty or occasional word searching; reads and writes as in the past
0.5 Consistent mild word finding difficulties, using descriptive terms or takes longer to get point across, mild problems with comprehension, decreased conversation; may affect reading and writing
1 Moderate word finding difficulty in speech, cannot name objects, marked reduction in work production; reduced comprehension, conversation, writing, and/or reading
2 Moderate to severe impairments in speech production or comprehension; has difficulty in communicating thoughts to others; limited ability to read or write
3 Severe deficits in language and communication; little to no understandable speech is produced

9. Mood _____B

0 No changes in mood, interest, or motivation level
0.5 Occasional sadness, depression, anxiety, nervousness, or loss of interest/motivation
1 Daily mild issues with sadness, depression, anxiety, nervousness, or loss of interest/motivation
2 Moderate issues with sadness, depression, anxiety, nervousness, or loss of interest/motivation
3. Severe issues with sadness, depression, anxiety, nervousness, or loss of interest/motivation

10. Attention and concentration _____B

0 Normal attention, concentration, and interaction with his or her environment and surroundings
0.5 Mild problems with attention, concentration, and interaction with environment and surroundings, may appear drowsy during day
1 Moderate problems with attention and concentration, may have staring spells or spend time with eyes closed, increased daytime sleepiness
2 Significant portion of the day is spend sleeping, not paying attention to environment, when having a conversation may say things that are illogical or not consistent with topic
3 Limited to no ability to pay attention to external environment or surroundings

Cognitive subtotal (questions 1, 2, 3, 8) **Total of C Scores** _______
Behavioral subtotal (questions 4, 5, 6, 7, 9, 10) **Total of B Scores** _______
Total QDRS score _______

A total score of ≥ 2 suggests a problem causing limitations or issues, and may need a detailed workup. Please return this instrument to your physician.

Informant Questionnaire (IQCODE)

Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) Short Form

Name of Patient
Date

Name of Informant
Sex
Age

Relation to the Patient
Years Known

	Compared with 10 years ago, how is this person at:	**Much Improved**	**A bit improved**	**Not much change**	**A bit worse**	**Much worse**
		1	**2**	**3**	**4**	**5**
1	Remembering things about family and friends, e.g. occupations, birthdays, addresses?					
2	Remembering things that happened recently?					
3	Recalling conversations a few days later?					
4	Remembering his/her address and telephone number?					
5	Remembering what day and month it is?					
6	Remembering where things are usually kept?					
7	Remembering where to find things which have been put in a different place from usual?					
8	Knowing how to work familiar machines around the house?					
9	Learning to use a new gadget or machine around the house?					
10	Learning new things in general?					
11	Following a story in a book or on TV?					
12	Making decisions on everyday matters?					
13	Handling money for shopping?					
14	Handling financial matters, e.g. the pension, dealing with the bank?					
15	Handling other everyday arithmetic problems, e.g. knowing how much food to buy, knowing how long between visits from family or friends?					
16	Using his/her intelligence to understand what's going on and to reason things through?					
	Total Score					

Add up the scores and divide the number by 16. The result is a score from 1 to 5. A score of 3 means that the subject is rated on average as "no change." A score of 4 means an average of "a bit worse." A score of 5 on average is "much worse." A cutting point of 3.31/3.38 achieves a balance of sensitivity and specificity.

Servicio Andaluz de Salud
CONSEJERÍA DE SALUD

(IQCODE) Short Form Spanish

Nombre **Fecha**

Unidad/Centro **Nº Historia**

CRIBADO DE DEMENCIAS - TEST DEL INFORMADOR -

Población diana: Población informante clave de una persona con sospecha de deterioro cognitivo. Se trata de un test **autoadministrado**.

Instrucciones para el informante clave:
Recuerde, por favor, cómo era su familiar hace 5 ó 10 años y compare cómo es él en este momento. Conteste si ha habido algún cambio a lo largo de este tiempo en la capacidad de su familiar para cada uno de los aspectos que le preguntamos. Puntúe con los siguientes criterios:

	Ha mejorado mucho	Ha mejorado un poco	Casi sin cambios	Ha empeorado un poco	Ha empeorado mucho
ITEMS	**1**	**2**	**3**	**4**	**5**
Capacidad para reconocer las caras de sus personas más íntimas (parientes, amigos)					
Capacidad para recordar los nombres de estas mismas personas					
Recordar las cosas de esas personas (dónde viven, de qué viven, cuándo es su cumpleaños)					
Recordar cosas que han ocurrido recientemente, en los últimos 2 o 3 meses (noticias, cosas suyas o de sus familiares)					
Recordar lo que habló en una conversación unos días antes					
Olvidar lo que se ha dicho unos minutos antes, pararse a la mitad de una frase y no saber lo que iba a decir, repetir lo que ha dicho antes					
Recordar su propia dirección o número de teléfono					
Recordar la fecha en que vive					
Conocer el sitio exacto de los armarios de su casa y dónde se guardan las cosas					
Saber dónde se pone una cosa que se ha encontrado descolocada					
Adaptarse a la situación cuando su rutina diaria se ve alterada (ir de visita, en alguna celebración, de vacaciones)					
Saber manejar los aparatos de la casa (teléfono, coche, lavadora, máquina de afeitar, etc.)					
Capacidad para aprender a manejar un aparato nuevo (lavadora, tocadiscos, radio, secador de pelo, etc.)					

(IQCODE) Short Form Spanish

Servicio Andaluz de Salud
CONSEJERÍA DE SALUD

	Ha mejorado mucho	Ha mejorado un poco	Casi sin cambios	Ha empeorado un poco	Ha empeorado mucho
ITEMS	**1**	**2**	**3**	**4**	**5**
Recordar las cosas que han sucedido recientemente (en general)					
Aprender cosas nuevas (en general)					
Capacidad para recordar cosas que ocurrieron o que aprendió cuando era joven					
Comprender el significado de palabras poco corrientes (del periódico, televisión, conversación)					
Entender artículos de periódicos o revistas en las que está interesado					
Seguir una historia del libro, la prensa, el cine, la radio o la televisión					
Redactar cartas a parientes o amigos o cartas de negocios					
Recordar gentes y hechos históricos del pasado (guerra civil, república, etc.)					
Tomar decisiones tanto en cuestiones cotidianas (qué traje ponerse, qué comida preparar) corno en asuntos a más largo plazo (dónde ir de vacaciones o invertir el dinero)					
Manejar asuntos financieros (cobrar la pensión, pagar la renta o los impuestos, tratar con el banco)					
Manejar dinero para la compra (cuánto dinero dar, calcular el cambio)					
Manejar otros problemas aritméticos cotidianos (tiempo entre visitas de parientes, cuánta comida comprar y preparar, especialmente si hay invitados)					
¿Cree que su inteligencia (en general) ha cambiado en algo durante los últimos 10 años?					
PUNTUACIÓN TOTAL					

Patient Health Questionnaire (PHQ-9)

NAME: ______________________________ DATE: ____________

Over the last *2 weeks*, how often have you been bothered by any of the following problems?
(use "√" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or helpless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

add columns ☐ + ☐ + ☐

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card). TOTAL: ☐

10. If you checked off *any problems*, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ________
Somewhat difficult ________
Very difficult ________
Extremely difficult ________

PHQ-9 Patient Depression Questionnaire

For initial diagnosis:

1. Patient completes PHQ-9 Quick Depression Assessment.
2. If there are at least 4 ✓s in the shaded section (including Questions #1 and #2), consider a depressive disorder. Add score to determine severity.

Consider Major Depressive Disorder

- if there are at least 5 ✓s in the shaded section (one of which corresponds to Question #1 or #2)

Consider Other Depressive Disorder

- if there are 2-4 ✓s in the shaded section (one of which corresponds to Question #1 or #2)

Note: Since the questionnaire relies on patient self-report, all responses should be verified by the clinician, and a definitive diagnosis is made on clinical grounds taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient.
Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning (Question #10) and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms.

To monitor severity over time for newly diagnosed patients or patients in current treatment for depression:

1. Patients may complete questionnaires at baseline and at regular intervals (eg, every 2 weeks) at home and bring them in at their next appointment for scoring or they may complete the questionnaire during each scheduled appointment.
2. Add up ✓s by column. For every ✓: Several days = 1 More than half the days = 2 Nearly every day = 3
3. Add together column scores to get a TOTAL score.
4. Refer to the accompanying **PHQ-9 Scoring Box** to interpret the TOTAL score.
5. Results may be included in patient files to assist you in setting up a treatment goal, determining degree of response, as well as guiding treatment intervention.

Scoring: add up all checked boxes on PHQ-9

For every ✓ Not at all = 0; Several days = 1;
More than half the days = 2; Nearly every day = 3

Interpretation of Total Score

Total Score	Depression Severity
1-4	Minimal depression
5-9	Mild depression
10-14	Moderate depression
15-19	Moderately severe depression
20-27	Severe depression

A2662B 10-04-2005

Cuestionario De Salud Del Paciente (PHQ-9) + 3

Lista de los Nueve Síntomas para Revisión de la Depresión

Nombre del Paciente: ___________________________ Fecha De Nacimiento: _______________ Fecha: _______________

¿En las últimas dos semanas, con qué frecuencia ha experimentado los siguientes síntomas?

PREGUNTAS	Nunca	Varios días	Más de la mitad de los días	Casi todos los días
Conteste las preguntas 1-9 inicialmente y después todos los Puntos de Decisión Crítica (PDC)	**0**	**1**	**2**	**3**
1. Poco interés o placer en hacer cosas	0	0	0	0
2. Sentirse desanimado, deprimido o sin esperanza	0	0	0	0
3. Tener problemas para dormir, mantenerse dormido o dormir demasiado	0	0	0	0
4. Sentirse cansado o tener poca energía	0	0	0	0
5. Poco apetito o comiendo demasiado	0	0	0	0
6. Sentir falta de amor propio o pensar que es un fracaso o fallarle a usted mismo o a su familia	0	0	0	0
7. Tener dificultad en concentrarse en cosas tales como leer el periódico o ver televisión	0	0	0	0
8. El moverse o hablar tan despacio que otras personas a su alrededor se dan cuenta; o todo lo contrario, que cuando está nervioso/a o inquieto/a usted se mueva muchísimo más de lo normal.	0	0	0	0
9. Pensamientos de que pudiera estar mejor muerto o hacerse daño a si mismo. (Si contestó afirmativamente, complete la Evaluación de Riesgo de Suicidio)	0	0	0	0
PHQ-9 Scoring Formula				
# Symptoms	**___ X 0 =**	**___ X 1 =**	**___ X 2 =**	**___ X 3 =**
Per Category	**______ +**	**_______ +**	**_______ +**	**_______ =**
		PHQ-9 Total Score:		_______

10. Si contestó afirmativamente a cualquiera de los problemas en el cuestionario, ¿cuánta dificultad le han causado estos problemas en el trabajo, al atender su hogar o llevarse bien con otras personas?

☐ Ninguna Dificultad ☐ Alguna Dificultad ☐ Mucha Dificultad ☐ Muchísima Dificultad

COMPLETE LAS PREGUNTAS 11 Y 12 SOLAMENTE EN LA VISITA INICIAL

11. ¿En los últimos dos años, se ha sentido deprimido/a o triste la mayoría de los días, a pesar de sentirse bien en otras ocasiones?

☐ Si ☐ No

12. ¿Ha habido un periodo, de al menos cuatro días, en los que se sentía tan feliz, con demasiada energía o tan irritable que se metió en problemas, o su familia o amigos se preocuparon o el médico le dijo que se encontraba en un estado maniaco?

☐ Si ☐ No

Número de Teléfono: _________________ ¿Se puede dejar mensaje? SI or NO Nota: ________________________

Medication: ___________________ Dose: _______________________ Frequency: __________________

1st copy to Medical Record 2nd copy to Initiate Phone Protocol

Geriatric Depression Scale (short form)

Instructions: Circle the answer that best describes how you felt over the past week.

1.	Are you basically satisfied with your life?	yes	no
2.	Have you dropped many of your activities and interests?	yes	no
3.	Do you feel that your life is empty?	yes	no
4.	Do you often get bored?	yes	no
5.	Are you in good spirits most of the time?	yes	no
6.	Are you afraid that something bad is going to happen to you?	yes	no
7.	Do you feel happy most of the time?	yes	no
8.	Do you often feel helpless?	yes	no
9.	Do you prefer to stay at home, rather than going out and doing things?	yes	no
10.	Do you feel that you have more problems with memory than most?	yes	no
11.	Do you think it is wonderful to be alive now?	yes	no
12.	Do you feel worthless the way you are now?	yes	no
13.	Do you feel full of energy?	yes	no
14.	Do you feel that your situation is hopeless?	yes	no
15.	Do you think that most people are better off than you are?	yes	no

Total Score ____________

Action Items for Clinicians to Discuss to Bridge the Medical/Social Divide

What to Talk About	How to Do It	Why
Medical Advance Care Planning	Ask the patient if they have selected a medical decision-maker and document the response in the EMR.	Ensure patient has a voice in their medical care regardless of how disease progresses, including minimizing unwanted burdensome care and maximizing wanted care.
	Give patient and care partner a Health Care Advance Directive document to guide discussion and documentation.	Prior discussions with care partners and clinicians about choices can help reduce conflict and complicated grief among family and friends when patient loses capacity and decisions need to be made.
	File completed document in the EMR.	Ensure health systems can access Advance Directive and act accordingly.
Financial and Legal Advance Care Planning	Encourage patient to complete a Durable Power of Attorney designating an Agent to act on patient's behalf for all fiscal and legal decisions when loses capacity.	Prevent need for conservatorship, which can be a lengthy and expensive process that does not fulfill patient's wishes.
	Encourage patient and care partner/s to work with legal and financial advisors to execute trust/living will, etc to fulfill patient's wishes.	Working through these decisions early in the disease process empowers the patient and assures their wishes are preserved.
	Suggest family research eligibility for public assistance programs. Refer to community resources, social workers, public agencies.	Medicare and MediCal, along with County and State programs may provide significant financial benefits, as dementia care is very expensive long term, and a variety of services may be needed.

Action Items for Clinicians to Discuss to Bridge the Medical/Social Divide

What to Talk About	How to Do It	Why
Caregiver Skills Training and Safety	Encourage care partners to educate themselves on disease process, effective communication, safety issues, etc. through online and print materials, classes.	A well-rested and prepared caregiver is able to provide the patient with the best care through this journey.
Patient and Caregiver Support	Encourage both patient and care partners to join support groups and receive peer support.	Patients and caregivers benefit from the wisdom of others also on the journey.
	Discuss options for respite services and assistance with activities of daily living. Discuss that "it takes a village" and that care partners cannot do everything along.	Caregivers must care for themselves and maintain those parts of their daily lives most important in order to be effective caregivers.
Long term Care Living Arrangements	Encourage patient and family members to have frank discussions about future goals and expectations; what would patient not want their caregivers to do, i.e., incontinence, etc.	Having family discussions as early in the disease process will help dissuade any guilt feelings later or conflicts among family members about the wishes of the individual with dementia.

Quick Provider Resources

General Informational Resources

Alzheimer's Association http://alz.org

Alzheimer's San Diego http://alzsd.org

Alzheimer's Disease Education and Referral (ADEAR) https://www.nia.nih.gov/alzheimers

Alzheimer's Drug Discovery Foundation (ADDF) information about risk factors. https://www.alzdiscovery.org

California Alzheimer's Disease Centers, California Department of Public Health. Assessment of Cognitive Complaints Toolkit. https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/CDPH%20Document%20Library/Alzheimers'%20Disease%20Program/ACCT-AD%20Toolkit%2012%2027%2018.pdf

Gerontological Society of America, KAER Toolkit: 4-Step Process to Detecting Cognitive Impairment and Earlier Diagnosis of Dementia. https://www.geron.org/Resources/Brain-Health-and-Dementia

American Academy of Neurology https://aan.com

Lewy Body Dementia Association http://www.LBDA.org

Association for Fronto-Temporal Degeneration (AFTD) http://www.theaftd.org

Hartford Institute for Geriatric Nursing Assessment Tools for Best Practices of Care of Older Adults
https://hign.org/consultgeri-resources/try-this-series
https://hign.org/consultgeri/try-this/dementia

Clinical Trials

Clinicaltrials.gov

https://clinicaltrials.gov/ct2/results?cond=dementia&term=&cntry=&state=&city=&dist=

Alzheimer Association TrialMatch https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials

Pharmacological Management - Beer's Criteria

American Geriatrics Society 2023 Updated AGS Beers Criteria® for Potentially Inappropriate Medication Use in Older Adults By the American Geriatrics Society https://agsjournals.onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.18372

Elder Abuse

San Diego County: https://www.sandiegocounty.gov/content/sdc/hhsa/programs/ais/Services/Adult-Protective-Services.html

San Diego City:¨ https://www.sandiego.gov/police/services/units/elderabuse

San Diego District Attorney https://www.sdcda.org/helping/elder-abuse

End of Life Planning and Care

www.prepareforyourcare.org

www.caringadvocates.org

www.coalitionccc.org

www.theconversationproject.org

Clinical Education

San Diego County Alzheimer's Project Clinical Roundtable

A collaborative of practitioners throughout all health systems; algorithms for screening, evaluation and diagnosis, and management of patients with cognitive disorders. A wide variety of information, resources, and on-demand CME webinars, as well as after visit summary attachments, and tools for caregivers. https://championsforhealth.org/alzheimers

Dementia Care Aware
Dementia Care Aware is a state-wide effort coordinated through UCSF, in partnership with UC San Diego and other California educational institutions. A series of trainings are available.
https://www.dementiacareaware.org
https://www.youtube.com/@dementiacareaware1/videos

UCI's Dementia Care Aware (DCA) ECHO Virtual Education Series
Every Friday, 12 to 1 p.m.
The ECHO Series provides training and support that empowers primary care teams to assess and address dementia through a variety of topics. Office hours featuring clinical experts are held on the 3rd Friday of every month from 12 to 1 p.m. Free CEs are available.
https://www.familymed.uci.edu//geriatrics/GWEP/gero-echo.asp

UCLA/Alzheimer's Association Alzheimer's & Dementia Care ECHO Program
Mentoring and support via care-based, interactive videoconference sessions. 12 bi-weekly sessions followed by group consultation on de-identified patients. No cost, CMEs available for physicians, nurses and social workers.
Contact rbgoldberger@alz.org

UCSF Memory and Aging Center Alzheimer's and Dementia Care ECHO Program
A collaboration between UCSF Memory and Aging Center (MAC) and the Alzheimer's Association. Brief lectures followed by in-depth case consultations on challenging patient cases brought by the primary care providers. See website to be added to the waitlist.
https://www.dementiacareaware.org/wp-content/uploads/2023/04/UCLA-ADC-ECHO-Application.pdf

Alzheimer's Association Clinical Education
https://www.alz.org/professionals/health-systems-medical-professionals/cme-activities

Resources for Clinicians on Effective Communications with Patients & Caregivers

Ask Me 3®
http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx
Designed by health literacy experts, Ask Me 3 is intended to help patients become more active members of their health care team, and improve communications between patients, families, and healthcare professionals.

Advanced Care Planning Worksheets for Patients and family members
https://www.nia.nih.gov/health/advance-care-planning/advance-care-planning-worksheets

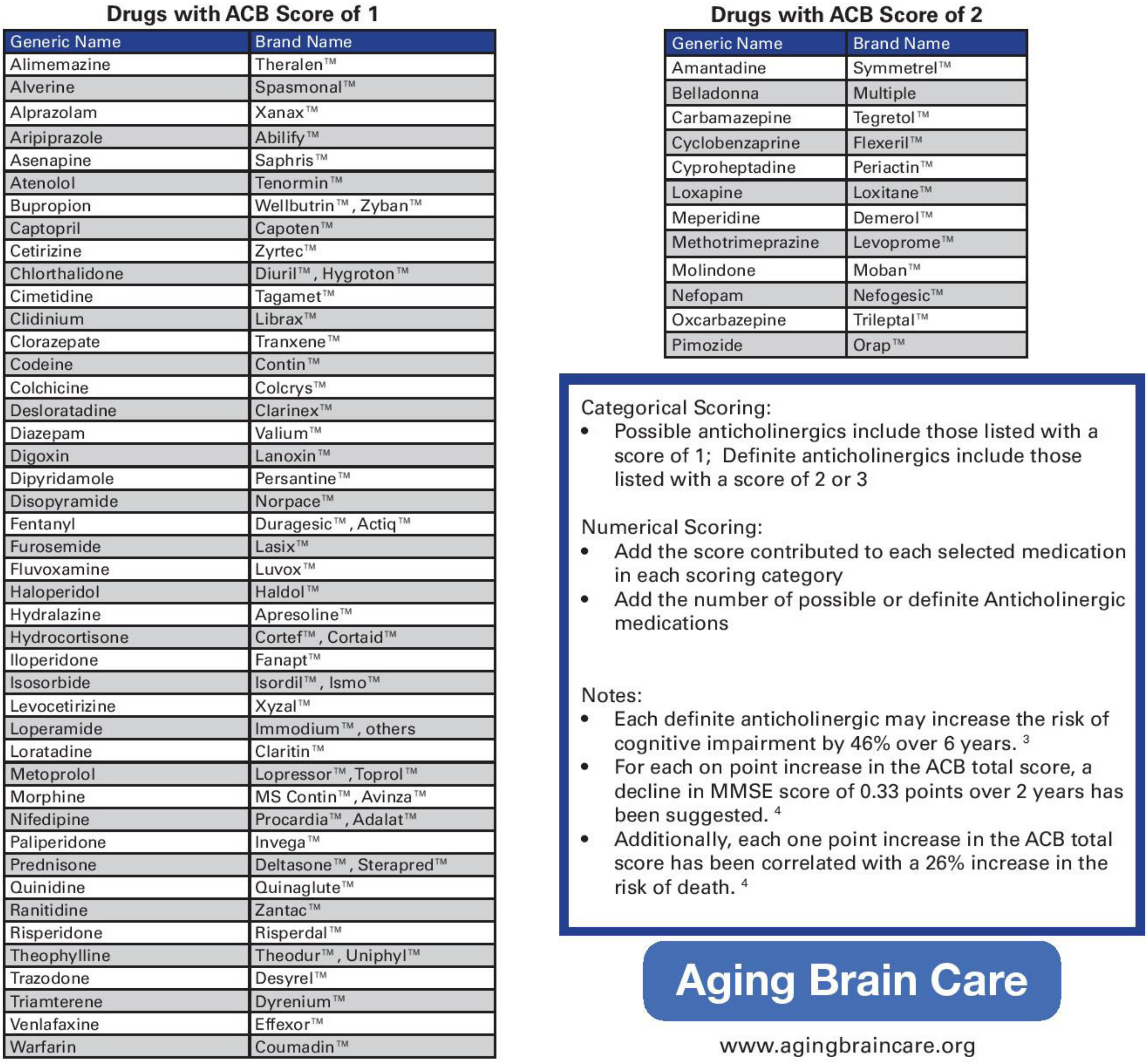
Medical Legal Partnership
Training/resources for providers on common legal issues facing those with dementia and their families.
https://www.dementiacareaware.org/mlp/

The impact of racism on clinician cognition, behavior, and decision making.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3993983/
Paper explores ways racism can interact with cognitive biases to affect clinicians' behavior and decisions and in turn, patient behavior and decisions.

Challenges of Cultural Diversity in Healthcare: Protect Your Patients and Yourself
https://www.thedoctors.com/articles/cultural-diversity-in-healthcare-strategies-for-culturally-appropriate-patient-care/
Article provides tools and strategies to help screen and address social determinants of health.

AHRQ Guide: Improving patient safety systems for patients with limited English proficiency
https://www.ahrq.gov/health-literacy/professional-training/lepguide/index.html

Anticholinergic Burden Index



Drugs with ACB Score of 1

Generic Name	Brand Name
Alimemazine	Theralen™
Alverine	Spasmonal™
Alprazolam	Xanax™
Aripiprazole	Abilify™
Asenapine	Saphris™
Atenolol	Tenormin™
Bupropion	Wellbutrin™, Zyban™
Captopril	Capoten™
Cetirizine	Zyrtec™
Chlorthalidone	Diuril™, Hygroton™
Cimetidine	Tagamet™
Clidinium	Librax™
Clorazepate	Tranxene™
Codeine	Contin™
Colchicine	Colcrys™
Desloratadine	Clarinex™
Diazepam	Valium™
Digoxin	Lanoxin™
Dipyridamole	Persantine™
Disopyramide	Norpace™
Fentanyl	Duragesic™, Actiq™
Furosemide	Lasix™
Fluvoxamine	Luvox™
Haloperidol	Haldol™
Hydralazine	Apresoline™
Hydrocortisone	Cortef™, Cortaid™
Iloperidone	Fanapt™
Isosorbide	Isordil™, Ismo™
Levocetirizine	Xyzal™
Loperamide	Immodium™, others
Loratadine	Claritin™
Metoprolol	Lopressor™, Toprol™
Morphine	MS Contin™, Avinza™
Nifedipine	Procardia™, Adalat™
Paliperidone	Invega™
Prednisone	Deltasone™, Sterapred™
Quinidine	Quinaglute™
Ranitidine	Zantac™
Risperidone	Risperdal™
Theophylline	Theodur™, Uniphyl™
Trazodone	Desyrel™
Triamterene	Dyrenium™
Venlafaxine	Effexor™
Warfarin	Coumadin™

Drugs with ACB Score of 2

Generic Name	Brand Name
Amantadine	Symmetrel™
Belladonna	Multiple
Carbamazepine	Tegretol™
Cyclobenzaprine	Flexeril™
Cyproheptadine	Periactin™
Loxapine	Loxitane™
Meperidine	Demerol™
Methotrimeprazine	Levoprome™
Molindone	Moban™
Nefopam	Nefogesic™
Oxcarbazepine	Trileptal™
Pimozide	Orap™

Categorical Scoring:

- Possible anticholinergics include those listed with a score of 1; Definite anticholinergics include those listed with a score of 2 or 3

Numerical Scoring:

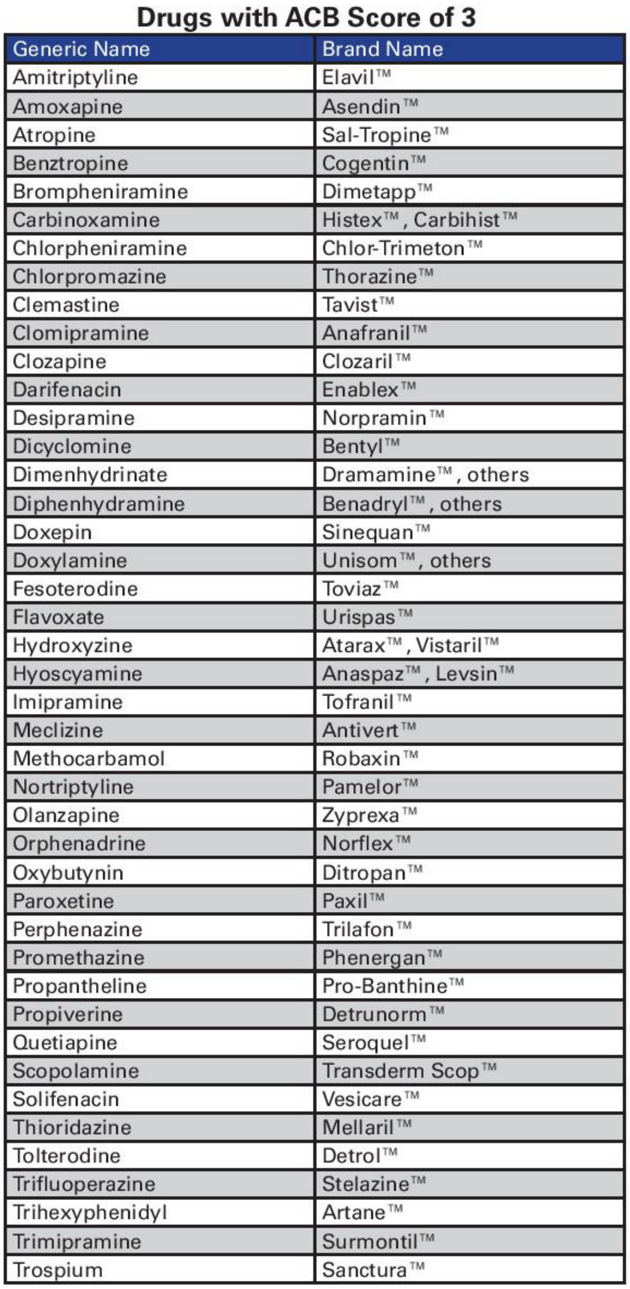
- Add the score contributed to each selected medication in each scoring category
- Add the number of possible or definite Anticholinergic medications

Notes:

- Each definite anticholinergic may increase the risk of cognitive impairment by 46% over 6 years. [3]
- For each on point increase in the ACB total score, a decline in MMSE score of 0.33 points over 2 years has been suggested. [4]
- Additionally, each one point increase in the ACB total score has been correlated with a 26% increase in the risk of death. [4]

Aging Brain Care

www.agingbraincare.org



Drugs with ACB Score of 3

Generic Name	Brand Name
Amitriptyline	Elavil™
Amoxapine	Asendin™
Atropine	Sal-Tropine™
Benztropine	Cogentin™
Brompheniramine	Dimetapp™
Carbinoxamine	Histex™, Carbihist™
Chlorpheniramine	Chlor-Trimeton™
Chlorpromazine	Thorazine™
Clemastine	Tavist™
Clomipramine	Anafranil™
Clozapine	Clozaril™
Darifenacin	Enablex™
Desipramine	Norpramin™
Dicyclomine	Bentyl™
Dimenhydrinate	Dramamine™, others
Diphenhydramine	Benadryl™, others
Doxepin	Sinequan™
Doxylamine	Unisom™, others
Fesoterodine	Toviaz™
Flavoxate	Urispas™
Hydroxyzine	Atarax™, Vistaril™
Hyoscyamine	Anaspaz™, Levsin™
Imipramine	Tofranil™
Meclizine	Antivert™
Methocarbamol	Robaxin™
Nortriptyline	Pamelor™
Olanzapine	Zyprexa™
Orphenadrine	Norflex™
Oxybutynin	Ditropan™
Paroxetine	Paxil™
Perphenazine	Trilafon™
Promethazine	Phenergan™
Propantheline	Pro-Banthine™
Propiverine	Detrunorm™
Quetiapine	Seroquel™
Scopolamine	Transderm Scop™
Solifenacin	Vesicare™
Thioridazine	Mellaril™
Tolterodine	Detrol™
Trifluoperazine	Stelazine™
Trihexyphenidyl	Artane™
Trimipramine	Surmontil™
Trospium	Sanctura™

capc Center to Advance Palliative Care

Short Form Zarit Burden Interview (ZBI-12)

	"Never" (0)	"Rarely" (1)	"Sometimes" (2)	"Quite frequently" (3)	"Nearly always" (4)
Do you feel…?					
That because of the time you spend with your relative that you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

→ Short form ZBI-12 validated as screening tool in advanced illness including dementia and cancer
→ Total ZBI-12 score: summation of 12 items (0 to 4 points per item, total score range 0 to 48)
→ Copyrighted, but available for free use by clinicians and for non-funded academic research
→ Suggested guidelines for scoring:
  - 0-10: no to mild burden
  - 10-20: mild to moderate burden
  - >20: high burden

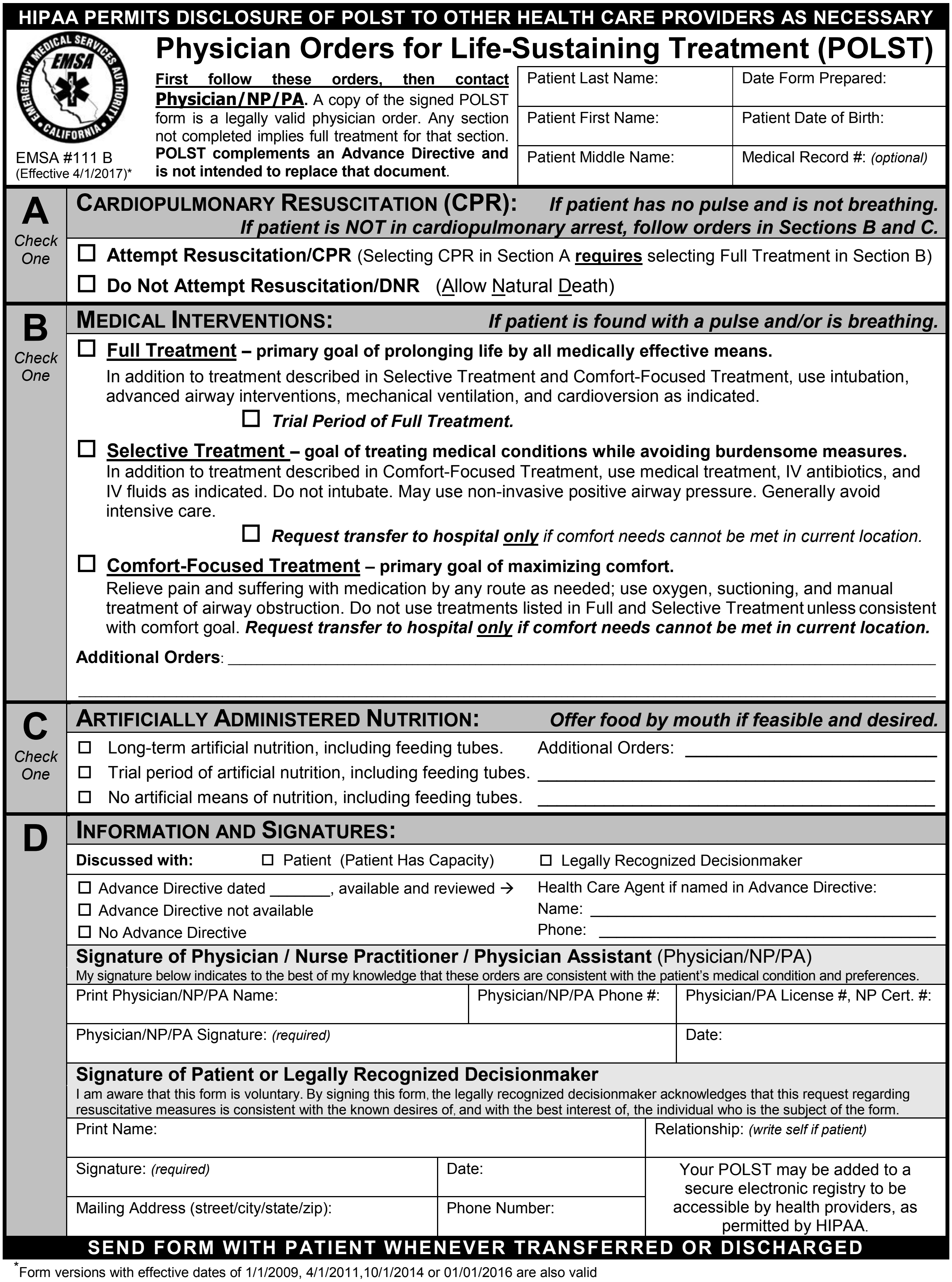
FAST Dementia Scale

Functional Assessment Scale	
1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.*
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g., patent may wear the same clothing repeatedly, unless supervised.*)
6	Occasionally or more frequently over the past weeks. * for the following: **A)** Improperly putting on clothes without assistance or cueing. **B)** Unable to bathe properly (not able to choose proper water temp). **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly, or properly dispose of toilet tissue). **D)** Urinary incontinence. **E)** Fecal incontinence.
7	**A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview. **C)** Ambulatory ability is lost (cannot walk without personal assistance). **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair). **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.
	*Scored primarily on information obtained from a knowing informant. Psychopharmacology Bulletin, 1988 24:653-659.

Palliative Care Scale Form

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort No evidence of disease	Full	Normal or Reduced	Full
70%	Reduced	Unable to do normal job/work Significant disease	Full	Normal or Reduced	Full
60%	Reduced	Unable to do hobbies/house work Significant disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40%	Mainly Sit/Lie	Unable to do most activity Extensive disease	Mainly Assistance	Normal or Reduced	Full or Drowsy ± Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or Reduced	Full or Drowsy ± Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to Sips	Full or Drowsy ± Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth Care Only	Drowsy or Coma ± Confusion
0%	Death				

POLST Form



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

EMSA #111 B
(Effective 4/1/2017)*

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A
Check One

CARDIOPULMONARY RESUSCITATION (CPR): ***If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.***

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A **requires** selecting Full Treatment in Section B)

☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B
Check One

MEDICAL INTERVENTIONS: ***If patient is found with a pulse and/or is breathing.***

☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.

☐ ***Trial Period of Full Treatment.***

☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Request transfer to hospital only*** *if comfort needs cannot be met in current location.*

☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: ____

____

C
Check One

ARTIFICIALLY ADMINISTERED NUTRITION: ***Offer food by mouth if feasible and desired.***

☐ Long-term artificial nutrition, including feeding tubes.
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.

Additional Orders: ______________________
____
____

D

INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _______, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: ______________________________
Phone: ______________________________

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

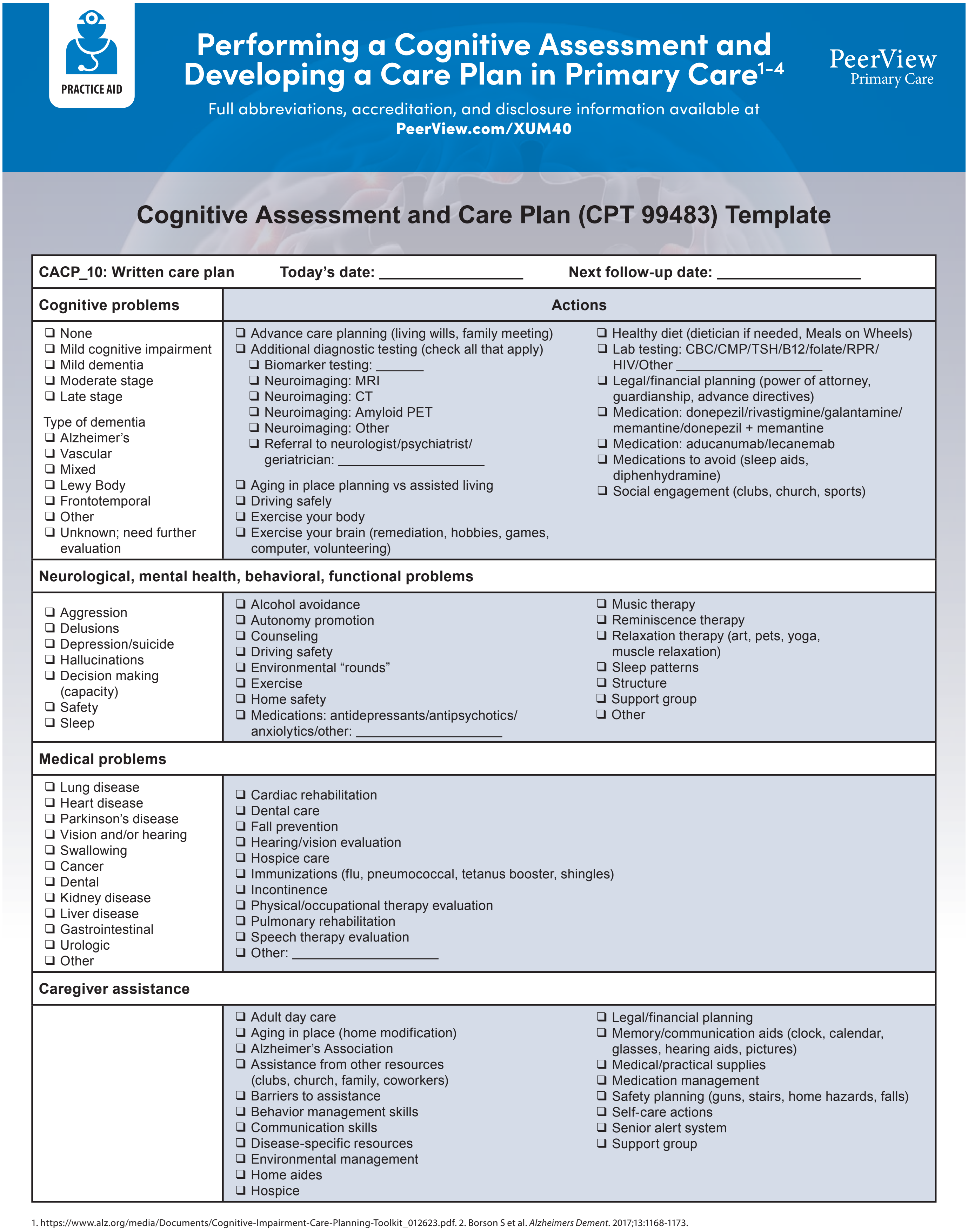
Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

---

*Form versions with effective dates of 1/1/2009, 4/1/2011,10/1/2014 or 01/01/2016 are also valid

Care Plan Template



PRACTICE AID

Performing a Cognitive Assessment and Developing a Care Plan in Primary Care[1-4]

Full abbreviations, accreditation, and disclosure information available at
PeerView.com/XUM40

PeerView
Primary Care

Cognitive Assessment and Care Plan (CPT 99483) Template

CACP_10: Written care plan **Today's date:** ________________ **Next follow-up date:** ________________

Cognitive problems	**Actions**	
☐ None ☐ Mild cognitive impairment ☐ Mild dementia ☐ Moderate stage ☐ Late stage Type of dementia ☐ Alzheimer's ☐ Vascular ☐ Mixed ☐ Lewy Body ☐ Frontotemporal ☐ Other ☐ Unknown; need further evaluation	☐ Advance care planning (living wills, family meeting) ☐ Additional diagnostic testing (check all that apply) ☐ Biomarker testing: _______ ☐ Neuroimaging: MRI ☐ Neuroimaging: CT ☐ Neuroimaging: Amyloid PET ☐ Neuroimaging: Other ☐ Referral to neurologist/psychiatrist/geriatrician: ________________ ☐ Aging in place planning vs assisted living ☐ Driving safely ☐ Exercise your body ☐ Exercise your brain (remediation, hobbies, games, computer, volunteering)	☐ Healthy diet (dietician if needed, Meals on Wheels) ☐ Lab testing: CBC/CMP/TSH/B12/folate/RPR/HIV/Other ________________ ☐ Legal/financial planning (power of attorney, guardianship, advance directives) ☐ Medication: donepezil/rivastigmine/galantamine/memantine/donepezil + memantine ☐ Medication: aducanumab/lecanemab ☐ Medications to avoid (sleep aids, diphenhydramine) ☐ Social engagement (clubs, church, sports)
Neurological, mental health, behavioral, functional problems		
☐ Aggression ☐ Delusions ☐ Depression/suicide ☐ Hallucinations ☐ Decision making (capacity) ☐ Safety ☐ Sleep	☐ Alcohol avoidance ☐ Autonomy promotion ☐ Counseling ☐ Driving safety ☐ Environmental "rounds" ☐ Exercise ☐ Home safety ☐ Medications: antidepressants/antipsychotics/anxiolytics/other: ________________	☐ Music therapy ☐ Reminiscence therapy ☐ Relaxation therapy (art, pets, yoga, muscle relaxation) ☐ Sleep patterns ☐ Structure ☐ Support group ☐ Other
Medical problems		
☐ Lung disease ☐ Heart disease ☐ Parkinson's disease ☐ Vision and/or hearing ☐ Swallowing ☐ Cancer ☐ Dental ☐ Kidney disease ☐ Liver disease ☐ Gastrointestinal ☐ Urologic ☐ Other	☐ Cardiac rehabilitation ☐ Dental care ☐ Fall prevention ☐ Hearing/vision evaluation ☐ Hospice care ☐ Immunizations (flu, pneumococcal, tetanus booster, shingles) ☐ Incontinence ☐ Physical/occupational therapy evaluation ☐ Pulmonary rehabilitation ☐ Speech therapy evaluation ☐ Other: ________________	
Caregiver assistance		
	☐ Adult day care ☐ Aging in place (home modification) ☐ Alzheimer's Association ☐ Assistance from other resources (clubs, church, family, coworkers) ☐ Barriers to assistance ☐ Behavior management skills ☐ Communication skills ☐ Disease-specific resources ☐ Environmental management ☐ Home aides ☐ Hospice	☐ Legal/financial planning ☐ Memory/communication aids (clock, calendar, glasses, hearing aids, pictures) ☐ Medical/practical supplies ☐ Medication management ☐ Safety planning (guns, stairs, home hazards, falls) ☐ Self-care actions ☐ Senior alert system ☐ Support group

1. https://www.alz.org/media/Documents/Cognitive-Impairment-Care-Planning-Toolkit_012623.pdf. 2. Borson S et al. *Alzheimers Dement*. 2017;13:1168-1173.

HEALTHY BODY, HEALTHY MIND


Keep Moving


Maintain Social Interactions


Eat Fruit and Vegetables Daily


Expand Your Thinking

LIVE YOUR BEST LIFE!

KNOW YOUR HEALTH NUMBERS

For more information, contact your health provider.

CHAMPIONS for HEALTH

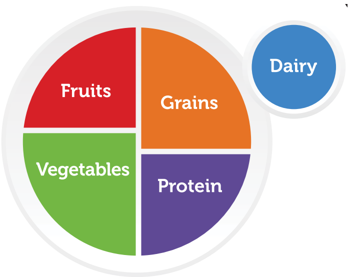
This flyer is supported by the California Department of Public Health Alzheimer's Disease Program. Funding is provided by the 2019 California Budget Act one-time General Fund expenditure authority over three State Fiscal Years from 2019 to 2022.

COUNTY OF SAN DIEGO

LIVE WELL SAN DIEGO

YOUR HEALTH IS UP TO YOU! MAKE IT FUN!

EATING HEALTHY IS EASY & COLORFUL!



- Try adding a new fruit or vegetable to your meals each month
- Pick foods of all different colors for your plate
- Olive and avocado oils are healthy fats to use instead of animal fats
- Have fresh fruit easily available for your family instead of candy and pastries
- Choose whole wheat and whole grains instead of white flour for breads
- Read package nutrition information and look for products with at least 5 grams of fiber
- Avoid fad diets that are hard to maintain and tend to promote weight gain after their use

HAVE FUN INCREASING YOUR ACTIVITY

- Pick one or two activities you really enjoy, and can do comfortably
- If you are getting started with activity, start slow and build up over a few weeks
- Try to get moderate exercise 30 minutes a day, three or four days a week
- Brisk walking, dancing, hiking can improve the health of your heart, lungs and circulatory system
- Make it a family activity! Get the kids out with you to improve their health as well.
- Gardening is a great strengthening activity for the whole family
- Try a new activity, like cycling, flying a kite with children, or exploring a new area of the community
- Be sure to stretch your muscles when you are done with your activity to keep muscles from aching

SOCIAL CONNECTION KEEPS YOU HAPPY

- Stay in touch with family and friends, even if it is on the telephone
- Plan and enjoy meals with friends and other families
- Your faith community can be an important social connection
- Take a class for social connection and testing your brain
- Find group activities you like, such as singing in a choir, joining a walking group or bowling league

TEST YOUR BRAIN

- Learn a new subject by reading or watching videos
- Sing songs from your childhood as well as new ones
- Try your hand at jigsaw puzzles or word games
- Tell your children and grandchildren stories about your life experiences
- Take a cooking class

KNOW YOUR HEALTH NUMBERS

- 0 smoking, vaping, or chewing tobacco
- 7 - 9 hours sleep nightly
- Know your blood pressure, weight, cholesterol, and blood sugar (A1c) and keep them in check
- 100% - Take all your medications as prescribed

CHAMPIONS *for* HEALTH

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COUNTY OF SAN DIEGO

LIVE WELL SAN DIEGO

Preparing for Your Doctor's Visit

Fill out the information below to the best of your ability. Share it with your doctor. Be open and honest in answering any questions your doctor may ask you about the changes you've been experiencing. It is recommended to bring someone with you, either a family member of someone who knows you well enough to contribute information and can take notes so you don't have to worry about remembering anything.

Has your health, memory or mood changed?

How did it change?

When did you first notice the change?

How often does it happen?

When does it happen? Is it always at a certain time of day?

What do you do when it happens?

What behaviors are the same?

Do you have problems with any of the following?

Please check the answer.

Repeating or asking the same thing over and over?
☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Remembering appointments, family occasions, holidays?
☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Writing checks, paying bills, balancing the checkbook?
☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Shopping independently (e.g., for clothing or groceries)?
☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Taking medications according to the instructions?
☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Getting lost while walking or driving in familiar places?
☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Medications and medical history

List of medications (dosage, frequency) including over-the-counter and prescription: (Bring all over-the-counter and prescription medications with you to your visit.)

____

____

List vitamins and herbal supplements:

____

____

List current medical conditions:

____

____

____

List past medical conditions:

____

____

What to bring with you to your doctor visit

Bring someone with you, either a family member or someone who knows you well enough to contribute information and can take notes so you don't have to worry about remembering everything.
Bring all over-the-counter and prescription medications.
Bring your Advance Directives if you have them.

Questions to ask the doctor

What are tests I need to take and how long will it take to get a diagnosis? Will you refer me to a specialist?
Could the medicines I'm taking be causing my symptoms?
Do I have any other conditions that could be causing my symptoms or making them worse?
What should I expect if it is Alzheimer's?
Which treatments are available for Alzheimer's? What are the risks and benefits and possible side effits?
What about participating in a clinical trial? What are the risks and benefits?
Is there anything else I should know?
When should I come back for another visit?
Where can I get information about Advance Directives if I don't have one yet?

This tool was amended from tools developed by the Alzheimer's Association. Some information in this tool was developed for the Chronic Care Networks for Alzheimer's Disease (CCN/AD) project and is the joint property of the Alzheimer's Association and the National Chronic Care Consortium.

Receiving a Diagnosis of Dementia

You have just received a diagnosis of dementia. Now what?

1. **Ask questions about the disease and make sure you understand the answers.** New questions will come up over the weeks and months to come, and your health care provider and team are here to walk this journey with you and your family.
2. **Learn as much as you can.** There are many resources available through local and national organizations, including educational programs and support groups, as well as online resources. Knowledge is power.
3. **Understand this is a marathon, not a sprint.** There will be many good years ahead, and now is the time to plan for what you want your life to look like now, while the individual with memory decline is able to enjoy life with family and friends.
4. **Get your docs in order!** There are a number of documents that should be written or updated. Establish with whom clinicians can discuss patient care with an updated HIPAA form, and who can make medical decisions when the individual with cognitive decline cannot (Advance Directive form). Discuss legal and financial issues with family and get help from professionals to plan now for future contingencies.
5. **Live a brain-healthy life.** Evidence has shown that the best options for enhancing quality of life is a healthy diet, physical activity, social connections, brain stimulation, and not smoking. And get plenty of rest. This applies to individuals with dementia and their care partners.

First Step Resources

Information and Community Resources

Alzheimer's Association
(800) 272-3900
www.alz.org

Alzheimer's San Diego
(858) 492-4400
www.alzsd.org

Southern Caregiver Resource Center
(800) 827-1008
http://caregivercenter.org/

Medical Advance Care Planning

PREPARE
https://prepareforyourcare.org/en/welcome

Legal and Financial Advance Care Planning

Elder Law and Advocacy
(858) 565-1392
http://www.seniorlaw-sd.org

Understanding your Health Insurance

Health Insurance Counseling and Advocacy Program
(858) 565-1392
https://cahealthadvocates.org

The Challenge of Caring for an Individual Living with Dementia

STRATEGIES FOR CAREGIVERS

1. Promptly evaluate and treat behavioral symptoms. This is even more important than ever because doing so will help protect caregivers from burn out.
2. Build a caregiving team/expand the caregiving team
3. Learn and utilize optimal communication approaches when caring for a person with dementia.
4. Create an optimal environment that includes structure and activities.
5. Use community, online resources, and other technologies to their fullest:
    - Online resources and learning modules
    - Assisted living communities
    - COVID-19 adaptations have been made which allow safety to be maintained in spite of COVID-19 e.g. video visits

RECOGNIZING AND RESPONDING TO BEHAVIOR CHANGES

- Behavior changes are a form of communication.
- When a person with dementia experiences a change in behavior the first goal is to determine the meaning or message being communicated.
- Sometimes the meaning or message will be simple or obvious but sometimes it may take a while to understand.
- Even though we are living through the COVID-19 pandemic, individuals living with dementia remain vulnerable to behavioral problems and the triggers for behavioral symptoms remain the same.
- Remember that the emotions and stress of a caregiver will likely be passed to the person who is living with dementia.

CREATE A CAREGIVING TEAM

- Share the caregiving burden with as many family members & friends as possible to help protect from stress related illnesses or burn out
- Make a list of family members (and friends and neighbors) who are willing and able to help and what special skills and talents they possess.
- Give family members specific tasks or assignments that, when possible, use their strengths and talents. Examples include: Preparing meals, running errands, walking the dog, mowing the lawn, doing laundry
- Assign out-of-town family members tasks that do not require them to be geographically close to the patient:
    - Using email to keep all those interested informed
    - Set up a phone tree for efficient communication
- Caring for a family member with dementia can be extremely stressful. Habits of behavior and communication between family members may be intensified by the stress of the situation.
- Periodically solicit feedback and offer praise and thanks
- Encourage all involved family members to become as educated as possible about their loved one's dementia, and their preferences and needs
- Encourage care giving family members to attend virtual support groups
- Do not hesitate to set limits if a particular family member is saying or doing things that hurt more than help
- Monitor each care giving family member for signs of physical or psychiatric illness or burn out
- Establish clear lines of authority and communication
- Utilize online courses on how best to communicate with and assist someone who has dementia (e.g. Teepa Snow teepasnow.com)

IMPROVING COMMUNICATION

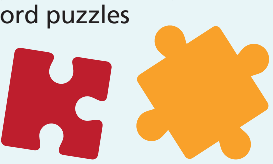
- Make one request at a time
- Speak clearly and slowly
- Allow time for the patient to respond
- Maintain eye contact
- Assume a comfortable posture with arms and hands relaxed
- Identify the patient's affect and verbalize this for him/her
- Time communications optimally based on circumstances (e.g. hunger, fatigue, background noise, etc.)
- Remember that even when words may no longer convey meaning, volume, rate, and melody of speech may still convey information
- The need to be seen, heard and understood is a part of human nature and does not disappear simply because someone is living with dementia
- Putting a thought, need or emotion into words for them can sometimes be powerfully helpful
- Someone living with dementia may have preserved emotional intelligence
- Strive to avoid triggering feelings of shame

DISTRACTION TECHNIQUES

- Presentation of options: "This door is closed but this door is open."
- A compliment: "My that's a beautiful sweater!"
- A request for help: "Please help me fold these towels."
- Other possibly helpful distractions include: food, drink, music, humor.

HELPFUL ACTIVITIES TO IMPROVE COMMUNICATIONS

- Arts and crafts
- Baking
- Current events
- Exercise
- Gardening
- Grooming
- Music
- Pets
- Reminiscing
- Singing
- Dancing
- Telling jokes
- Reading
- Card games
- Table games
- Word games including crossword puzzles



WORKING WITH CAREGIVERS FOR HIRE TO CARE FOR AN INDIVIDUAL LIVING WITH DEMENTIA

Southern Caregiver Resource Center and Alzheimer's San Diego can assist you to assess the qualifications of caregivers-for-hire. To be COVID-safe, follow these:

- Contact the home health care provider and learn their protocols to reduce the spread of COVID-19.
- Check the home health care professional's temperature before they enter your home. Anyone with a temperature over 100.4° F should be excluded from providing care.
- Ask health care professionals if they have been exposed to anyone who has tested positive and if so, do not allow them into your home.
- Ensure that the health care professional washes their hands upon arrival and regularly throughout their time in your home.
- Ask the health care professionals to wear a mask.
- Be aware that bringing anyone into your home increases the risk of COVID.

HELPING THE PERSON LIVING WITH DEMENTIA FOLLOW CDC COVID-19 GUIDELINES

- Provide extra written reminders regarding important hygienic practices.
- Consider placing signs in the bathroom and elsewhere to remind people with dementia to wash their hands with soap for 20 seconds.
- Demonstrate thorough hand-washing.
- Alcohol-based hand sanitizer with at least 60% alcohol can be a quick alternative to hand-washing if the person with dementia cannot get to a sink or wash his/her hands easily.
- Request prescriptions for a greater number of days than usual to reduce trips to the pharmacy.
- Think ahead and make alternative plans for the person with dementia should adult day care, respite, etc. be modified or canceled in response to COVID-19.
- Think ahead and make alternative plans for care management if the primary caregiver should become sick.

El desafío de cuidar a una persona que vive con demencia

ESTRATEGIAS PARA CUIDADORES

1. Evalúe y trate rápidamente los síntomas del comportamiento. Esto es aún más importante que nunca porque hacerlo ayudará a proteger a los cuidadores del agotamiento.
2. Crear un equipo de cuidadores / ampliar el equipo de cuidadores
3. Aprenda y utilice enfoques de comunicación óptimos al cuidar a una persona con demencia.
4. Crear un entorno óptimo que incluya estructura y actividades.
5. Utilice la comunidad, los recursos en línea y otras tecnologías al máximo:
   - Recursos en línea y módulos de aprendizaje
   - Comunidades de vida asistida
   - Se han realizado adaptaciones de COVID-19 que permiten mantener la seguridad a pesar de COVID-19, p. visitas de video

RECONOCER Y RESPONDER A LOS CAMBIOS DE COMPORTAMIENTO

- Los cambios de comportamiento son una forma de comunicación.
- Cuando una persona con demencia experimenta un cambio de comportamiento, el primer objetivo es determinar el significado o el mensaje que se omunica.
- A veces, el significado o el mensaje será simple u obvio, pero a veces puede llevar un tiempo comprenderlo.
- A pesar de que estamos viviendo la pandemia de COVID-19, las personas que viven con demencia siguen siendo vulnerables a los problemas de conducta y los factores desencadenantes de los síntomas de conducta siguen siendo los mismos.
- Recuerde que las emociones y el estrés de un cuidador probablemente se transmitirán a la persona que vive con demencia.

DESARROLLE UN EQUIPO DE CUIDADO

- Comparta la carga del cuidado con tantos familiares miembros y amigos como sea posible para ayudar a protegerse de enfermedades relacionadas con el estrés o agotamiento.
- Haga una lista de miembros de la familia (y amigos y vecinos) que estén dispuestos y puedan ayudar y qué habilidades y talentos especiales poseen.
- Dé a los miembros de la familia tareas o asignaciones específicas que, cuando sea posible, utilicen sus fortalezas y talentos. Los ejemplos incluyen: preparar comidas, hacer mandados, caminar al perro, cortar el césped, lavar la ropa
- Asigne tareas a familiares de fuera de la ciudad que no exijan que estén geográficamente cerca del paciente:
  - Usar el correo electrónico para mantener informados a todos los interesados
  - Configurar un árbol telefónico para una comunicación eficiente
- Cuidar a un familiar con demencia puede ser extremadamente estresante. Los hábitos de comportamiento y comunicación entre los miembros de la familia pueden verse intensificados por el estrés de la situación.
- Solicite periódicamente comentarios, proporcione elogios y agradezca.
- Anime a todos los miembros de la familia involucrados a que se eduquen lo más posible acerca de la demencia y de las preferencias y necesidades del ser querido.
- Anime a los familiares que brindan cuidados a participar en grupos de apoyo virtuales
- No dude en establecer límites si algún familiar dice o hace cosas que duelen más que ayuden
- Monitorear a cada miembro de la familia que brinde cuidados para detectar señales de enfermedad física o psiquiátrica o agotamiento
- Establecer líneas claras de autoridad y comunicación.
- Utilice cursos en línea sobre la mejor manera de comunicarse y ayudar a alguien que tiene demencia (por ejemplo, Teepa Snow teepasnow.com)

MEJORANDO LA COMUNICACIÓN

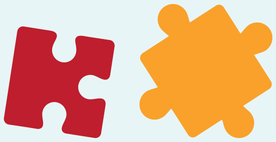
- Pida una cosa a la vez
- Hable clara y lentamente
- De tiempo para que el paciente responda
- Mantenga contacto visual
- Adopte una postura cómoda con brazos y manos relajados.
- Identifique el afecto en el paciente y verbalizarlo por el/ ella
- Programe las comunicaciones de manera óptima en función de las circunstancias (por ejemplo, hambre, fatiga, antecedentes, ruido, etc.)
- Recuerde que incluso cuando las palabras ya no transmitan significado, volumen, ritmo y melodía del habla aún puede transmitir información
- La necesidad de ser visto, escuchado y entendido es una parte de la naturaleza humana y no desaparece simplemente porque alguien vive con demencia
- Expresar un pensamiento, una necesidad o una emoción en palabras para ellos puede ser de gran ayuda
- Alguien que vive con demencia puede haber conservado la inteligencia emocional.
- Esfuércese por evitar provocar sentimientos de vergüenza

TÉCNICAS DE DISTRACCIÓN

- Presentación de opciones: "Esta puerta está cerrada pero esta puerta está abierta ".
- Un cumplido: "¡Vaya, es un suéter hermoso!"
- Una solicitud de ayuda: "Por favor ayúdame a doblar estas toallas".
- Otras distracciones posiblemente útiles incluyen: comida, bebida, música, humor.

ACTIVIDADES ÚTILES PARA MEJORAR COMUNICACIÓN

- Artes y manualidades
- Hornear
- Eventos actuales
- Ejercicio
- Jardinería
- Aseo
- Música
- Mascotas
- Rememorando
- Canto
- Bailar
- Contar chistes
- Lectura
- Juegos de cartas
- Juegos de mesa
- Juegos de palabras incluidos crucigramas



TRABAJAR CON CUIDADORES CONTRATADOS PARA CUIDAR A UNA PERSONA QUE VIVE CON DEMENCIA

Southern Caregiver Resource Center y Alzheimer's San Diego pueden ayudarlo a evaluar las calificaciones de los cuidadores a sueldo. Para estar seguro durante COVID, siga estos pasos:

- Comuníquese con el proveedor de atención médica y conozca sus protocolos para reducir la propagación de COVID-19.
- Verifique la temperatura del profesional de la salud antes de que ingrese a su hogar. Cualquier persona que tenga una temperatura superior a 100,4 ° F debe excluirse de brindar atención.
- Pregunte a los profesionales de la salud si han estado expuestos a alguien que haya dado positivo en la prueba y, de ser así, no los deje entrar a su casa.
- Asegúrese de que el profesional de la salud se lave las manos a su llegada y con regularidad durante el tiempo que estén en su hogar.
- Pida a los profesionales de la salud que usen una mascarilla.
- Tenga en cuenta que traer a alguien a su hogar aumenta el riesgo de COVID

AYUDANDO A LA PERSONA QUE VIVE CON DEMENCIA SIGA LAS PAUTAS DE CDC COVID-19

- Proporcione recordatorios adicionales por escrito sobre prácticas higiénicas importantes.
- Considere colocar letreros en el baño y en otros lugares para recordar a las personas con demencia que deben lavarse sus manos con jabón durante 20 segundos.
- Demuestre lavarse las manos minuciosamente.
- Desinfectante de manos a base de alcohol con al menos un 60% dl alcohol puede ser una alternativa rápida al lavado de manos si la persona con demencia no puede lavarse las manos fácilmente.
- Solicite recetas por una mayor cantidad de días de lo habitual para reducir los viajes a la farmacia.
- Piense en el futuro y haga planes alternativos para persona con demencia para el cuidado para adultos y cuidados de respiro por si los programas son modificado o cancelado en respuesta a COVID-19.
- Piense en el futuro y haga planes alternativos para el cuidado por si el cuidador principal llega a enfermarse.

Information and Resources for Caregivers

Information, Organizations and Services

- 211: County-wide info/resources, http://211sandiego.org
- Access & Crisis Line: Behavioral Health Services for triage and referral to Mobile Crisis Response Team, as appropriate. (888-724-7240) https://www.sandiegocounty.gov/mcrt/
- Aging & Independence Services: (800) 339-4661, specific info/resources for older adults, including Adult Protective Services, http://sandiegocounty.gov/hhsa/programs/ais/
- Alzheimer's Association: (800) 272-3900, Alzheimer's disease specific; https://alz.org
- Alzheimer's San Diego: (858) 492-4400, San Diego based resource organization; http://alzsd.org
- Caregiver Coalition of San Diego; (858) 505- 6300, education and online resources, https://caregivercoalitionsd.org
- Jewish Family Service Older Adult Helpline (858) 637-3210, http://www.jfssd.org
- Southern Caregiver Resource Center: (800) 827-1008, Caregiver focused information and resources http://caregivercenter.org/
- UC San Diego Shiley-Marcos Alzheimer's Disease Research Center: (858) 822-4800, http://adrc.ucsd.edu
- VA San Diego Healthcare System Caregiver Support. www.caregiver.va.gov (858) 642-1215

Respite and In-Home Services

- Southern Caregiver Resource Center including respite voucher program: (800) 827-1008, http://caregivercenter.org
- Respite Volunteer Program: Alzheimer's San Diego;(858) 492-4400, http://alzsd.org
- In-Home Care Resources: In-Home Supportive Services, (800) 339-4661, http://sandiegocounty.gov/hhsa/programs/ais/

Memory Care Living Communities

- ChooseWell: Listings and ratings of assisted living facilities; County HHSA; http://choosewellsandiego.org

Day Programs

(PACE= Program of All-Inclusive Care for the Elderly)

- Family Health Centers of San Diego PACE; (619) 515-2445, https://fhcsd.org/pace
- Glenner Center: (619) 543-4700, http://glenner.org
- St. Paul's PACE Program; (619) 239-6900, https://stpaulspace.org
- San Diego PACE Program; (619) 662-4100, www.syhc.org/sdpace
- Gary & Mary West Senior Wellness Center; (619) 235-6572, https://servingseniors.org
- Gary & Mary West PACE (North County); (760) 280-2230, https://westpace.org

Financial, Insurance and Legal Resources

- California Department of Aging, (916) 322-5290, https://aging.ca.gov
- Health Insurance Resources: Health, Information, Counseling & Advocacy Program (HICAP), (858) 565-1392, https://cahealthadvocates.org
- Legal Resources: Elder Law & Advocacy, (858) 565-1392, http://www.seniorlaw-sd.org

Print Resources

- Caregiver Handbook, Caregiver Coalition of San Diego, https://www.caregivercoalitionsd.org
- Mace, N. & Rabins, P. *The 36-Hour Day: A Family Guide to Caring for People with Alzheimer's Disease, other Dementias, and Memory Loss in Later Life.*
- California DHS, https://www.takeonalz.com/find-a-path-forward/formal-diagnosis/

Safety Resources

- Adult Protective Services: (800) 510-2020, for elder and dependent adult abuse reporting
- GPS Tracker Options: https://safewise.com/best-gps-trackers-dementia-patients/
- SD County Sheriff's "Take Me Home" Program and "You Are Not Alone" Program: www.sdsheriff.net/tmh (info on registering)

Transportation

- San Diego County Volunteer Driver Coalition; (888) 924-3228, http://sdcvdc.org
- SANDAG, http://factsd.org

Effective Communication with Individual with Cognitive Issues

Tips for improved communications:

- Make just one request at a time.
- Speak slowly with good diction.
- Allow time for the individual to respond to your question or request.
- Use many of the five senses with the individual: sight, smell, touch, taste, sound.
- Maintain eye contact.
- Assume a comfortable, relaxed posture to make the individual at ease.
- Identify and reflect the individual's concerns, "I see you are uncomfortable…"
- Use simple, direct statements or requests.

Using Redirection to Improve Communications

Redirection is an intention method of refocusing the individual to remain calm, cooperative, content and safe. Often, individuals with cognitive issues may be frustrated or agitated due to their inability to effectively communicate or have their needs met. It is key to enter the individual's reality, approach in a calm manner, and communicate your desire to help.

- Present options: "Would you like this or this?"
- Compliment: "My that's a beautiful sweater!"
- Request Help: "Can you please help me fold these towels?"
- Helpful Distractions: Food, drink, reminiscent stories, music, humor
- Validate: "You look worried."
- Distract: "Let's look over there…" "Let's plan to do that later. In the meantime, …"
- Redirect: "That coffee smells good. Do you want a cup?"

Common Delusions in Individuals with Dementia

- Accusations of infidelity,
- Persons or images from TV are real,
- Fear of abandonment,
- Accusations of theft of one's property,
- Claims of impersonation (spouse is an imposter),
- Current residence is not one's home,
- Misidentification of familiar persons.

Notes

THE ALZHEIMER'S Project
San Diego unites for a cure and care

CHAMPIONS for HEALTH
PHYSICIANS
IMPROVING HEALTH
CHANGING LIVES

championsforhealth.org/alzheimers

The Alzheimer's Project
Clinical Roundtable is supported by

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