



# Practical Guidelines for Dementia Care

*BEHAVIORAL AND PHYSIOLOGICAL CHANGES*

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# Our Mission

## **We will do whatever it takes to:**

- Lead and excel in health outcomes while reducing total cost through aggressive prevention
- Care for the dignity and health of the whole person—body, mind, and spirit
- Thoughtfully challenge the status quo

## **Through a model of care that:**

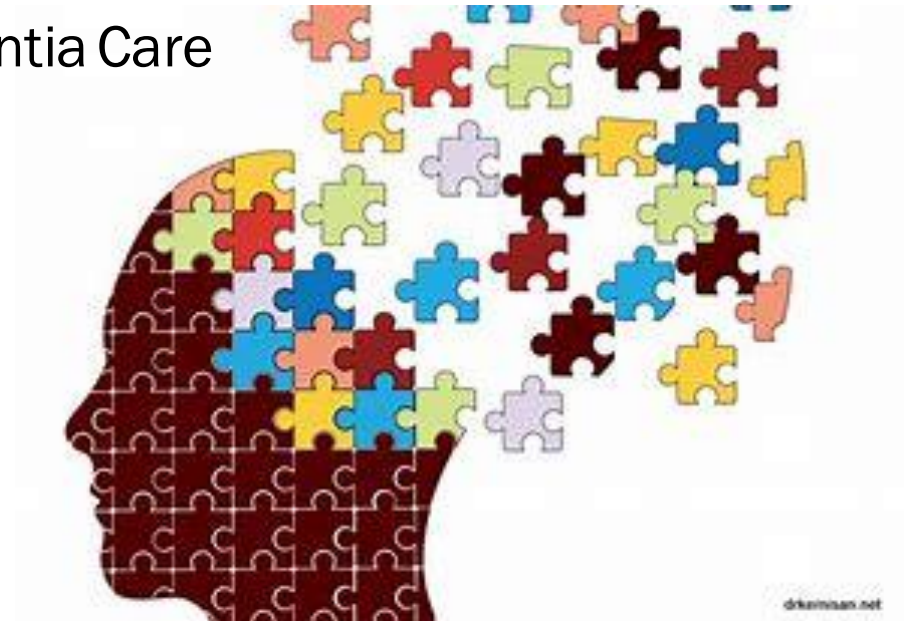
- Makes decisions and advances innovations based on medical evidence, data, and common sense
- Delivers a seamless experience that is uniquely tailored to each individual and family
- Restores the joy of delivering healthcare

# Memory Care & Support Program



# Objectives

1. Identify Signs and Symptoms of Dementia
2. What are Risk Factors and Predictors for Dementia?
3. How Do We Assess Cognition & Function?
4. Identify Behavioral Changes in Dementia
5. Practical Guidelines & Caregiver Strategies for Dementia Care
6. Treatment and Prevention of Dementia



# Overview of Dementia Impact

- *5.7 million Americans living with Alzheimer's dementia*
- *Dementia is the 5th leading cause of death among adults aged 65 years or older*
- *2/3 of Americans with Alzheimer's are Women*
- *Ethnicity: African Americans & Hispanics > Whites*
- *Costs \$277 billion, \$186 billion to Medicare and Medicaid*
- *Dementia costs exceeds the total cost of care for cancer and heart failure combined.*
- *Friends and family of people with dementia provided an estimated 17.9 billion hours of unpaid care worth half a trillion dollars*
- *Dementia patient's hospital stays are 44% longer than other older adults.*
- *The greatest cost to family members and caregivers is not financial but emotional.*
- *60% of dementia caregivers rate the emotional stress of caregiving as high or very high.*
- *40% of dementia caregivers suffer from depression*

# Mild Cognitive Impairment

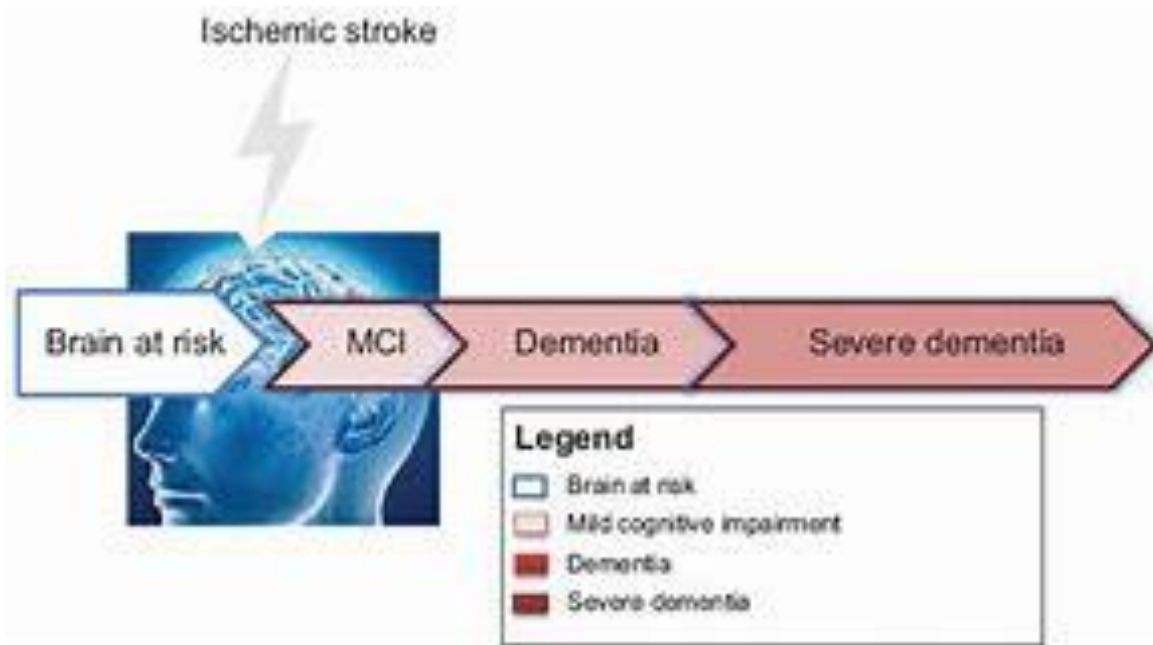


Figure 1 VCI spectrum and dementia.

Abbreviations: VCI, vascular cognitive impairment; MCI, mild cognitive impairment.

Mild cognitive impairment (MCI) is generally defined by the presence of memory difficulty and objective memory impairment but preserved ability to function in daily life. Patients with MCI are at increased risk of dementia.

Also referred as Pre-Dementia.

# Dementia Definition

**Dementia** is a disorder that is characterized by impairment of **cognition**, typically involving memory and at least one other cognitive domain (language, visuospatial, executive function). These must represent a **decline from previous level of function** and be severe enough **to interfere with daily function** and independence

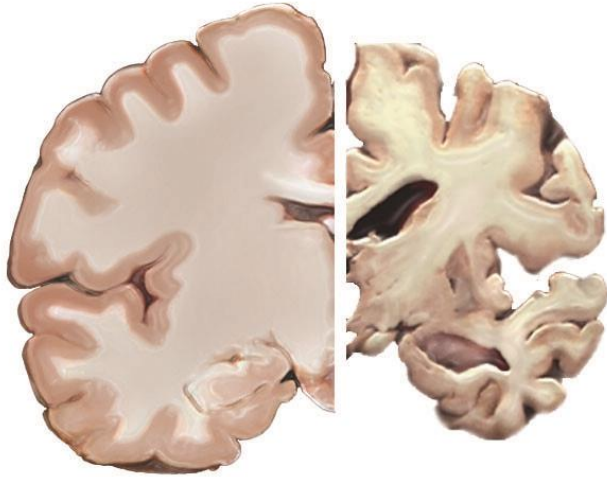
- Decline in memory or other thinking skills
- Old memories vs new memories



# DSM Criteria

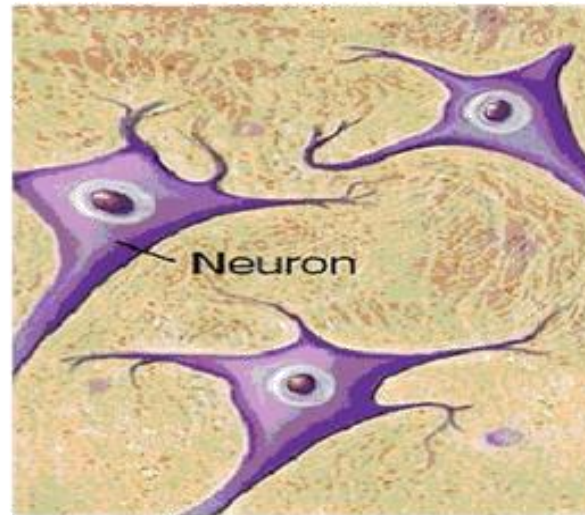
DSM-IV criteria for dementia	DSM-5 criteria for major neurocognitive disorder (previously dementia)
<p><b>A1.</b> Memory impairment</p> <p><b>A2.</b> At least one of the following:</p> <ul style="list-style-type: none"> <li>- Aphasia</li> <li>- Apraxia: difficulty with the motor planning to perform tasks or movements</li> <li>- Agnosia: loss of ability to recognize objects, persons, sounds, shapes, or smells</li> <li>- Disturbance in executive functioning</li> </ul>	<p><b>A.</b> Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains*:</p> <ul style="list-style-type: none"> <li>- Learning and memory</li> <li>- Language</li> <li>- Executive function</li> <li>- Complex attention</li> <li>- Perceptual-motor</li> <li>- Social cognition</li> </ul>
<p><b>B.</b> The cognitive deficits in A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning</p>	<p><b>B.</b> The cognitive deficits interfere with independence in everyday activities. At a minimum, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications.</p>
<p><b>C.</b> The cognitive deficits do not occur exclusively during the course of delirium</p>	<p><b>C.</b> The cognitive deficits do not occur exclusively in the context of a delirium</p>
	<p><b>D.</b> The cognitive deficits are not better explained by another mental disorder (eg, major depressive disorder, schizophrenia)</p>

Healthy Brain      Severe AD

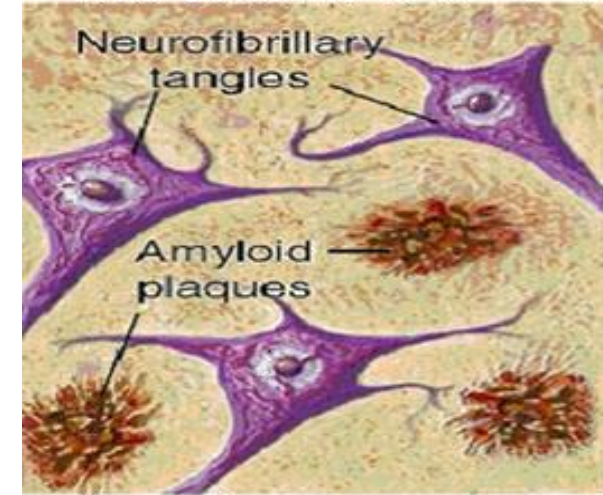


1. Neuritic plaque= amyloid protein core surrounded by astrocytes, microglia dystrophic neurites
2. Neurofibrillary tangles= in cell body of neuron, paired helical filaments of abnormal phosphorylated **tau protein**
3. Loss neurons/dendrites in **hippocampus**, nucleus basalis (decrease Ach), locus ceruleus (decrease NE), raphe nuclei (low 5 HT), B Amyloid protein cause cell death, inflammation, **neurofibrillary tangles & amyloid plaques.**

Normal



Alzheimer's



# Types of Dementia

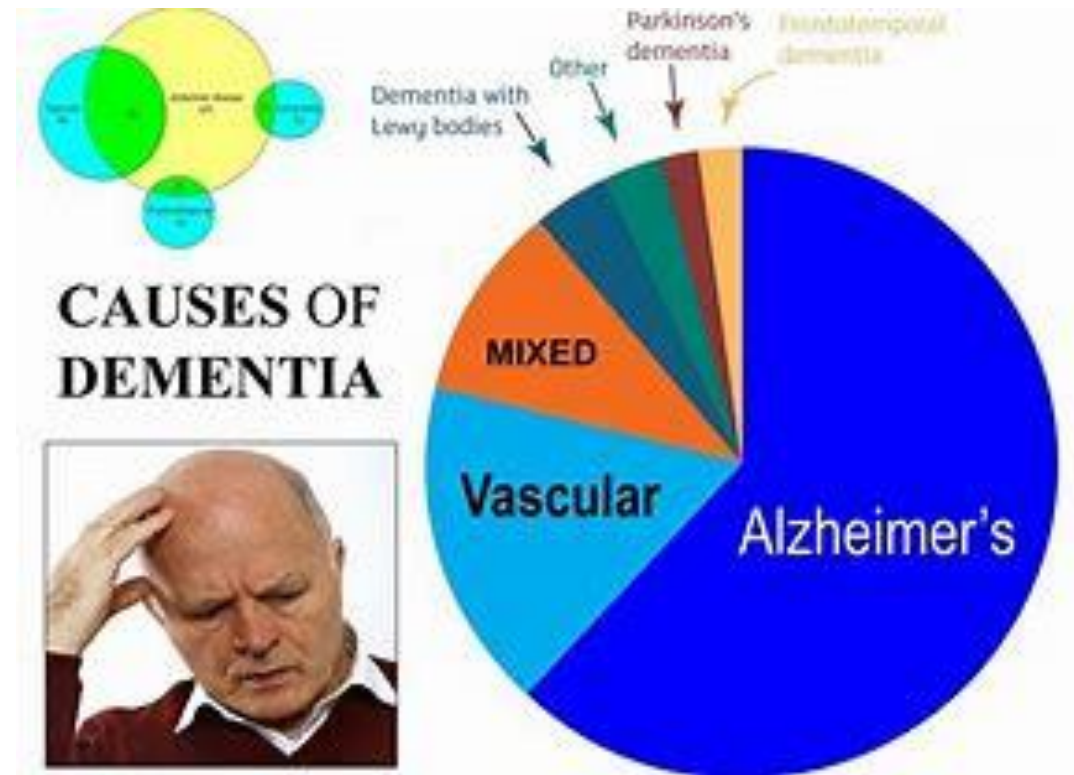
## ■ Alzheimer's Disease

- 60-80% of dementia cases
- More than 5 million people diagnosed
- Plaques are formed in the brain

## ■ Vascular Dementia

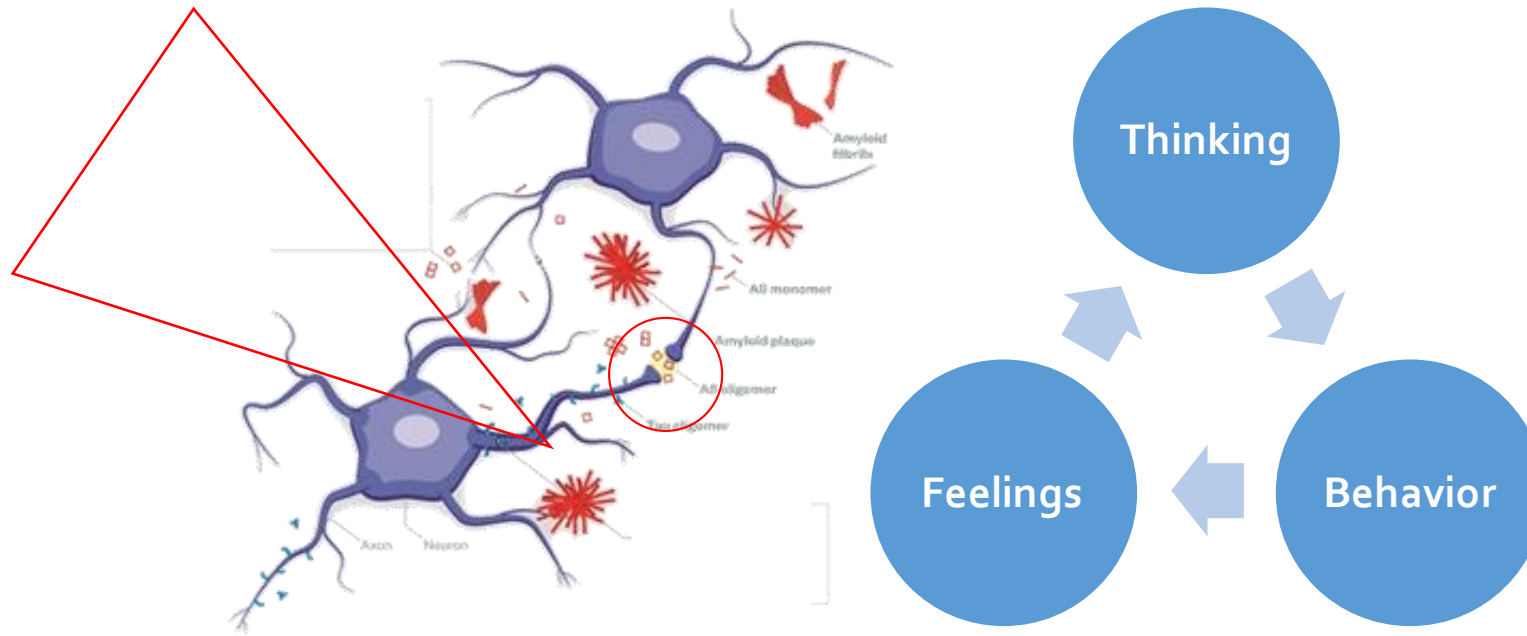
- 10-15% of dementia cases
- Blockages in blood vessels to brain (diabetes, hypertension, aging process, stroke)

## ■ 5-10% other types of dementia



# Causes

- Damage or death of brain cells
- Damage interferes with the ability of brain cells to communicate with each other



# Changes

## **Cognitive and sensory changes:**

Memory loss, generally noticed by the near and dear ones  
Difficulty in communication, especially finding the right words to communicate  
Reduced ability to organize, plan, reason, or solve problems  
Difficulty handling complex tasks  
Confusion and disorientation  
Difficulty with coordination and motor functions  
Loss of or reduced visual perception  
Metallic taste in mouth, decreased sense of smell  
Agnosia (inability to interpret sensations and hence to recognize things)

## **Psychological changes:**

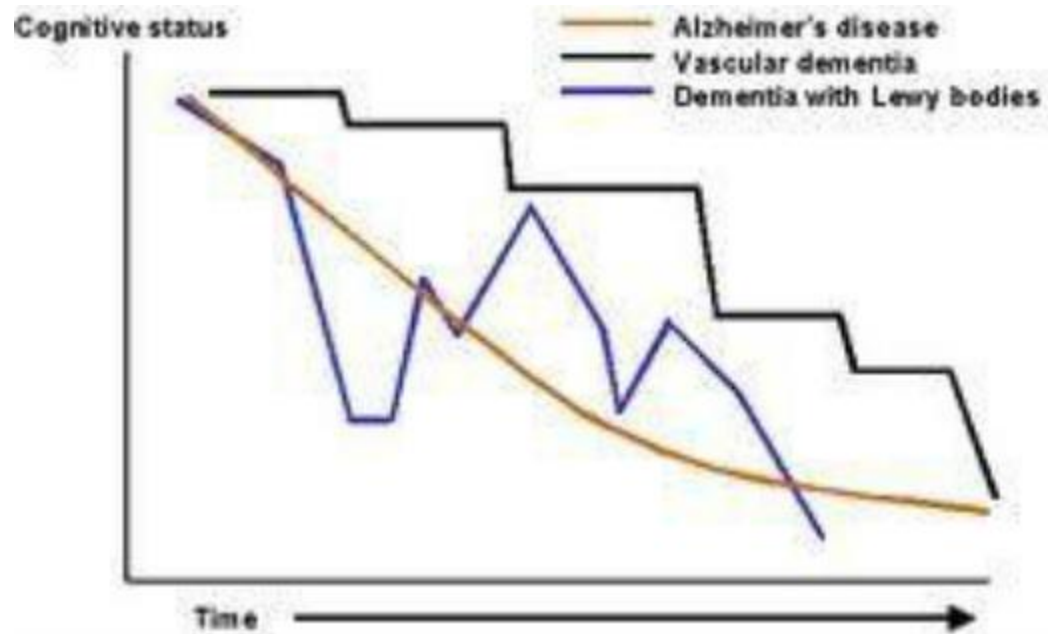
Changes in personality and behavior  
Depression  
Anxiety  
Hallucinations  
Mood swings  
Agitation  
Apathy



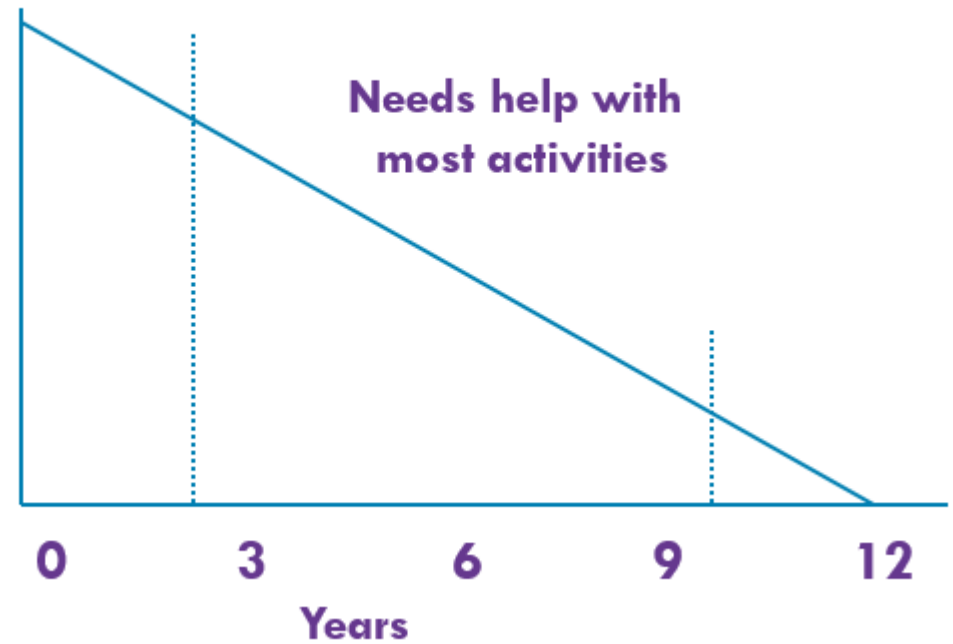
# Patients with dementia may have difficulty with one or more of the following

- Retaining new information (eg, trouble remembering events)
- Handling complex tasks (eg, balancing a checkbook)
- Reasoning (eg, unable to cope with unexpected events)
- Spatial ability and orientation (eg, getting lost in familiar places)
- Language (eg, word finding)
- Behavior (agitation, anxiety)

# Progression of Cognition



## Changes in memory & behavior



# Risk for Dementia

- Increasing **age** is the strongest known risk factor for cognitive impairment: 5% (>65 yo); 35-50% (>85 yo). Increases **exponentially with each decade**
- Cardiovascular risk factors (such as **diabetes, tobacco use, hypercholesterolemia, and hypertension**)
- Headtrauma, learning disabilities (such as the Down syndrome), depression, alcohol abuse, physical frailty, low education level.
- Other medical conditions that might increase the risk of dementia include atrial fibrillation, excessive alcohol, chronic kidney disease and other medical illnesses, depression, head trauma, hearing loss, exposure to certain medications and toxins, and obstructive sleep apnea (OSA)
- **Low educational attainment, physical inactivity, and social isolation** are associated with increased risk for cognitive decline and dementia. **Social Determinants of Health(SDOH)**
- Low social support and having never been married.



# Predictors of Dementia

- **Diagnosis was missed in 20% of demented or delirious patients** on a general medical ward, while 20% of non-demented patients were misjudged as demented
- **Informant-reported memory loss is a much better predictor** of the current presence and future development of dementia
- **Aging was associated with decline in learning of new information** but not in memory retention
- The US Preventive Services Task Force (USPSTF) has concluded that there is **insufficient evidence to recommend for or against routine screening for dementia in older adults.**
- Pretest probability of dementia in an older person with **reported memory loss is estimated to be at least 60%**



\* Social Determinants of Dementia and Caregivers' Perspectives in the Field Practice Villages of Rural Health Training Centre, Thiruvannainallur: J Gurukartick, Amol R Dongre, and Dharav Shah

# Study

- This study was undertaken in the field practice area of 55 villages of three Primary Health Centres in Villupuram District of Tamil Nadu
- India is amidst a demographic transition with a growing trend toward an ageing population. The aging population (aged  $\geq 60$  years) has been estimated to double-up from 8% in the year 2010 to 19% in the year 2050. Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consequently, the person loses his ability to perform even everyday activities and develops various behavioral problems. It cripples not only the people who have it, but also overwhelms their caregivers and families.
- Rising age, male sex, better socioeconomic status, and lack of previous involvement of the old person in the family decision were the social determinants of dementia.
- Sociocultural factors like cognitively stimulating activities, active socialization, and living in joint families were protective against dementia.

# Genetic Factors

- Genetic risk factors for dementia are studied best in AD. Early detection mutations in genes that alter amyloid-beta ( $A\beta$ ) protein production, aggregation, or clearance, including amyloid precursor protein (*APP*), presenilin 1 (*PSEN1*), and presenilin 2 (*PSEN2*).
- late-onset AD is more complex, with susceptibility likely conferred by a variety of more common but less penetrant genetic factors such as apolipoprotein E (*APOE*) alleles interacting with environmental and epigenetic influences. The genetic basis of AD is discussed in detail separately. (See ["Genetics of Alzheimer disease"](#).)
- A family history of dementia is commonly present in patients with frontotemporal dementia (FTD) as well. Mutations in genes such as *C9ORF72*, *MAPT*, and *GRN* together explain approximately 15 percent of familial FTD
- A family history of dementia is commonly present in patients with frontotemporal dementia (FTD) as well. Mutations in genes such as *C9ORF72*, *MAPT*, and *GRN* together explain approximately 15 percent of familial FTD

- Researchers from the National Institute on Aging, who presented the study at the Society for Neuroscience conference in Washington, D.C., gathered blood samples from 174 participants. Of the 174 participants, 70 had Alzheimer's, 20 had diabetes and 84 were healthy. They found that the participants who had Alzheimer's had higher amounts of the inactive form of IRS-1 and lower amounts of the active form than those adults who were healthy.
- University of Otago has also revealed another blood marker that could help diagnose Alzheimer's through a simple blood test. Researchers found that participants with a small number of molecules found in the blood and brain called microRNAs can correctly detect Alzheimer's with 86% accuracy.
- A team of researchers from Washington University in St. Louis and the German Center for Neurodegenerative Diseases in Tübingen found that a simple blood test that evaluates changes in neurofilament light chain protein levels can detect early signs of brain changes from Alzheimer's before symptoms occur.

It has not been approved by the FDA to diagnose or predict an individual's risk of Alzheimer's



# Modifiable Risk Factors

- The Lancet Commission estimates that approximately 35 percent of dementia cases are attributable to a combination of nine potentially modifiable risk factors [1]:
- Low educational attainment
- Midlife hypertension
- Midlife obesity
- Hearing loss
- Late-life depression
- Diabetes
- Physical inactivity
- Smoking
- Social isolation



Among 4761 participants having sustained hypertension throughout one's mid-40s to mid-60s and late-life hypotension, compared with midlife and late-life normal BP, were associated with increased risk of dementia later in life, compared with those with normal blood pressure, researchers report August 13 in JAMA, 2019.



# Association Between Patient Cognitive and Functional Status and Medicare Total Annual Cost of Care(TACC)

Kenton J. Johnston, PhD; HefeiWen, PhD; Jason M. Hockenberry, PhD; Karen E. Joynt Maddox, MD, MPH

JAMA Intern Med. Published online September 17, 2018. doi:10.1001/jamainternmed.2018.4143

- Findings This observational study of data from the Medicare Current Beneficiary Survey and Area Health Resources File found that patient depression, dementia, limitations in activities of daily living, and residence in areas of mental health care shortage or high unemployment were associated with substantially higher TACC.
- The mean TACC was \$9,117. Those with higher than mean TACC included beneficiaries with depression (\$14,436), dementia (\$18,311), and difficulty daily living (ADLs, \$19,113) or instrumental ADLs (\$17,443).

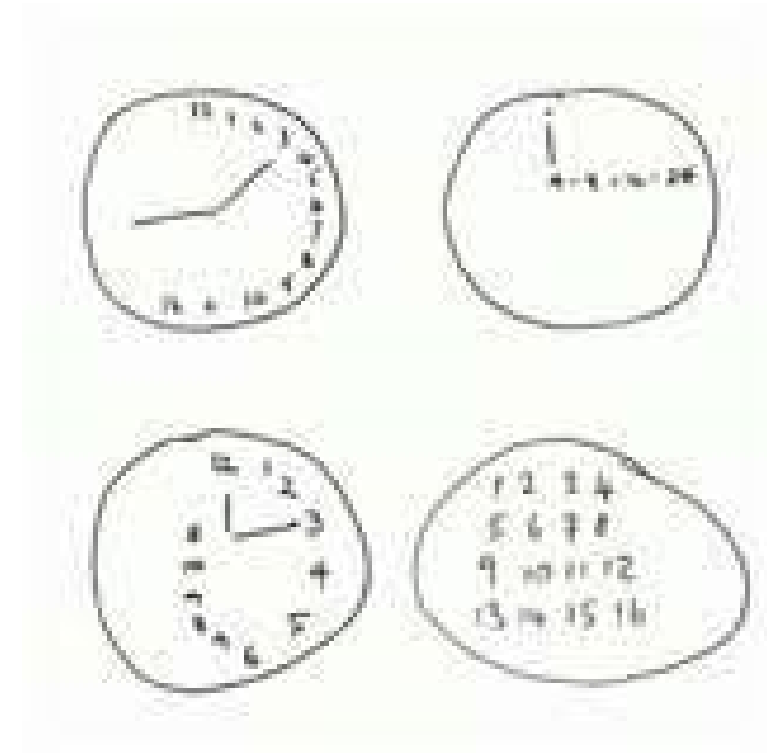
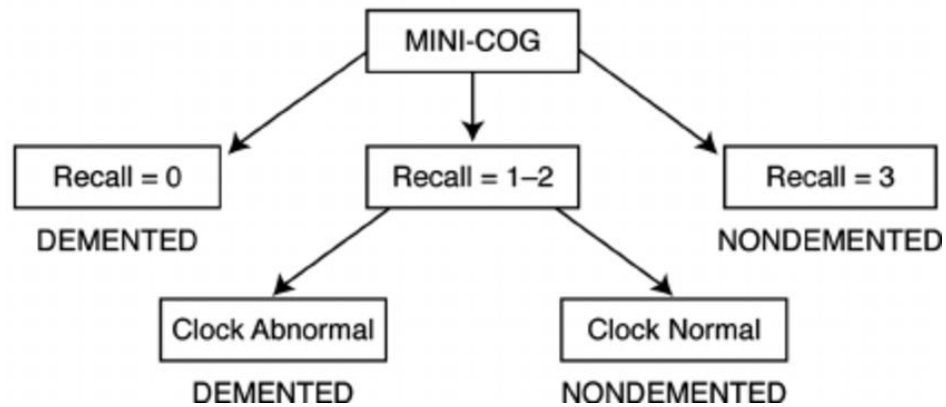


# Screening Instrument

- Depressive patients: "I just can't do this", while those with dementia often try hard but respond with incorrect answers
- Delirious patients have fluctuations in their level of consciousness and have difficulty maintaining attention and concentration
- Screening tests for cognitive impairment in the clinical setting generally include asking patients to perform a series of tasks that assess 1 or more cognitive domains (memory, attention, language, and visuospatial or executive functioning).
- The most widely studied instrument is the Mini-Mental State Examination.
- Other instruments with more limited evidence include the Clock Drawing Test, Mini-Cog Test, Memory Impairment Screen,
- Abbreviated Mental Test, Short Portable Mental Status Questionnaire, Free and Cued Selective Reminding Test, 7-Minute
- Screen, Telephone Interview for Cognitive Status, and Informant Questionnaire on Cognitive Decline in the Elderly.

# How Do We Assess Cognition?

The Mini-Cog scoring algorithm. The Mini-Cog uses a three-item recall test for memory and the intuitive clock-drawing test. The latter serves as an "informative distractor," helping to clarify scores when the memory recall score is intermediate.



\*Aging was associated with decline in learning of new information but not in **memory retention**

# AD8

- Sensitivity > 84%
- Specificity > 80%
- 0 – 1: Normal cognition
- >2 : Cognitive impairment is likely to be present

AD8 has proved more useful than the MMSE in picking out patients with the very earliest signs of cognitive impairment

It is preferable to administer the AD8 to an informant (caregiver/family). Informant-reported memory loss is a much better predictor of the current presence and future development of dementia

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. <b>Daily</b> problems with thinking and/or memory			

## Caregiver Tip Sheets

# Communication



### WHY DOES THIS HAPPEN?

*People with Alzheimer's or dementia might have changes in their brains that cause them to:*

- have a tough time finding the right word
- lose their train of thought
- have problems following a conversation
- not be able to understand what you are saying

People with Alzheimer's or dementia can lose their ability to speak clearly and understand what you are saying. This can be frustrating both for the person with Alzheimer's and for you.

### WHAT CAN YOU DO?

#### USE SHORT SENTENCES & SIMPLE WORDS

- give short, one sentence answers
- offer one step directions
- slowly repeat instructions or sentences if not understood the first time
- be patient and positive, even when it takes a long time to answer
- try not to remind them that they forgot or already told you something
- ask a question and offer a simple choice of answers such as "What do you want for dinner? Fish or chicken?"
- ask questions that can be answered with yes or no
- try not to use "baby talk" or a "baby voice"
- avoid negative words. Instead of "Don't go out that door!" try "Let's go this way!" and gently guide the person away

#### FOCUS THEIR ATTENTION ON YOU

- get on their eye level
- call the person by name
- remove distractions — turn off TV, go to a quiet room
- pay attention to your tone, how loudly you are speaking and your body language — which often "speak" louder than words
- be an active listener — make eye contact, nod your head

- speak only in their native or first language



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#### OTHER IDEAS TO TRY

- put up signs or pictures to explain what is in the room or cabinet
- have the person's hearing tested to make sure they can hear
- use a chalk or white board to write the schedule for the day or the answers to frequently asked questions
- respond to the person's feelings or emotions, not only to words
- if conversation is hard but you want to do something together, try listening to music or looking at old family photos

<https://www.alzheimersla.org/caregiver-tip-sheets/>

# How Do We Assess Function?

Edmonton Frail Scale				
Functional performance	I would like you to sit in this chair with your back and arms resting. Then when I say 'GO', please stand up and walk at a safe and comfortable pace to the mark on the floor (approximately 3 m away), return to the chair and sit down	0 - 10 s	11 - 20 s	One of: > 20s, or patient unwilling, or requires assistance



Functional abilities have been related to **cognition**, specifically to detriment of instrumental activities of daily living (IADL) which are more associated with cognitive decline. The IADL dysfunction is easier to recognize by the family and sometimes easier to evaluate by a non-specialized clinician

## Activities of Daily Living

Activities of Daily Living (ADLs)	Instrumental Activities of Daily Living (IADLs)
Bathing	Grocery shopping
Dressing	Laundry
Eating	Preparing meals
Using the toilet	Housework
Transferring	Managing medication
Continence	Transportation

# Functional Assessment

Let's talk  
about  
dementia



## I. Functional Assessment Staging (FAST)

Stage	
1	No objective or subjective difficulties
2	Subjective complaints of forgetting
3	Decreased job functioning evident to coworkers; difficulty traveling to new locations
4	Decreased ability performing complex tasks, eg, planning dinner for guests, handling finances
5	Requires assistance to choose proper clothes for day, season, or occasion
6a	Cannot dress without assistance; occasionally or more frequently
6b	Cannot bathe without assistance; occasionally or more frequently
6c	Cannot toilet without assistance; occasionally or more frequently
6d	Incontinent of urine; occasionally or frequently
6e	Incontinent of bowel; occasionally or frequently
7a	Speech limited to fewer than six intelligible words during an average day
7b	Speech limited to single intelligible word during an average day
7c	Unable to ambulate independently
7d	Cannot sit up independently
7e	Cannot smile
7f	Cannot hold head up independently

# MMSE

- 30 questions pts; 10 pts for orientation(day of the week, month, date, year, season, location, city, county, state); Registration/Recall (3 items recall); Attention(count backward from 100 by 7); Language(Naming, repetition, command, reading, writing, copy)
- Cognitive impairment & MMSE Score out of 30:
  - Normal cognition(>24 points)
  - Mild (19–23 points)
  - Moderate (10–18 points)
  - Severe (≤9 points)

## The Mini-Mental State Exam

Patient \_\_\_\_\_ Examiner \_\_\_\_\_ Date \_\_\_\_\_

Maximum	Score
5	( )
5	( )
3	( )
5	( )
3	( )
2	( )
1	( )
3	( )
1	( )
1	( )
1	( )

### Orientation

What is the (year) (season) (date) (day) (month)?  
Where are we (state) (country) (town) (hospital) (floor)?

### Registration

Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record.  
Trials \_\_\_\_\_

### Attention and Calculation

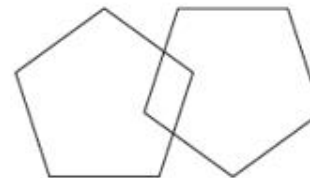
Serial 7's. 1 point for each correct answer. Stop after 5 answers. Alternatively spell "world" backward.

### Recall

Ask for the 3 objects repeated above. Give 1 point for each correct answer.

### Language

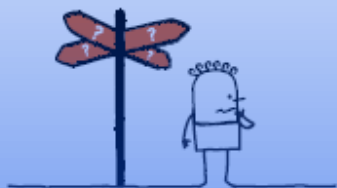
Name a pencil and watch.  
Repeat the following "No ifs, ands, or buts"  
Follow a 3-stage command:  
"Take a paper in your hand, fold it in half, and put it on the floor."  
Read and obey the following: CLOSE YOUR EYES  
Write a sentence.  
Copy the design shown.



\_\_\_\_\_ Total Score

ASSESS level of consciousness along a continuum \_\_\_\_\_  
Alert Drowsy Stupor Coma

# Getting Lost



People with Alzheimer's disease or dementia can get lost outside of their home. Sometimes they wander away in a public place. They may go for a walk or to the store and not be able to find their way home. They may not remember their address or phone number.

Getting lost is scary and can be dangerous.

## WHY DOES THIS HAPPEN?

*People with Alzheimer's or dementia might:*

- be confused... mainly in the afternoon or evening
- feel fearful... home may not seem the same
- try to go somewhere they used to go often — work, church, etc.
- attempt to get away from noise or too much activity
- be bored — not having anything to do
- have a reaction to a new medicine


## WHAT CAN YOU DO?

### BE PREPARED

- get a MedicAlert® bracelet for your person with dementia
- sew or write his or her name and your phone number onto clothes
- don't leave him or her alone near an unlocked door
- ask your neighbors to keep an eye out and tell you if they see your person with dementia outside alone or walking away from home
- help him or her exercise during the day... take a walk or dance to music
- put away purses, coats, keys, sunglasses... things that might make your person think about leaving
- close the curtains so he or she doesn't think about going out

### MAKE HOME A SAFE PLACE

- put child-proof locks on doors, gates, and windows
- place locks very high or low so your person with dementia can't see or reach the locks
- place a bell on doors, gates, or windows so you know if they are opened

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### BE COMFORTING

- offer food or do something that will take his or her mind off wanting to leave
- ask for help... folding clothes, making dinner, etc.
- sit quietly with him or her... listen to music or watch a TV show

<https://www.alzheimersla.org/caregiver-tip-sheets/>

# Behavioral Changes

## Neuropsychiatric symptoms of dementia

Delusions
Hallucinations
Depression
Anxiety
Euphoria
Aggression
Apathy
Irritability
Disinhibition
Wandering or pacing
Sleep disturbances



### Depression score ranges:

- 5 to 9: mild
- 10 to 14: moderate
- 15 to 19: moderately severe
- ≥20: severe

PATIENT HEALTH QUESTIONNAIRE - 9				
Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems?	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 hopeless	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 in some way	0	1	2	3
<b>FOR OFFICE CODING</b> 0 + _____ + _____ + _____ =Total Score: _____				
If you checked off <b>any</b> problems, how <b>difficult</b> 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 <input type="checkbox"/>	Somewhat difficult <input type="checkbox"/>	Very difficult <input type="checkbox"/>	Extremely difficult <input type="checkbox"/>	
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# Depression Screening

# Sundowning



Sundowning, or sundown syndrome, is a neurological phenomenon associated with increased confusion and restlessness in patients with delirium or some form of dementia.

It's also known as "late-day confusion."

Behavioral deterioration seen in the evening hours, typically in demented, institutionalized patients.

Research shows that 20–45% of Alzheimer's patients will experience some sort of sundowning confusion.

Impaired circadian regulation or nocturnal factors in the institutional environment (eg, shift changes, noise, reduced staffing).

# Sundowning



## WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- more tired in the late afternoon
- confused by changing amounts of light

People with Alzheimer's or dementia may become more confused or nervous later in the day, often as the sun sets. This is called sundowning. They may see or hear things that are not there. They may accuse people of things that are not true, like stealing or lying, and may pace or walk back and forth. This is not done on purpose, and people with dementia cannot control it.

## WHAT CAN YOU DO?

### MAKE CHANGES AT HOME

- turn lights on early in the afternoon to make the house brighter
- turn down (or turn off) the television or radio
- turn on soothing music
- avoid loud or confusing noises
- clear a path for the person to walk back and forth

### PAY ATTENTION TO MEALS AND SNACKS

- provide a large meal at lunch and a light meal at dinner
- allow less caffeine, sugar, coffee, tea, and soda after 3PM
- remove access to alcohol and cigarettes

- scared by shadows
- reacting to your feelings of being tired

### KEEP A SCHEDULE

- make going to bed and waking up at the same time every day
- take walks or dance to use up extra energy
- plan doctor visits, outings, baths in the morning

### OTHER IDEAS

- be calm and reassuring
- be flexible... if one idea doesn't work, try another
- comfort her and say or do something to calm her fears
- try a new activity, like sorting coins or dancing



# Nonpharmacologic Therapies

Caregivers should be counseled in strategies involving **distraction and redirection**, structured routines, and **providing calm, reassuring responses** when patients seem anxious

## Psychosocial interventions for management of behavioral and psychotic symptoms in patients with dementia

- Routine activity.
- Separate the person from what seems to be upsetting him or her.
- Assess for the presence of pain, constipation, or other physical problem.
- Review medications, especially new medications.
- Travel with them to where they are in time.
- Don't disagree; respect the person's thoughts even if incorrect.
- Physical interaction: Maintain eye contact, get to their height level, and allow space.
- Speak slowly and calmly in a normal tone of voice. The person may not understand the words spoken, but he or she may pick up the tone of the voice behind the words and respond to that.
- Avoid finger-pointing, scolding, or threatening.
- Redirect the person to participate in an enjoyable activity or offer comfort food he or she may recognize and like.
- If you appear to be the cause of the problem, leave the room for a while.
- Validate that the person seems to be upset over something. Reassure the person that you want to help and that you love him or her.
- Avoid asking the person to do what appears to trigger an agitated or aggressive response.

# Anger, Frustration, & Fighting



## WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- be confused by:
  - new places or people
  - something they see and don't know
- become frustrated because they can't:
  - pull on a sweater
  - open a door
  - find a lost item like a purse, wallet or glasses

People with Alzheimer's or dementia can get confused, depressed, and angry. Their feelings and actions are sometimes hard for them to control.

They may hit and yell.

Don't take their words or actions personally.

Listen to what they mean, not what they are saying.

## WHAT CAN YOU DO?

### KEEP THINGS SIMPLE

- try to match tasks and what you expect with what your person can do
- keep your home quiet and calm when you can
- speak slowly and try not to say too much at one time

### MAKE A CHANGE

- offer a treat like a cookie or some ice cream
- lead your person to a different room
- offer to watch a TV show or listen to music
- ask a question about a topic your person enjoys

### BE SAFE

- remove or lock away all weapons (guns, knives, etc.)
- back away slowly if the behavior is scary
- call 911 if you are afraid for your or someone else's safety

- be frightened/scared of:
  - the shower or bath
  - a new place or person

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# Stages of Dementia



## Early Stage

The early stage of dementia can be gradual and is often overlooked or attributed to ‘senior moments’.

### Presentation

- Forgetfulness
- Losing track of the time
- Getting lost in familiar places

### Goals of Care

- Talk with patient and family about what the patient considers to be an acceptable quality of life given the reality of the diagnosis.
- Appoint health care proxy
- Help patient and family know what to expect

# Stages of Dementia

- Since dementia cannot be cured, the clinician's responsibility is to relieve suffering. In order to address suffering, both clinicians and caregivers must understand that:
- Dementia can prevent a person from expressing the cause of their distress in words
- Agitated or restless behavior is due to pain or discomfort until proven otherwise.
- Treating symptoms and providing an environment that meets the patient's needs and preferences are the most effective ways to address behaviors.
- Pain and other symptoms (such as constipation or urinary retention) may manifest as any of the following behaviors:
- Agitation
- Aggression
- Wandering
- Sleep disturbances
- Withdrawal
- Resistance to care

# Stages of Dementia



## Middle Stage

As dementia progresses, memory loss, confusion and agitation become prominent.

### Presentation

- Forgetful of recent events and people's names
- Getting lost at home
- Difficulty with communication
- Needing help with grooming, personal care
- Behavior changes (wandering, repeated questioning, agitation, anxiety)

### Goals of Care

- Encourage completion of important tasks and increased attention to relationships
- Support family to prepare for increasing personal care needs and associated out of pocket costs

# Stages of Dementia

- Example 1:

Incorporate the patient's life story in his/her care plan. For example, since Bernard knows that Martha loves Broadway musicals, he is able to make her less anxious by playing tunes from her favorite shows.



- Example 2:

Encourage caregivers to let the patient make decisions and be in control whenever possible. Arguing or fighting with the patient will not improve their behavior and will be stressful for both patient and caregiver.



Liberalized diets

Flexible meal times

Flexible wake times

Flexible bathing options



# Stages of Dementia

## Late Stage

Late in the disease progression, a patient becomes fully dependent, including loss of ability to walk, sit up, swallow, and speak.

### Presentation

- Unaware of the time and place
- Difficulty recognizing relatives and friends
- Need help with self-care
- Difficulty walking
- Behavior changes that may escalate and include aggression.

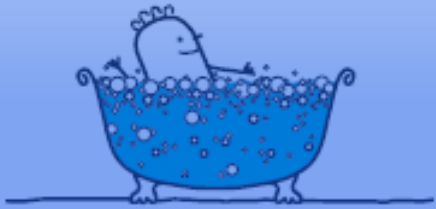


### Goals of Care

- Help family explicitly plan for a peaceful death
- Encourage completion of important tasks (saying goodbye) and increased attention to relationships
- Recommend hospice if prognosis <6m (repeated infection, hospitalizations, aspiration)

## Caregiver Tip Sheets

# Bathing



People with Alzheimer's disease or dementia may be afraid of bathing or uneasy with having someone help them with bathing. Sometimes they worry about falling or can have trouble knowing which is the hot versus the cold water faucets.

## WHAT CAN YOU DO?

### WHY DOES THIS HAPPEN?

*People with Alzheimer's or dementia might:*

- afraid of falling
- feeling uneasy getting undressed in front of you
- scared or confused
- feeling helpless

### PREPARE THE BATHROOM IN ADVANCE

- make sure the room is calm and warm
- run the water so it is not too hot or too cold
- don't use bright lights if possible

### MAKE THE BATHROOM SAFE

- use a non-slip mat in the tub or shower as a bath mat
- consider a tub seat
- fill the tub with only 4 inches of water
- remove things that may be dangerous such as razors, nail clippers, hair dryer, etc.
- watch carefully — don't leave him or her alone

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### ALLOW TIME & BE POSITIVE

- allow your person to enjoy it... if he or she finds bath time relaxing
- stay calm
- be direct... "Your bath is ready now"
- instead of "Do you want to take a bath?" give one step directions
- "Let's wash your left arm... good!, now your other one" be patient... don't rush

### BE REALISTIC

- don't argue or get frustrated... a daily bath may be too much
- consider a sponge bath instead of a tub bath
- show what you need from them... pretend to wash your arm so that he or she can copy

<https://www.alzheimersla.org/caregiver-tip-sheets/>

# Falls

Cognitively impaired patients are at high risk for falls and serious injury.

Interventions include:

- Physical assessment for orthostasis and lower extremity or back pain:
- **Look for sedating, anticholinergic medications**
- Look for drug interactions
- **Remove loose throw rugs, electrical wires, shoes, or toys from the floor.**
- Eliminate high heels and open-backed shoes.
- Ensure a clear and well-lit pathway from bed to bathroom
- Order a home occupational therapy (OT) evaluation and equipment such as grab bars in the bathroom, **elevated toilet seats**, and appropriate furniture

Supporting the Patient and Caregiver

Despite the lack of effective treatments to slow disease progression, support that is focused on aligning care with goals, knowing what to expect, and quality of life can improve all stages of the disease for individuals with



# Falls

## FIVE THINGS YOU CAN DO TO PREVENT A FALL!

- 1 Speak with your doctor to review your medications at least annually. Many medications can increase your risk for falls! Ask your personal doctor if any medicines you take can add to your risk for falls.
- 2 Make sure you get an annual eye exam and wear corrective glasses if they are recommended to you.
- 3 Talk to your doctor about vitamin D. Several studies show that taking as little as 800 to 1000 units of vitamin D3 can reduce the risk for falls.
- 4 Start a regular exercise program. Remember, the keys to success are to find a program that challenges you and you can maintain consistently. CareMore offers Nifty after Fifty fitness for older adults, or consider other exercise classes or a home exercise program recommended by a physical therapist. **A general exercise class may not help you reduce falls. Attend a fall prevention program to help with your balance, strength and flexibility.**
- 5 Review the attached Household Fall Safety Checklist and make sure you complete a survey of your home to help lower your risk of falling.



# Incontinence



Incontinence of urine is the loss of bladder control, meaning you cannot always control when you urinate. People of all ages and both sexes can have difficulty controlling the bladder, but it is more common among women and the elderly. Some find that they need to go to the toilet more often during the day and night, while others may experience regular accidents. Nearly 13 million Americans experience urine leakage at some point in their lives.

IS THERE **MORE THAN ONE TYPE**  
OF URINARY INCONTINENCE?

Most patients with Alzheimer's disease will become incontinent in late stages of the disease.

Incontinence does not occur because the patient forgets how to locate the bathroom or is unable to communicate this need; it is a consequence of progressive cortical damage.

Urinary incontinence can be managed with the use of disposable, adult-sized diapers. Diapers must be checked regularly and changed expeditiously when soiled.

In general, **indwelling catheters should not be used** to manage incontinence; they are generally not well-tolerated, increase risk of infection, and often require restraints.

- Paradigm shift is beginning to happen in nursing homes and other dementia care settings. Instead of trying to force the dementia patient to adhere to the rules and rituals of the facility, the care is structured to be responsive to the needs and preferences of the person.
- Which of the following care approaches for dementia is most effective? Patient vs Facility Center
  - A: Assuming agitation or restlessness is due to pain or discomfort
  - B: Consistent bathing schedules and structured meal times
  - C: Ruling out fecal impaction or bladder obstruction or infection as possible causes of distress.
  - D: Treating agitated or violent behavior with antipsychotics or other restraints
  - E: Sleeping late, going to bed late



Which of the following care approaches for dementia is most effective?

## Patient vs Facility Center

A: Assuming agitation or restlessness is due to pain or discomfort (**Patient Center**)

B: Consistent bathing schedules and structured meal times (**Facility Center**)

C: Ruling out fecal impaction or bladder obstruction or infection as possible causes of distress (**Patient Center**)

D: Treating agitated or violent behavior with antipsychotics or other restraints (**Facility Center**)

E: Sleeping late, going to bed late (**Patient Center**)



# THERAPIES WITH **UNPROVEN** BENEFIT

- Estrogen replacement
- NSAIDS: naproxen, hydroxychloroquine, diclofenac, rofecoxib, and aspirin
- Dietary supplements: . An 18-month randomized trial of high-dose vitamin B-complex supplementation (folate, B6, B12) in 340 patients with mild to moderate AD found no beneficial effect on cognitive measures.
- vitamin E, vitamin C, beta-carotene, and selenium, has shown no impact on cognitive change or incident dementia.
- Vitamin D
- Multivitamins
- Docosahexaenoic acid (DHA)
- Ginkgo biloba

# The Togetherness Program

- 43% of senior feel lonely on a regular basis
- Loneliness is more dangerous than Obesity and as damaging to health as smoking 15 cigarettes a day & ETOH
- 45% risks for fall, Cognitive dysfunctional, place to SNF
- 56% of seniors ask health care providers to offer programs to help manage their health
- Predictors for loneliness: loss of spouse, moving, lost of mobility, independent



## CareMore's Togetherness Program Addresses a Symptom of Living With Chronic Illness: Loneliness

Robin Caruso, MSW, LCSW

CareMore's program is a first-in-industry approach to targeting loneliness as a health condition that can be diagnosed and treated through community-based interventions and close engagement with patients.

Over the last century, America has endured numerous health epidemics affecting individuals, families, and communities: polio, diphtheria, whooping cough, measles. Each resulted in the creation of vaccines, changes in health practice, and health education campaigns to help us address the epidemic.

# TREATMENT FOR DEMENTIA

- Cholinesterase inhibitor: Donepezil(Aricept), galantamine(Razadyne), and rivastigmine(Exelon)
- Adding mamentine(Namenda) to a cholinesterase for moderate AD
- Supplementation with vitamin E (2000 international units daily): not recommended in healthy adults for the purposes of preventing dementia, it may have a modest benefit in slowing disease progression in patients with established mild to moderate Alzheimer disease
- **Drugs to Avoid:** Benzodiazepine(Lorazepam) side effects include worsening gait, potential paradoxical agitation, and possible physical dependence

# Prevention of Cognitive Decline

- Regular aerobic exercise appears to delay hippocampal atrophy in older amyloid-positive patients with amnesic mild cognitive impairment (aMCI), new research suggests.
- The single-blind, proof-of-concept study also showed that patients who were previously sedentary and who participated in an aerobic exercise program experienced improvements in memory and executive function, although they still experienced progressive overall brain atrophy and amyloid beta (A $\beta$ ) deposition.
- The study was funded by the National Institutes of Health. The authors have disclosed no relevant financial relationships.
- J Alzheimers Dis. Published online August 8, 2019. Abstract
- Music Therapy For Dementia: Awakening Memories
- Music & Memory organization through a YouTube video



# Cognitive Training from [www. Uptodate.com](http://www.Uptodate.com)

- Various cognitive interventions including memory training, the use of external memory cues, and organizational aids have shown positive short-term effects on cognition in healthy older adults, but the long-term impacts are less clear:
- The ACTIVE trial randomly assigned 2832 older adults to one of three cognitive interventions or a control group, and found that a 10-week training program in inductive reasoning (but not in verbal memory or speed of processing) resulted in improved performance on the Instrumental Activities of Daily Living that was sustained at five years. The rate of incident dementia at five years was unaffected, and longer-term follow up of the cohort is still in progress.
- The FINGER trial tested a multidomain intervention that included diet, exercise, cognitive training, and vascular risk monitoring in 1260 at-risk elderly adults. Compared with controls who were given general health advice, individuals who were randomly assigned to the intervention showed greater improvements in neuropsychological test battery scores at two years. The magnitude of benefit was relatively small, however, and longer follow up is needed to determine whether the intervention has any impact on rates of cognitive decline or dementia.
- The Multidomain Alzheimer Preventive Trial (MAPT) tested a multidomain intervention of physical activity, cognitive training, and nutritional advice with or without omega-3 fatty acid supplementation versus placebo in 1525 older adults with subjective memory complaints. At three years, there were no differences in cognitive test scores among the groups

# Prevention of Cognitive Decline

- We encourage all patients, especially those with early dementia and those with risk factors for dementia, to maintain or increase physical activity and exercise as long as there are no contraindications. Similarly, we encourage cognitive leisure activities and social interaction for as long as these are feasible. However, we recognize that these lifestyle factors remain unproven as a means of preventing dementia.
- ●Hypertension is associated with an increased risk of both vascular dementia and Alzheimer disease (AD), and treatment of hypertension is recommended to reduce the risk of cerebrovascular disease, among other benefits
- ●Mediterranean-style diets that are high in fruits, vegetables, whole grains, beans, nuts, and seeds and include olive oil as an important source of fat have been associated with a variety of health benefits, including reduced cardiovascular risk, which may directly or indirectly reduce dementia risk.
- ●Prospective studies and randomized controlled trials have not shown an overall benefit from vitamins, statins, cholinesterase inhibitors, estrogen replacement, or nonsteroidal antiinflammatory drugs (NSAIDs) for the prevention of dementia.
- ●While vitamin E is not recommended in healthy adults for the purposes of preventing dementia, it may have a modest benefit in slowing disease progression in patients with established mild to moderate Alzheimer disease.

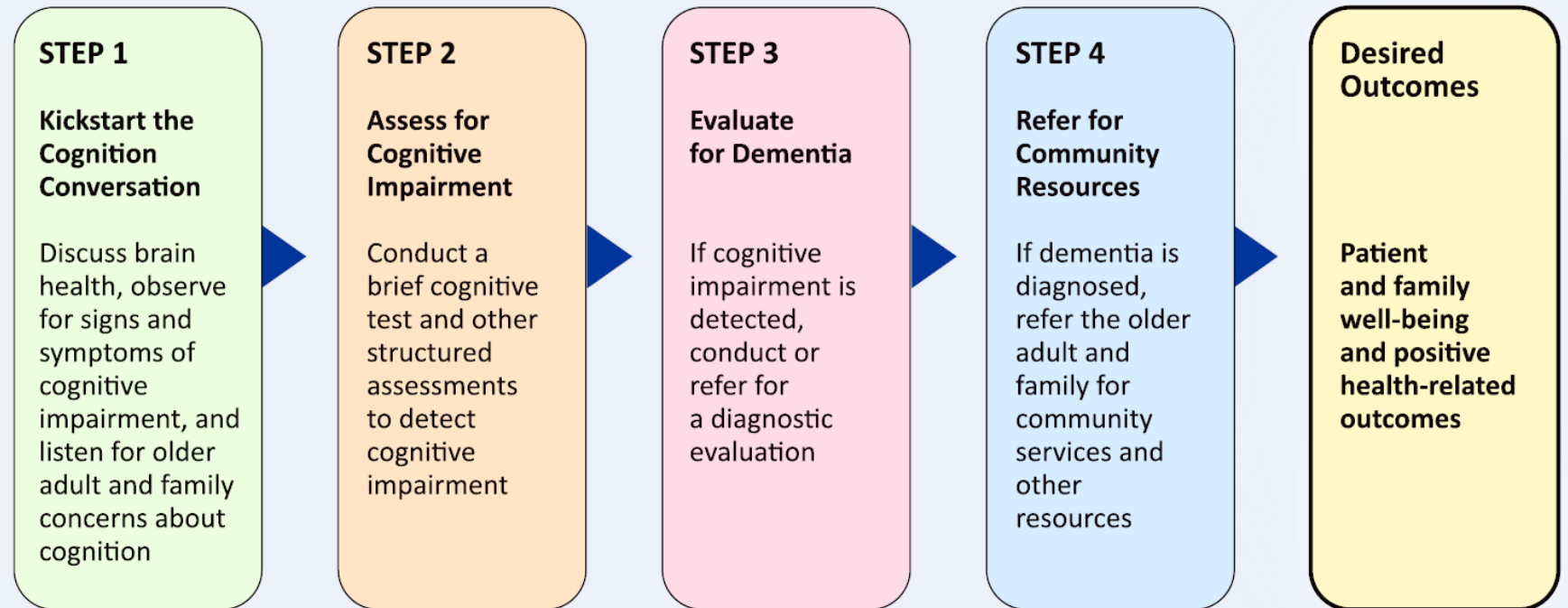
# KAER Model

(Kickstart, Assess, Evaluate, Refer) tool kit

4 step process to detecting cognitive impairment and earlier diagnosis of dementia

[www.geron.org/KAER](http://www.geron.org/KAER)

Figure 1. Steps in the KAER Model to Increase Cognitive Awareness, Detection of Cognitive Impairment, Diagnosis, and Post-Diagnostic Referrals and Medical Care



We aim to integrate dementia as part of holistic care for our members, to assess cognitive functions, to monitor disease progression , to support caregiver and family, and to collaborate dementia treatment with our clinicians and Primary Care Physician.

1. Focus on promoting health, optimizing medical conditions, reducing hospitalizations, and falls
2. Prepare family/caregiver for exigencies or crisis & burdens
3. Provide periodic outreaches to address needs & support

# Credits & References

- <https://careersmart.com/alzheimers-dementia-education/>
- [www.uptodate.com](http://www.uptodate.com)
- <https://www.alzheimersla.org/caregiver-tip-sheets/>
- \* **Social Determinants of Dementia and Caregivers' Perspectives in the Field Practice Villages of Rural Health Training Centre, Thiruvennainallur: J Gurukartick, Amol R Dongre, and Dharav Shah**



# Thank you for your attention!

Dr. John Khoa Do

Diplomate of The American Board of Internal Medicine

CAREMORE HEALTH

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