

The Dementia Leadership Course

Development. Knowledge. Practice. Networking.

Update on Dementia

Raj C. Shah, MD
Rush University Medical Center
312-563-2902
Raj_C_Shah@rush.edu





The Diagnosis of Dementia – A Practical Guide



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Raj C Shah, MD

Associate Professor, Family Medicine & Rush Alzheimer's Disease Center

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Disclosure (Presentation Specific)

I have no relevant financial disclosures related to this presentation.

I will not discuss off-label use or investigational use in my presentation.



Disclosure (Generic)

I report

- receiving grants for clinical research from National Institutes of Health; the Centers for Medicare and Medicaid Services; the Department of Defense; PCORI; PCRF, and the Illinois Department of Public Health
- being a non-compensated board member of the Alzheimer's Association -- Illinois Chapter; and,
- being the site principal investigator or sub-investigator for clinical trials for which his institution (Rush University Medical Center) is compensated [Amylyx Pharmaceuticals, Inc., Eli Lilly & Co., Inc., Genentech, Inc., Merck & Co, Inc., Navidea Biopharmaceuticals, Novartis Pharmaceuticals, Inc., Roche Holdings AG, and Takeda Development Center Americas, Inc.].

<u>Objectives</u>

- Understand the barriers associated with effective diagnosis and treatment of Alzheimer's disease and dementia
- Identify the key component of a comprehensive memory evaluation.
- Highlight treatment and research options for individuals with memory concerns and their families.



Today's Discussion Points

- What we know and do about memory loss now?
- Why we still need to know and do more about memory loss?
- How can we work together to learn and do more about memory loss?

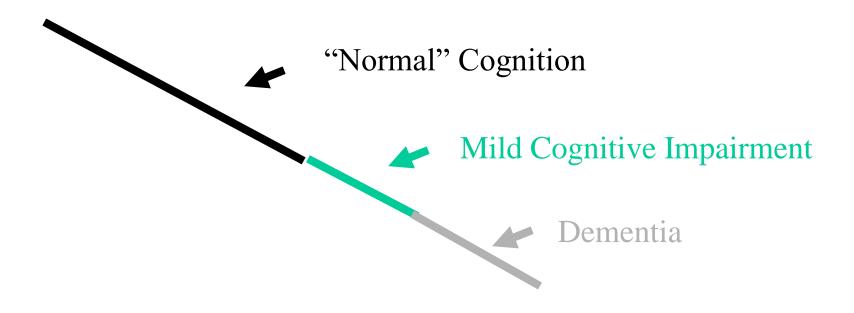
Polling Question

TRUE or FALSE:

Dementia is part of the aging process.

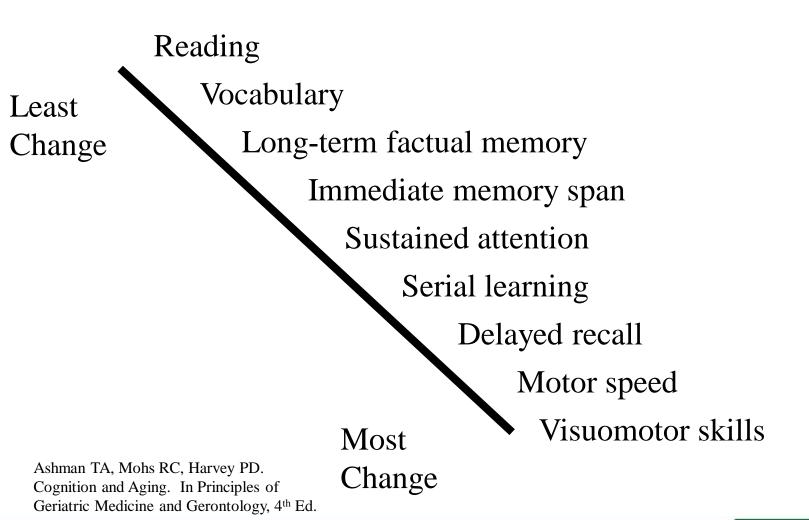
What We Know about Memory Loss?

Dementia is part of the Cognitive Spectrum





"Normal" Cognition with Aging





Mild Cognitive Impairment (MCI)

- Subjective complaint of memory difficulty
- Objective memory impairment
- Normal other cognitive function
- No functional loss
- No dementia

Petersen RC, Smith GE, Waring SC. Mild Cognitive Impairment – Clinical Characterization and Outcome. Archives of Neurology. 56: 303-308, 1999 Mar.

Polling Question

TRUE or FALSE:

Alzheimer's disease and dementia are the same thing.

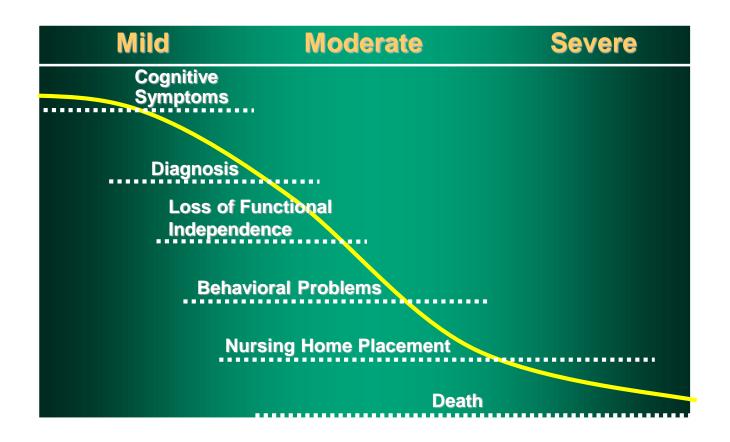


Dementia

- Chronic memory loss
- The development of multiple cognitive deficits
- The cognitive deficits cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning
- The deficits do not occur exclusively during the course of a delirium
- The disturbance is not better accounted for by another disorder

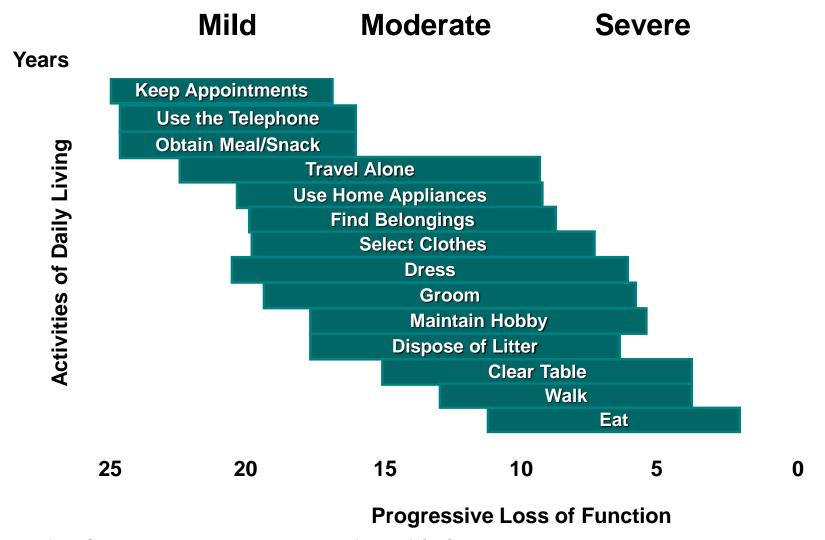


Clinical Disease Progression



Reprinted from *Clinical Diagnosis and Management of Alzheimer's Disease*, H Feldman and S Gracon; Alzheimer's Disease: symptomatic drugs under development, pages 239-259, copyright 1996, with permission from Elsevier.

Loss of Activities of Daily Living



Adapted from Galasko D, et al. Eur J Neurol. 1998;5(suppl 4):S9-S17.

Polling Question

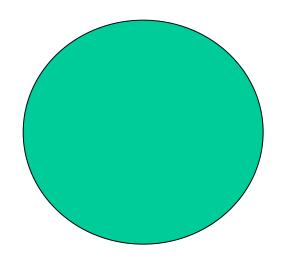
TRUE or FALSE:

The only causes of dementia are vascular, Alzheimer's disease, and Lewy Body disease.



What are the types of dementia?

Alzheimer's Disease



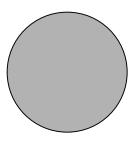
Frontotemporal Dementia



Lewy Body Dementia



Vascular Dementia



Features for Dementia Causes

- Alzheimer's Disease
 - Slow, progressive loss of short-term memory
- Vascular Dementia
 - Stepwise decline with stroke features or cardiovascular risk factors
- Lewy Body Dementia
 - Significant daily fluctuations, hallucinations, adverse reaction to antipsychotics, +/- significant parkinsonism
- Fronto-temporal Dementia
 - Significant behavioral difficulties with limited memory difficulties



Breakout: Case Example

- You have recently been promoted to the role of Dementia Manager in your community's senior care facility with over 150 residents that provides full spectrum support from independent living to palliative care. You have heard that estimates of dementia in senior care facilities can be as high as 50%. However, in your chart review of all residents, you see dementia diagnosed in 10% of the records.
- What are the barriers you are going to face understanding if a resident in your facility has developed a dementia?
- In your break-out group, spend some time highlighting the barriers at the (1) system level outside the facility, (2) at the system level inside the facility, (3) at the staff level, (4) at the family level, and (5) at the resident level. Then we will have a report back.

What We Know about Memory Loss?

- There are significant barriers for seeking diagnosis and treatment for:
 - Patients and Families
 - Health Care Providers
 - Community Service Providers
- Barriers have individual and public health consequences

Barriers to Dementia Care

- Barriers for Patients and Families
 - Lack of self-awareness of disease process
 - Fear of diagnosis
 - Stigma of "going crazy"
 - Assuming changes part of normal aging
 - Ability to access care services
 - Ability to afford diagnosis and treatment

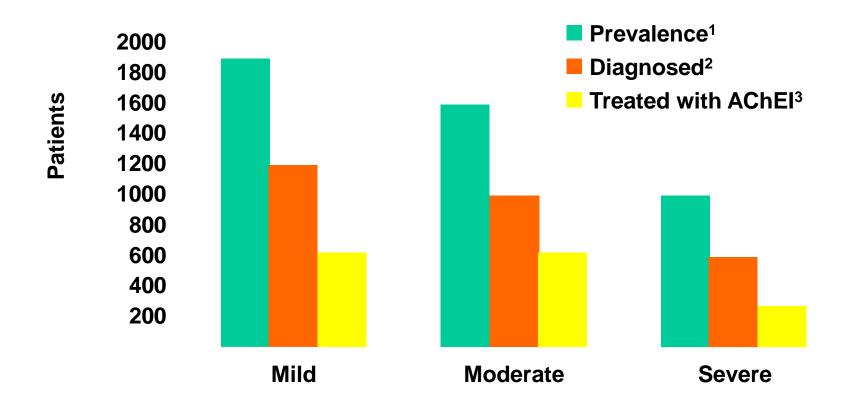
Barriers to Dementia Care

- Barriers for Health Care Providers
 - Nihilistic Attitudes
 - Difficulty Recognizing Symptoms
 - Practice Constraints

Barriers to Dementia Care

- Barriers for Community Services
 Providers
 - Lack of significant reimbursement
 - Lack of coordination of service providers

Barriers Have Consequences



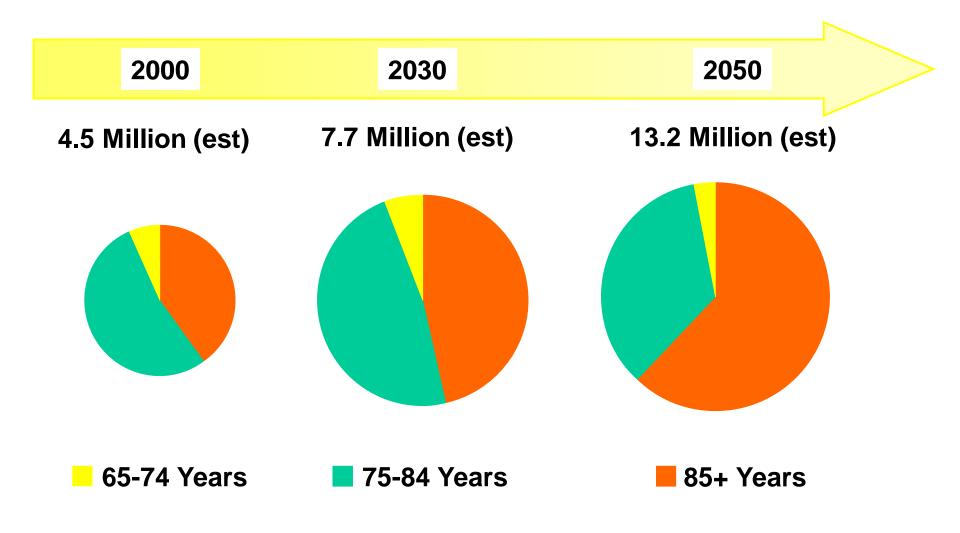
Sources: 1. Hebert LE, Scherr PA, Bienias J, et al. Arch Neurol. 2003;60:1119-1122.

- 2. Datamonitor AD Treatment Algorithms. 2002.
- 3. Market Measures. 2003.

The Problem of Memory Loss

- In 2020, an estimated 5.8 million Americans have Alzheimer's disease
- Alzheimer's disease and related disorders are the third most costly disease state behind heart disease and cancer in the United States
- Approximately \$305 billion is spent on the direct and indirect costs of care
- Hospitalization costs for an individual who has Alzheimer's disease are higher than for someone with normal memory

Why We Need to Know More?



Source: Hebert LE, et al. Arch Neurol. 2003;60:1119-1122

Polling Question

TRUE or FALSE:

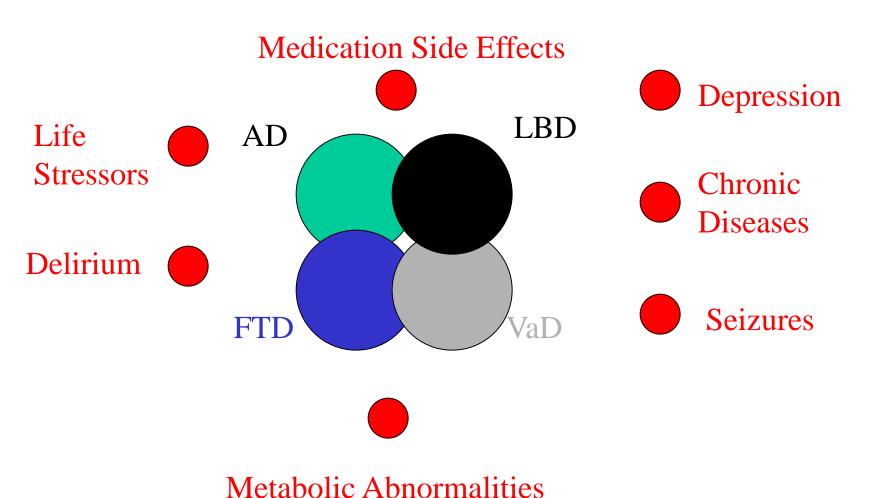
The only provider who can diagnose and treat dementia is a cognitive neurologist.

Polling Question

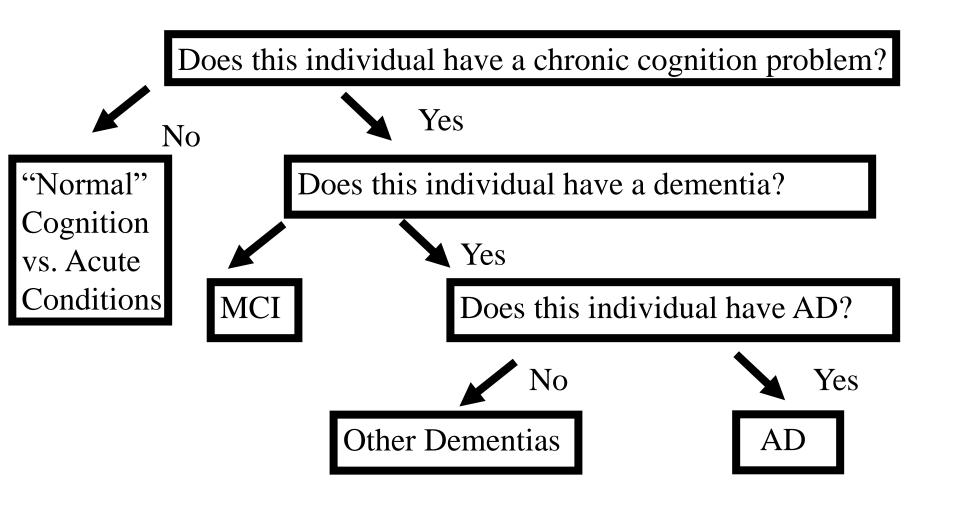
TRUE or FALSE:

There is at least one medication currently available to prevent dementia due to Alzheimer's disease.

How Do We Evaluate Memory Loss?



How Do We Evaluate Memory Loss?



The Key Evaluation Step

- Did the Health Care Provider Listen?
 - History, history, and more history
 - Need corroboration from another source & Push for timeline
 - Memory History of Present Illness
 - Memory Review of Systems
 - Depression Screening
 - Functional Assessment
 - Medication Review

Other Evaluation Steps

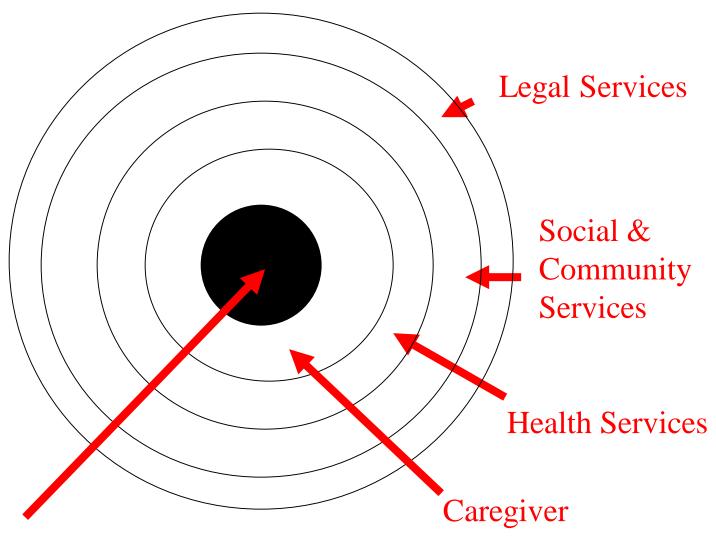
- Physical Exam
 - Vitals (Blood pressure, pulse, weight)
 - Cognitive Assessment via Testing
 - One example is Mini-Mental State Examination
 - Neurologic Exam
 - Looking for parkinsonian features
 - Looking for stroke features

Other Evaluation Steps

- Laboratory & Imaging
 - CBC, BMP, TSH, B12 (RPR as needed)
 - Imaging study (CAT scan vs MRI)
 - Looking for large strokes and masses



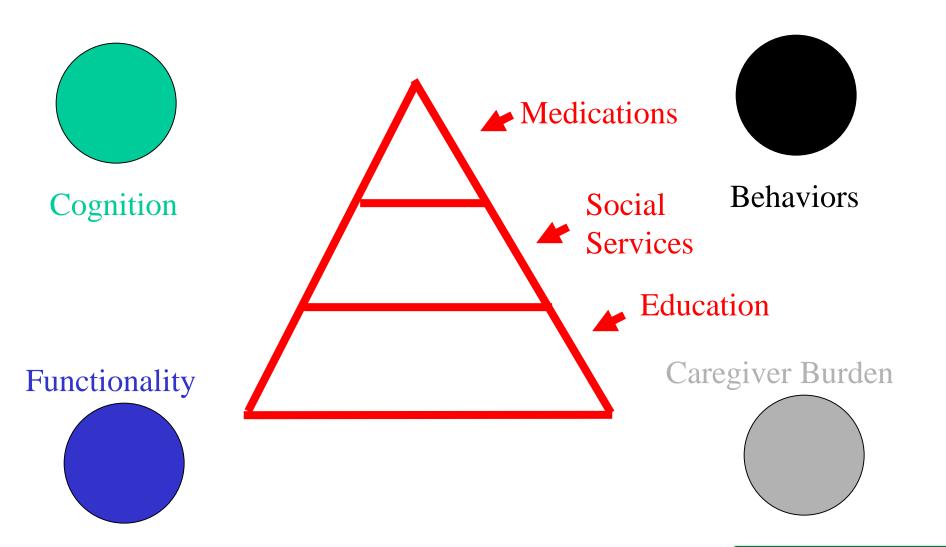
How We Treat Memory Loss



Individual with Memory Loss



How Do We Treat Memory Loss?



MCI -- Treatment

Education

 MCI is a risk factor for developing dementia (a 3 fold increased risk in 4-5 years)

Social Services

 Assist in beginning to put together a team of family providers, medical providers, physician providers, social service providers, and legal providers to manage care.

Medications

- No approved medications for MCI
- In published results of vitamin E, donepezil or placebo in MCI to prevent progression to AD
 - Donepezil showed decreased progression in first 6 months but effect between placebo, and vitamin E and donepezil equalized by end of study

Dementia -- Education

- Handling Fear and Anxiety
 - Learning about the disease
 - » ADEAR Caregiver Information (online at http:// https://www.nia.nih.gov/health/alzheimers/caregiving)
 - » Alzheimer's Early Stages by Daniel Kuhn
 - » The 36 Hour Day by NL Sage and PV Rabins
 - Taking active role to develop team of family providers, physician providers, social service providers and legal providers to help manage care.
- Slowly progressive disease
- No cures now but lots to still do
- Healthy choices are important
 - Remaining physically and mentally active
 - Controlling other medical conditions
 - Preventing polypharmacy

<u> Dementia – Social Services</u>

- Social Services
 - ADEAR (https://www.nia.nih.gov/health/alzheimers/)
 - Alzheimer's Association
 - 1-800-272-3900 or www.alz.org
 - Local Department of Aging or Senior Services
 Center
 - Helpful resources
 - Adult Day Care
 - Driving Evaluation Programs
 - Alzheimer's Association Safe Return Program
 - Caregiver Support Groups
 - Homemaker Services
 - Assisted Living Facilities & Nursing Home Facilities with special dementia units

Dementia -- Treatments

Medications

- Donepezil
 - Start at 5mg once a day and, if tolerated for one month, increase to 10mg once a day
- Rivastigmine
 - Start at 1.5mg twice a day and, if tolerated for one month, increase to 3mg twice a day. May want to keep at 3mg twice a day for 3 months before switching to 4.5mg twice a day. Again, wait three months before increasing to 6mg twice a day
- Galantamine
 - Start at 4mg twice a day and, if tolerated for one month, increase to 8mg twice a day. After one month on 8mg twice a day, increase to 12mg twice a day
- Memantine
 - Start at 5mg once a day for one week, 5mg twice a day for second week, 10mg and 5mg for third week, and 10mg twice a day for long term

Dementia -- Treatment

Other Medications

- Antipsychotics
 - Limited usefulness and only after behavioral techniques have failed to control agitation or psychosis
 - Increased risk of death in older persons
- Antidepressants
 - Occurrence of depression approximately 30% with Alzheimer's Disease
 - Choice of antidepressant dependent on side-effect profile (SSRIs most commonly used at present).

Dementia -- Treatment

Medications

- Estrogen or HRT not helpful in prevention or treatment of dementia in women
- COX-2 inhibitor therapy with Celebrex not helpful
- High dose B12, B6, folic acid not helpful
- Statins (simvastatin) not helpful
- DHA not helpful
- Multiple, multiple other dementia modifying treatments have not been shown to be effective in clinical trials.



Questions about Memory Loss

- What causes memory loss?
- What risk factors for memory loss can be modified?
- Are there markers to identify memory loss before symptoms show up?
- What brings out the symptoms associated with dementia?
- What are accelerators of dementia?
- What are better ways to provide care and reduce health disparities?

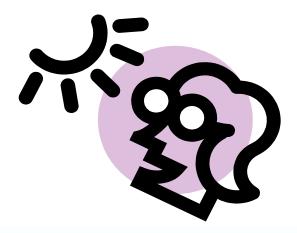
What is Research All About?

- –Alleviating Fear
- —Providing Hope
- –Clearing a Path
- –Giving Direction



Interested in Learning

- For more information
 - Visit www.alz.org (TrialMatch), or
 - Visit www.nia.nih.gov/alzheimers, or
 - Visit www.clinicaltrials.gov, or
 - Visit www.rush.edu/radc



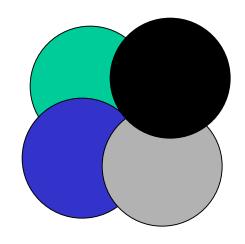
Conclusion

- Cognitive disorders are going to be increasingly common and have substantial health and social impacts.
- Diagnosing and treating cognitive disorders early will provide the most benefit.
- The treatment of individuals with cognitive disorders requires an integrated and team approach.
- Encourage all older persons along the cognitive spectrum to participate in clinical research regarding maintaining memory.



Finding Answers about Memory Loss

Communities



Persons & Families

Health Care Providers

Researchers



Dementia Friendly America/Dementia Friends





References

- https://www.nia.nih.gov/health/alzheimers
- https://www.nia.nih.gov/health/caregiving
- https://www.alz.org/alzheimersdementia/facts-figures

Contact Information

Raj Shah, MD

Associate Professor, Family Medicine and Rush Alzheimer's Disease Center

Rush University Medical Center

1750 West Harrison, Suite 1000

Chicago, IL 60612

Tel: (312) 563-2902

Fax: (312) 942-4154

E-mail: Raj_C_Shah@rush.edu

- An otherwise healthy 72 year-old woman is evaluated in your office because of forgetfulness for 4 years. Over the past year, she has been struggling to recall names of friends and relatives. She recently drove down a one-way street in the wrong direction and is no longer able to manage her own finances. She denies feelings of depression. Her mother had similar symptoms in her 70s and died in a nursing home at age 79. The patient's physical examination is notable only for a Mini-Mental State Examination score of 23/30 (including failure to recall all three items after a 5-minute delay). Routine laboratory studies are normal, and an MRI scan of the brain shows moderate diffuse cerebral atrophy.
- The diagnosis is . . .

- A 75 year-old man comes for an office visit because he is concerned about memory loss. He reports a family history of Alzheimer's disease, with dementia affecting three first-degree relatives in their 50s. His difficulties are not apparent to his spouse or close friends, and have not affected his ability to perform his daily activities. He is an active and successful financial officer. Past medical history is remarkable for treated hypertension and osteoarthritis. There is no evidence of depression. Physical examination is normal. Mental status examination discloses mild to moderate memory impairment and no abnormalities in other areas of cognition. Levels of thyroid-stimulating hormone and vitamin B12 are normal, as is magnetic resonance imaging of the brain.
- The diagnosis is . . .

- A 57-year old man with a clerical job is brought to the office by his wife for evaluation of changes in memory, personality, and behavior. Over the past 3 years, he has become progressively insensitive to his wife's concerns, to the point that she has considered separation. He makes loud, inappropriate comments in public, and recently received a poor review from his work supervisor. Past medical history is unremarkable; he takes no medications. His mother, a maternal uncle, and the maternal grandfather had dementia. Physical examination is normal. The Mini-Mental State Examination score is 28 of 30.
- The diagnosis is . . .

- A 75 year-old man is brought to the office because he is confused on a regular basis, particularly at night, and sometimes moment to moment during the day. He woke up thinking he was tied to the bed. He hallucinates that people are in the house, and sometimes believes his wife has been replaced by a look-alike. On some days he needs help with basic activities. Medical history is significant for a confusional episode due to prescription of meclizine for acute peripheral vestibulopathy 2 years earlier. Meclizine was discontinued, and at follow-up office visit 1 month later the confusion was much improved. He currently takes no medications. There is no family history of dementia or parkinsonism. Masked facies, mild bradykinesia, and rigidity are evident. His score on the Mini-Mental State Examination is 20 of 30. The remainder of the examination is normal.
- The diagnosis is . . .



- An otherwise healthy 78 year-old woman who was diagnosed with Alzhiemer's disease two years ago. She is being treated with an acetylcholinerase agent approved by the FDA for the symptomatic treatment of mild to moderate Alzheimer's disease. She has worked with her family to put together a support network of medical providers, social service providers, and legal providers to help her now and in the future. She had her family have accessed the National Institute on Aging Alzheimer's Disease Education and Referral (ADEAR) website for information about the disease and have attended support groups by the local Alzheimer's Association chapter. She and her family are asking about what else they can do.
- Options you provide are...

Risk Factors for Alzheimer's

- Age
 - Risk doubles every 10 years after age 65
- Family History
- Presence of APO ε4
 - Lifetime risk without ε4 allele is 9%. With one allele is 29%
- Gender
 - Women have relative risk of 1.2 to 1.5
- Education
- Head Trauma
- Down's Syndrome

Depression -- SIGECAPS

- S = Sadness and sleep difficulty
- I = Interest decline
- G = Guilty Feelings
- E = Energy level decline
- C = Concentration decline
- A = Appetite change
- P = Psychomotor agitation or retardation
- S = Suicidal Thoughts



Instrumental ADL

Do you need assistance with:

Transportation

Medications

Finances

Grocery shopping

Cooking

Housecleaning

Telephone use

Adapted from Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969. 9. 179-86.



Basic ADL

Do you need assistance with:

Transferring out of bed

Walking

Grooming (brushing teeth, dressing)

Toileting (maintaining continence)

Bathing

Feeding



Thank you for your participation and leadership with those living with dementia.

Join the Dementia Leadership Network at

www.DementiaLeaders.net



