Dealing with Dementia at Home: Overcoming Challenges and Being Open to Options

Elizabeth Galik, PhD, CRNP, FAANP
University of Maryland School of Nursing
galik@umaryland.edu

Objectives

- Discuss common challenges to health, safety, and quality of life for individuals with dementia who wish to remain at home.
- Describe an assessment process that can be used to help to determine the level of care for someone with dementia.
- Discuss strategies that can be used to improve in-home care or consider transitions to alternative care.

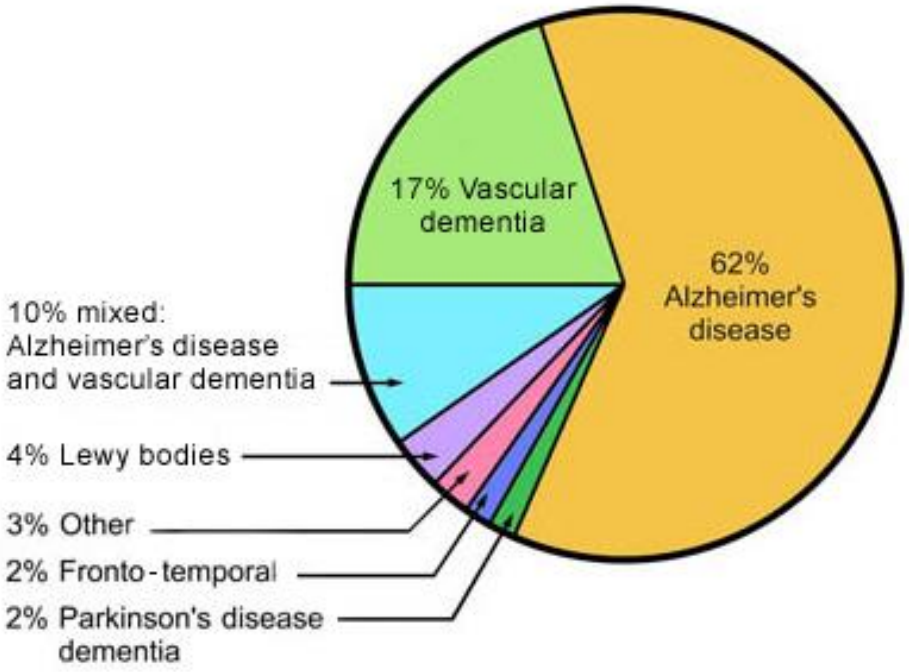
Dementia Defined

- A general term for a group of disorders characterized by at least two of the following:
  - Decline in memory (amnesia)
  - Aphasia
  - Apraxia
  - Agnosia
  - Disturbance in executive function
- Results in a loss of independent functioning
- Absence of delirium
  - DSM 5

How Common is Dementia?

- Affects 5.8 million Americans
- 6th leading cause of death in the US
- $290 billion cost annually
- 1 in 10 people over 65 years of age have AD (the most common cause of dementia)
- Age is the most significant risk factor for dementia
  - Alzheimer's Association, 2019

Causes of Dementia



Caregivers

- Family members provide 85% of unpaid help to older adults.
- Provide 18.5 billion hours of informal caregiving (22 hours of care/week/caregiver)
- 2/3rd are women
- 34% are over the age of 65
- Almost half have a household income of $50,000 or less
- 66% live with the care recipient
- Impact on physical and psychological health
  - Alzheimer's Association, 2019

What are memory symptoms or behaviors that need further evaluation?

- Memory loss that disrupts daily function
- Difficulty with planning or solving problems
- Challenges completing daily activities or tasks
- Disorientation with time and place
- Difficulty understanding visual images or spatial relationships
- New challenges in finding words or difficulty writing

Need for Further evaluation (continued)

- Decreased judgment
- Social withdrawal
- Frequently misplacing things and cannot retrace steps
- Changes in personality or mood

What are some things that could be causing these more significant changes?

- Depression
- Medication
- Vitamin and mineral deficiencies
- Infection, stroke, tumor
- Under active thyroid
- Poorly controlled blood sugar
- Hypoxia
- Acute exacerbation of heart failure
- Anemia
- Minor cognitive impairment
- Dementia

When are most people diagnosed with dementia?

Functional Assessment Staging Test

The Functional Assessment Staging Test (FAST) is the most well validated measure of the course of AD in the published, scientific literature.
The stages of Alzheimer's disease as defined by FAST are:

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0

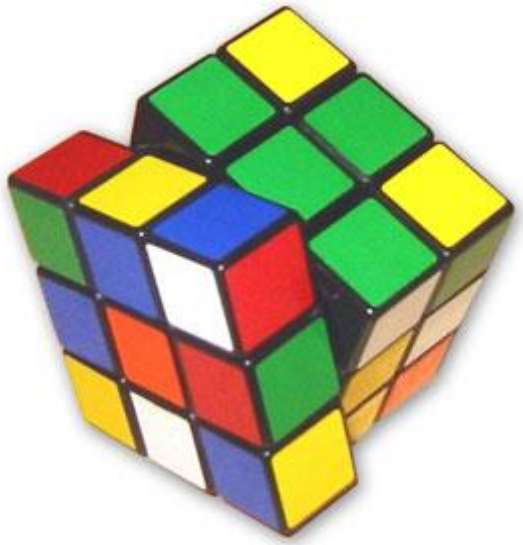
Case 1

- 86 year old man who lives alone in his home of 50 years.
- His wife died 2 years ago and he was her primary caregiver.
- In the past year, he has been hospitalized 3 times following falls at home.
- He had skilled rehabilitation stays after each hospitalization, but always returns home.

Case 1 (continued)

- His daughter-in-law and grand-daughter visit 3 times a week to bring him food, check on him, and encourage him to shower. They call him to remind him to take his medications because he is forgetful.
- He has urinary incontinence. He won't use his walker. His last fall was 4 months ago.
- Two months ago, his daughter-in-law found him wandering in his backyard after dark without any clothes on.
- His daughter-in-law is seeking advice about how much care he requires.

Where to Begin?



Case 1

- What else do you want to know?
  - From the patient
  - From the family
  - From other health care professionals
- What are some of the challenges to his health, safety, and quality of life?
- What are the goals?
  - Patient
  - Family
  - Yours
- What are his resources?

Assessment

Understand where they are coming from

- What is the chief complaint?
- Why is the individual seeking care now?
- What is the understanding of the problem?
- Who are the players?
- What is the motivation?
  - Patient
  - Caregivers

Learn the facts

- Has the change in cognition, function or behavior been explored before? If so, what were the recommendations?
- What has been tried? (reason for failure or success)
- What is the client's current condition?
- What are the potential resources? (personal, family, friend, financial)

Physical Examination

- Cough, shortness of breath
- Activity intolerance
- Range of motion
- Strength
- Balance, gait
- Tremors
- Weight
- Signs of pain or discomfort

What is in a mental status exam?

- A thorough mental status examination has several basic components that are essential in diagnosing dementia, delirium, or other syndromes.
- Attention should focus on each of these components in a systematic manner.
- Several factors may influence performance: educational level, primary language, impaired hearing, or poor baseline intellectual function.

Components of a Mental Status Exam

- Level of consciousness
- Appearance, grooming, and behavior
- Speech and language
- Mood
- Thought content and process
- Insight and judgment
- **Cognition**

Now for the Fun Stuff: The Cognitive Exam

- Memory
- Orientation
- Verbal fluency
- Visual spatial issues
- Insight & Judgment
- Executive function

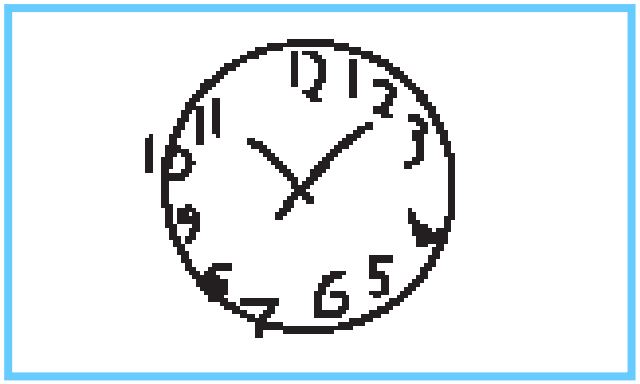
Testing of Executive Function

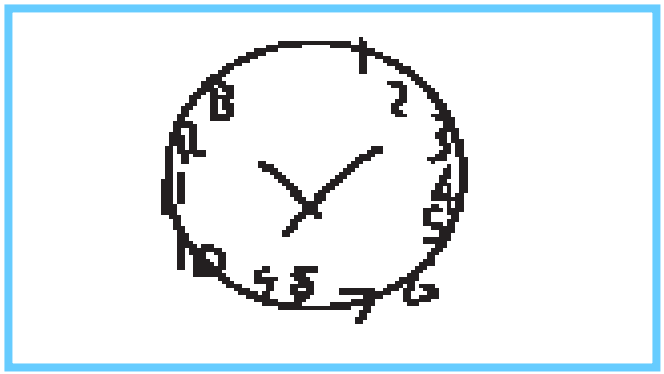
- As a quick screen, ask the patient to name as many four-legged animals as possible in 1 min. *Fewer than 10-12 animals or repetition of the same animals is abnormal and suggests the need for further evaluation.
- Verbal trails…..A1, B2, C?????? Should be able to reach at least M13 in 1 minute

Clock Drawing Test

- The clock-drawing test is also valuable because it assesses executive control and visual-spatial skills, two domains of cognition that are not tested or incompletely tested by the MMSE.
- In the clockdrawing test, the patient is asked to draw the face of a clock and to place the hands correctly to indicate 2:50 or 11:10.

Clock Examples





Mini-Cog

- The clock-drawing test is combined with the three-item recall in the Mini-Cog Assessment
- This only takes about 3 min to administer.

It Helps To Include Others

- Both the patient and a reliable informant should be interviewed.
- Determination of onset and nature of symptoms can help differentiate clinical syndromes.

COGNITIVE ASSESSMENT

- Recall 3 items after 1 minute
- Folstein's Mini-Mental State Examination (MMSE)
  - Widely used but now proprietary
- Montreal Cognitive Assessment (MoCA) and St. Louis University Mental Status Examination (SLUMS)
- BIMS
  - Other validated tools to assess cognition
- Tests of executive control
  - Clock-drawing test
  - Listing 4-legged animals test

Tools for Cognitive Assessment

- Mini-Cog http://www.hospitalmedicine.org/geriresource/toolbox/mini_cog.htm
- Confusion assessment method http://www.hospitalelderlifeprogram.org/pdf/The%20Confusion%20Assessment%20Method.pdf htm
- Montreal Cognitive Assessment http://www.mocatest.org/
- Saint Louis University Mental Status Examination (SLUMS) http://aging.slu.edu/index.php?page=saint-louis-university- mental-status-slums-exam

Developing a Problem List and Prioritizing

- Are there any immediate safety risks that cannot be temporarily addressed with current resources?
- What other information or what other referrals would be helpful?
  - Home safety evaluation
  - Driving evaluation
  - Appointment with primary care provider
  - Memory disorders specialist
  - AERS, social services, APS,
- Addressing the patient and caregivers chief complaint
- Sharing your recommendations

Case 2

- 86 year old man with multiple medical comorbidities (DM, HF, HTN, CAD, osteoarthritis, CKD), but intact cognitively who lives with his 78 year old wife who has Alzheimer's disease with behavioral disturbance, but physically is doing well
- They live in their own home with their grandson who has a history of substance abuse and has only been able to maintain part time employment.
- Their daughter lives nearby and is concerned about their ability to function in the home.

Case 2 (continued)

- The wife resists going to bed at night and gets verbally irritable and sometimes pushes her husband away when he is trying to get her ready for bed.
- He wants a medication to fix her and does not want to leave the house. He does not want someone coming in to help either.
- The daughter works full time and is overwhelmed with their care needs.

Case 2

- Clarify the chief complaint and motivation of patient and caregivers
- Any previous evaluations or past history that is important to consider
- How is the patient physically? Cognitively?
- What are the resources?
- Are there immediate safety risks?
- What is your problem list and plan for treatment?

Case Study 3

- You are a visiting health care provider who is asked to evaluate a patient with Alzheimer's disease who was recently discharged from the hospital for HF.
- The patient's daughter and primary caregiver has a long history of bipolar disorder.
- The living room and dining room are full of clutter, mostly holiday decorations and purchases from craft stores. You are able to walk through the rooms. The patient's bedroom and the family kitchen is clean and uncluttered and the patient appears well cared for.

Case Study 3 (continued)

- What else might you want to assess before you leave the house?
- Are there immediate safety risks?
- How might you resource this family?

Case Study 3 (continued)

- Three weeks later, you receive a telephone call from the patient's daughter who is upset because her mother is not sleeping at night. The daughter tells you that she stopped her psychiatric medications 10 days ago so that she would have enough energy to stay awake with her mother?
- What should you do?
- What might you expect to find in the home?

Case 3 (continued)

- Clarify the chief complaint and motivation of patient and caregivers
- Any previous evaluations or past history that is important to consider
- How is the patient physically? Cognitively?
- What are the resources?
- Are there immediate safety risks?
- What is your problem list and plan for treatment?

When there is a need for a higher level of care

- Explain the reason for your concern
- Review what has been tried and failed
- Reasonable options
- Will they commit to try and come and tell you about it at a future visit?
- Attempt to minimize disruption
- Let caregivers see you explain this to the client.
- Do you have any leverage?
- Consult APS if needed