Lewy Who?
A discussion of Lewy Body Dementia, other dementing diseases

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Disclosures

No financial conflicts of interest
Off label use of medications may be discussed
Helpful Web Addresses

• [www.lbda.org](http://www.lbda.org) Lewy Body Dementia Assoc
• [www.alz.org](http://www.alz.org) Alz Association
• [www.nia.gov](http://www.nia.gov) National Institute on Aging
• [www.alzfdn.org](http://www.alzfdn.org) Alz Foundation of Amer
• [www.healthcare.uiowa.edu/igec](http://www.healthcare.uiowa.edu/igec)
  • U of IA Iowa Geriatric Education Center
Objectives/Goals

1. Describe the most common types of dementia, with an emphasis on Lewy Body Dementia compared with Alzheimers
2. Define executive dysfunction and anosognosia
3. Audience participation on screening tools
4. Questions?
Dr. Lewy
Cartoon of a Lewy Body
Microscopic/Stained Lewy Body

(A) The large pink circle is a Lewy body within a brain cell.
(B) The brown section to the left of the Lewy body is normal brain pigmentation.
(C) The nucleus, the cell's control center, is to the far left of the cell.
THE BAD NEWS IS WE LEFT A CLAMP IN YOUR TEMPORAL LOBE...
THE GOOD NEWS IS THAT YOU WON'T REMEMBER WHAT I JUST SAID...
Old definition of dementia
Memory deficit + 1 or more other deficits + Decline

• Amnesia: Impairment in memory

• Aphasia: Impairment in language

• Apraxia: Impairment in using familiar objects

• Agnosia: Impairment in naming

• Anosognosia: Impairment in insight

• Executive Functioning Impairment
New Recommendations 2011: National Institute on Aging: Dementia Diagnosis

1. Decreased function impairing occupation/activities
2. Decline from previous levels of functioning
3. Not due to delirium or major psychiatric disorder
4. Cognitive impairment is detected and diagnosed through a combination of
   (1) history-taking from the patient and a knowledgeable informant
   (2) an objective cognitive assessment
5. The cognitive or behavioral impairment involves a minimum of two of the following domains:
   a. Impaired ability to acquire and remember new information
   b. Impaired reasoning and handling of complex tasks/poor judgment
   c. Impaired visuospatial abilities
   d. Impaired language functions (speaking, reading, writing)
   e. Changes in personality

DSM-5
Neurocognitive Disorders (NCD)

• Delirium
• Major NCD (= Dementia)
• Mild NCD
• (NCD Not Otherwise Specified)

(American Psychiatric Association, 2013)
DSM 5 Criteria

• The defining characteristics of these disorders are that their
  • core deficits are in cognition
  • deficits represent a decline from a previous level of cognitive functioning

(American Psychiatric Association, 2013)
DSM 5 Criteria for Neurocognitive Disorders

• Disorders in this section are attributable to changes in
  • brain structure
  • function
  • chemistry

• The etiologies of these syndromes, when known, are to be coded as subtypes

(American Psychiatric Association, 2013)
Subclassification by Etiology

Alzheimer’s disease
Lewy body Disease
Frontotemporal dementia
Vascular neurocognitive impairment
Traumatic brain injury
HIV
Huntington’s disease
Other causes

(American Psychiatric Association, 2013)
DSM 5 Criteria Delirium vs Other Neurocognitive Disorders

• Delirium is distinguished from Minor or Major Neurocognitive Disorder based on its core characteristics:
  • A disturbance in level of awareness and the ability to direct, focus, sustain, and shift attention.

• However, delirium can, and frequently does, co-exist with Major or Minor Neurocognitive Disorder.

(American Psychiatric Association, 2013)
Descriptive Features

- With Psychosis
- With Mood Disturbance
- With Apathy
- With Agitation
- With Other Behavioral Disturbance (Specify)
DSM 5 Alzheimer’s Disease (AD)

• Evidence of AD associated genetic mutation
• All 3 of following
  • Clear evidence of decline in memory and learning
  • Steady progressive decline
  • No evidence of mixed etiology

(American Psychiatric Association, 2013)
DSM 5 Neurocognitive Disorder with Lewy Bodies (LBD)

- Insidious onset and gradual progression
- 2 core features or 1+ core and 1+ suggestive

1. Core features
   - Fluctuating cognition with pronounced variations in attention and alertness; recurrent well formed, detailed visual hallucinations; spontaneous features of parkinsonism after onset of cognitive decline

2. Suggestive features
   - REM sleep behavior disorder, severe neuroleptic sensitivity
Major Causes of Dementia

• Alzheimers Dementia +/- Vascular Dementia
  (Vascular Dementia = Multi Infarct Dementia)
• Frontal Temporal Lobe Dementia
  • (of which a few have Pick's Disease)
• Parkinsons Disease Dementia
• Lewy Body Dementia
• Huntington's Disease
• Dementia Due to Alcohol
• Dementia Due to Head Injury (TBI)
Dementia Types

Graph provided by alzwsc.com
Dr Alzheimer's First Case

- Auguste D
  - 1901, 51 year old female at the Frankfurt Asylum
  - Hx of progressive cognitive impairments, and...
  - **Reason for admission: Hallucinations, delusions and psychosocial incompetence**
  - Example of one of Dr. Alzheimer’s notes:

  - During physical examination she cooperates and is not anxious.
  - Auditory Hallucinations: “*Just now a child called, is he there?*”
  - Delusions that she was going to be assaulted

- Maurer K et al: Lancet 349: 1546-9, 1997

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First Case of Alzheimers

• Auguste D.
  • She died in 1906
  • Case and autopsy findings presented at 37th Conference of Southwest German Psychiatrists Tubingen
Alzheimers Dementia (AD)

- Most Common type of dementia - Over 50% of cases; Probably present in 70% of cases

- Realization that "senility" is not normal aging in 1970’s
  - Pathological changes were the same as AD

- No cases of remission reported

- 100% of people who live with Alzheimer’s progress to incompetence
Cartoon View of the Brain: Normal vs Alzheimer's
Cartoon of plaques and tangles
Impairment in Alzheimer’s

• Hippocampus
  • impaired ability to form new memories

• Parietal/Temporal Lobes
  • deficits in understanding and using language, praxis (knowing how to use objects), perception, visual-spatial skills

• Frontal Lobe Impairment
  • complex cognition (executive functioning)
  • Insight (anosognosia)
Typical AD Symptoms

• Trouble with and then inability to form a new memory
• Word finding problems – vagueness or word substitution errors
• Getting lost in familiar places
• Loss of abilities – paying bills, knowing how to cook, knowing how to use tools – the less overlearned skills lost first
PET scan: Normal Brain vs Alzheimers
Alzheimers Disease – Blue areas are working; grey are not
“Typical” Alzheimer’s

• 74 yo Beatrice drives to same store using same streets for decades
• Streets barricaded with detour signs
• Returning home from the store, Beatrice crashes through the barricade on the parade route
• She becomes extremely anxious and pleads with the police officer that she needs to get home to her young children
Mental Status Exam

• Conversational Speech Normal
• Inability to form new memories
  • Denies accident occurred
• Executive Functioning Deficits
  • Unable to follow detour sign
• Word finding problems
  • Vague speech, word substitution errors
• Anosognosia
  • No idea that anything was wrong with her mind
Treatment Planning for AD

• Alzheimer’s Dementia responds positively to structure and simple routine
• ADL independence may be encouraged and maintained by simplifying tasks, providing setup, and problem solving routine
• Validation- communicate with emotions
• Distraction- decreases false ideas
• Provide long term memory based activities
• Positive response to social norms, “familiar life patterns”
• Educate family and caregivers
Usual Pharmacological Treatment

• Avoid medications that worsen cognition
• Begin dementia specific medications (memantine and cholinesterase inhibitors)
• If depressive symptoms consider antidepressant
• If paranoia, agitation, or aggression exist – use an atypical antipsychotic
• If anxiety, impulsiveness, manic-type symptoms consider mood stabilizer or medication that calms the sympathetic nervous system
Lewy Body Dementia

• Affects 1.3 million Americans
• Second most common type of dementia
• Less well known and so less diagnosed
• Includes both
  • Lewy Body Dementia
  • Parkinsons Disease Dementia
Lewy Body Dementia

- Dementia
- Hallucinations and sometimes delusions
- Memory problems begin with retrieval difficulty
- Waxes and wanes within 24 hour period “mini-delirium”
  - Attention, concentration
- Parkinsonian type movement disorders
  - Shuffling gait, tremor, rigidity
- REM sleep disorder (can precede dementia)
- Autonomic instability
- Falls
- Depression
Classic LBD triad

• Fluctuations
  • Attention, concentration or alertness

• Parkinsonian type movement disorders
  • Shuffling gait, tremor, rigidity

• Visual Hallucinations
Lewy Body Dementia

• Visual Hallucinations or Paranoia/Delusions often presenting symptom
• Usual treatment for psychosis often worsens symptoms
• Insight, when not floridly psychotic, often present in people with early and moderate disease
• Perseveration (inability to change set or severe mental rigidity) can be severe
PET in LBD
PET in LBD
LBD and sensitivity to Medications

- Anticholinergics or antispasmodics like oxybutynin and other incontinence meds
- Older antidepressants
- OTC meds like diphenhydramine, benadryl, sleeping aids
- Surgical anesthetics
- Benzodiazepines like valium
Robert

• 74 year old living independent senior living apartment for three years.

• Independent in basic ADLS and still driving.

• Tells peers about his “friend Johnny”. Johnny is invisible. One night he calls 911 telling them that his friend Johnny has fallen and cannot get up off the floor.

• Robert is taken to the ER. MMSE 29/30. Cooperative.
More about Robert

• Prescribed risperidone

• 3 days later he presents with a marked decrease in mobility and is “stiff all over”

• He has been up all night knocking on doors and yelling “fire!”

• Became aggressive with manager who tried to tell him there was no fire

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CDT 9/10
What we found out later.....

• Robert demonstrated a huge fluctuation in behavior from sitting and talking with staff, and participating in groups to biting and punching with care.

• During periods of “psychosis”, unable to correctly orient to environment or cooperate with additional evaluations.

• Fluctuations in mobility and ADL abilities.
Pharmacological Treatment of Robert

- Discontinue risperidone
- Discontinue lorazepam
- Add dementia specific medications:
  - 1st memantine
  - 2nd rivastigmine
  - Quetiapine 12.5-25mg at bedtime to help with nighttime VH and delusions
Pharmacological Treatment in LBD

- Discontinue medications that are anticholinergic
- Add dementia specific medications:
  - 1st memantine (namenda)
  - 2nd rivastigmine (exelon) or donepezil (aricept)
- Quetiapine (seroquel) low dose for VH and delusions
- Sinemet for movement disorder if severe
Nonpharmacological Treatment

- Physical therapy for strengthening, balance
- Speech therapy for low voice or swallowing
- Occupational therapy for maximizing abilities to perform ADLs
- Home assessment for environmental safety
- Support groups for caregivers
Treatment Planning for LBD

- Varies greatly person to person
- Plan for “the safest” when looking at level of care
- Monitor side affects of medications
- Caregiver Education
- Home safety evaluation
- Do not over react to hallucinations
- Provide a variety of activities to accommodate for cognitive fluctuations, grade appropriately
- Structure, support, and predictable environment
Other Considerations

• What is a safe living situation for Robert?
• Family education is very important
• Daughter brings patient to my office every 6 months for follow-up. Large part of each visit is educating the daughter on how to interact with her father
• For several years after discharge, patient has intermittent mental clarity and knows what is real and what isn't
Psychosis +/- Behavior Disturbance in LBD and PDD

• Quetiapine has been shown to be effective, lower dose better

• Side effects: somnulence, dizziness, postural hypotension, worsening Parkinsonian symptoms

• One open label study found the mean dose to be 137.5mg (Fernandez et al), I use much lower doses

• Clozapine is also used in these illnesses for the same symptoms with fewer motor side effects, but intrusive lab testing required

• ? Pimavanserin? PD psychosis – new, few studies

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Motor symptoms treatment

• May require sinemet (often used for Parkinson’s Disease)
• I often use small doses of sinemet throughout the day along with small doses of sinemet
• Avoid strongly dopaminergic medications like ropinirole (requip), pramipexole (mirapex)
Cognitive testing LBD vs Alzheimers

• Early on in illness, LBD patients perform less well on
  • Visual perceptual
  • Attention
  • Working memory
  • Timed tests
Testing data

![Graph A](chart1.png)

**A**

<table>
<thead>
<tr>
<th></th>
<th>CONTROL</th>
<th>ALZHEIMER</th>
<th>LEWY</th>
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<td>colour</td>
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<td>face</td>
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<td>motion</td>
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### Sauer J et al. Brain 2006;129:1780-1788

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Cleo

• 91yo living in her own house.

• Independent in basic ADLS. Not driving anymore.

• Every night before she goes to sleep she sees a small cherub sitting in the corner of her room near the ceiling. It never talks to her. When she closes her eyes it disappears but it is there when she opens them. Only happens at night.

• She is not frightened by it.
Mary

• 84 year old in an apartment.

• Independent in basic ADLS. Not driving due to legal blindness.

• Feels threatened that a man named Jack was coming into her apartment at night, moving things around. She has seen him a number of times at night at her window or in her apartment. He does not speak to her.

• “I don’t know what he’ll do to me!”
Beatrice

- 74 year old Beatrice drives to same store using same streets for decades
- Streets barricaded with detour signs
- Returning home from the store, Beatrice crashes through the barricade on the parade route
- She becomes extremely anxious and pleads with the police officer that she needs to get home to her young children
Looking at function and behavior through DSM 5 Cognitive Domains

(American Psychiatric Association, 2013)
Neurocognitive Domains DSM 5

Complex Attention
  - Executive Function
    - Planning
    - Decision Making
  - Working Memory
  - Inhibition
  - Error Correction
  - Flexibility

Learning and Memory
  - Working Memory
  - Short Term Memory
  - Explicit and Implicit Memory
  - Semantic

Social Cognition
  - Theory of Mind
  - Perspective Taking
  - Emotional Recognition

Perceptual-Motor
  - Construction
  - Visual Perceptual
  - Gnosia
  - Praxis

Language
  - Expressive
  - Grammar
  - Syntax
  - Receptive

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# Complex Attention

<table>
<thead>
<tr>
<th>Mild</th>
<th>Major</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal tasks take longer; than errors occur in routine tasks;</td>
<td>Slowed thinking, inability to do calculations, easily distracted</td>
</tr>
<tr>
<td>Concentration more difficult with competing stimuli</td>
<td></td>
</tr>
</tbody>
</table>

(American Psychiatric Association, 2013)
Trail-Making Test

• Part A
  • Numbers 1→25
  • Ave 29 sec

• Part B
  • Numbers + letters
  • 1A→13M
  • Ave 75 sec

• Advantages
  • Free
  • Often used by DMV

• Disadvantage
  • Difficult for patients to understand at times

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www.granddriver.net/data/media/docs/Ulowa_trailMaking.pdf
# Executive Function

<table>
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<tr>
<th>Mild</th>
<th>Major</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased effort for multistep actions, limited multitasking. Extra fatigue with tasks that require organization, planning, and decision making. Avoidance of large social situations; fatigued and taxed by social demands.</td>
<td>Abandons complex projects. Dependency in IADLs; completes one step activities</td>
</tr>
</tbody>
</table>

(American Psychiatric Association, 2013)
What does Executive function loss look like?

**MILD NCD**
- Poor social awareness
- Decreased recognition of errors
- Agreeable
- Decreased follow through
- Impaired IADL performance
- Impairment and change in relationships

**MAJOR NCD**
- Apathy and poor initiation
- Poor ADL performance
- Passivity
- Repetitive behaviors
- Inappropriate physical contact
- Impulsive speech

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ACL
Developed by Occupational therapist Claudia Allen, 1978
Last revision 2007 ACLS-5

• Looks at “functional cognition”
• Establishes a pattern of function to predict ADL and IADL function in multiple contexts
• Provides an estimate of a person’s capacity to participate in goal directed activity
• Focuses on a cognitive baseline allowing a therapist to estimate current capabilities
• Scored on level 1-6
• Involves not only initial screening, but a battery of validating tests to establish reliable score

(Allen, Earhart., McCraith,& Riska-Williams, 2007)
ACL Levels

ACL LEVELS

• **Level One**: Coma
• **Level Two**: Reflexes/Reactions
• **Level Three**: Decreased Goal Directed
• **Level Four**: Goal Directed Activity
• **Level Five**: New Learning/Adaptive
• **Level Six**: Independence

MILESTONES ON ACL

1.4 Swallow
2.4 Ambulation
3.6 Cause and Effect
4.0 Completes Self Care with structure
4.6 Lives alone with daily assistance
5.0 Weekly checks to manage medications
5.6 Social bonding, Driving, Childcare

(Allen, Earhart., McCraith, & Riska-Williams, 2007)
**Figure 3: 8-item Informant Interview to Differentiate Aging and Dementia**

(Positive Predictive Value = 87% for CDR 0 vs CDR ≥ 0.5)

<table>
<thead>
<tr>
<th>Report only a change caused by memory and thinking difficulties</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is there repetition of questions, stories, or statements?</td>
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<tr>
<td>2. Are appointments forgotten?</td>
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<tr>
<td>3. Is there poor judgment (e.g., buys inappropriate items, poor driving decisions)?</td>
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<tr>
<td>4. Is there difficulty with financial affairs (e.g., paying bills, balancing checkbook)?</td>
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<td>5. Is there difficulty in learning or operating appliances (e.g., television remote control, microwave oven)?</td>
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<td>6. Is the correct month or year forgotten?</td>
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<td>7. Is there decreased interest in hobbies and usual activities?</td>
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<tr>
<td>8. Is there overall a problem with thinking and/or memory?</td>
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</tbody>
</table>

**TOTAL AD8 SCORE**

---

*Adapted from Galvin et al, “The AD8: A Brief Informant-Interview to Detect Dementia”, Neurology. 2005;65:559-564.*
Clock Drawing Test

Normal
Score 10

A
CDT
4
MMSE
20

B
CDT
2
MMSE
20

C
CUT
2
MMSE
19

D
CUT
1
MMSE
14

E
CMT
2
MMSE
19

Cognitive Impairment
Score 2

Sunderland, 1989

UB


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## Learning and Memory

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<th>Major</th>
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<tbody>
<tr>
<td>Decreased ability recalling recent events, Reminders, making lists, or needing to re-reading to keep track of new information. Occasionally may repeat self. over a few weeks to the same person. Decreased ability to remember if bills are paid, appointments, etc.</td>
<td>Repeats self within a single conversation. Requires frequent reminders to orient to task during activity. Needs assistance with IADLs.</td>
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(American Psychiatric Association, 2013)
## COGNITIVE STATUS PROFILE

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<tr>
<th></th>
<th>LOC</th>
<th>ORI</th>
<th>ATT</th>
<th>LANGUAGE</th>
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</table>

Write in lower scores

### ABBREVIATIONS

- **ATT**: Attention
- **CALC**: Calculations
- **COMP**: Comprehension
- **CONST**: Constructions
- **IMP**: Impaired
- **LOC**: Level of Consciousness
- **MEM**: Memory
- **NAM**: Naming
- **JUD**: Judgment
- **ORI**: Orientation
- **REP**: Repetition
- **S**: Screen
- **SIM**: Similarities
## COGNITIVE STATUS PROFILE

<table>
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<tr>
<th>LOC</th>
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**ABBREVIATIONS**

- ATT: Attention
- CALC: Calculations
- COMP: Comprehension
- CONST: Constructions
- IMP: Impaired
- JUD: Judgment
- LOC: Level of Consciousness
- MEM: Memory
- NAM: Naming
- ORI: Orientation
- REP: Repetition
- S: Screen
- SIM: Similarities

Write in lower scores
St. Louis University Mental State Exam (SLUMS)

http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf
Retrieved January 2016
### Social Cognition

<table>
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<th>Major</th>
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<td>Subtle behavior changes:</td>
<td>Behavior out of social norms</td>
</tr>
<tr>
<td>• Decreased ability to recognize social</td>
<td>• Shows insensitivity to social standards</td>
</tr>
<tr>
<td>cues</td>
<td>• Focuses excessively on a topic despite redirection.</td>
</tr>
<tr>
<td>• Decreased empathy</td>
<td>• Behaviors shows no regard to others.</td>
</tr>
<tr>
<td>• Change in social behavior</td>
<td>• No safety awareness</td>
</tr>
<tr>
<td>• Decreased inhibition</td>
<td>• No insight into changes.</td>
</tr>
<tr>
<td>• Episodic apathy</td>
<td></td>
</tr>
<tr>
<td>• Restlessness</td>
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(American Psychiatric Association, 2013)
Perceptual- Motor

<table>
<thead>
<tr>
<th>Mild</th>
<th>Major</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Shows more reliance on maps, notes or others to find new places.</td>
<td>• Significant difficulties with previously familiar activities</td>
</tr>
<tr>
<td>• May find self lost when not concentrating on task.</td>
<td>• Poor ability to navigate familiar environments</td>
</tr>
<tr>
<td>• Decreased ability to park.</td>
<td>• More confused in evening/ low light</td>
</tr>
<tr>
<td>• Needs greater effort for spatial tasks</td>
<td></td>
</tr>
</tbody>
</table>

(American Psychiatric Association, 2013)
## Language

<table>
<thead>
<tr>
<th>Mild</th>
<th>Major</th>
</tr>
</thead>
</table>
| • Observable word-finding difficulty.  
• Uses general terms for specific terms.  
• Errors include omission or incorrect use of articles, prepositions, auxiliary verbs, etc. | • Significant difficulties with expressive or receptive language  
• Uses vague terms and non-specific nouns.  
• May not even recall names  
• Idiosyncratic word usage, grammatical errors, and spontaneity of output and economy of utterances occur.  
• Echolalia and automatic speech  
• Eventual mutism. |

(American Psychiatric Association, 2013)
Mini Mental State Exam (MMSE)

Advantages
- Long considered the Gold Standard/ Common language between clinician
- Can be useful for serial screening
- Differentiating moderate disease (score 10-26+) with severe disease (below 10)

Disadvantages
- Score less than 27 should raise concern
- No measure of executive function
- Much less useful in someone who is intelligent or educated
- Someone can be moderately impaired with a score of 30
- Affected by education and intelligence
- Insensitive to early dementia

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(Folstein, 1975)
Montreal Cognitive Assessment (MoCA)

- www.mocatest.org
- Includes the CDT and Trails B

(Nasreddine, 2005)
Referrals to Therapy

**Occupational Therapy**
Functional cognition, Activities of daily living, UE disability

**Physical Therapy**
Mobility, pain, lower extremity disability

**Speech Therapy**
Swallowing, cognition, communication
Mental Capacity

• Results from a combination of memory, logic, ability to calculate, and the ‘flexibility’ to turn attention from one task to another

• Affected by many things including age, illness and medications. Also affected by fatigue, dehydration, and stress.

www.preventelderabuse.org/elderabuse/issues/capacity.html
Consent

• Understands the question
• Understands the choices, and the implications/ramifications of the choices
• Can express a choice
• The choice is stable over time

www.preventelderabuse.org/elderabuse/issues/capacity.html
Medication Informed Consent

• What are you treating: illness or symptom
• Is symptom significant enough to treat
• Medication Side Effects
  • Common, minor, decrease with time
  • Rare but serious
  • Potentially life threatening
• Where do those pharmacy handouts come from? What do they mean?
• Risks and Benefits of tx vs no tx
Procedure/surgery Informed Consent

• What are you treating: illness or symptom
• Is target worthwhile treating
• Risks of treatment
  • Common, minor, decrease with time
  • Rare but serious
  • Potentially life threatening
• Benefits of treatment
• Risks and Benefits of No Treatment
Consent and Capacity in Dementia

• Specific to Alzheimers
  • Difficulty then inability to form a new memory is particularly disabling
  • Listen for vague speech patterns, word substitutions
  • Ability to participate in a conversation outlasts ability to comprehend by years
Consent and Capacity in Dementia

• Specific to LBD
  • Variations within a day or week can easily lead one to believe the person is much less or much more impaired (because they are at that moment)
  • Trouble with mental flexibility is particularly challenging
  • Safe treatment planning means planning for the most impaired a person is which is not usually the least restrictive
“Testing” for capacity

• Ask the person to summarize what the question is, what the choices are and what are the specific risks, benefits and alternatives of each choice including the choice of doing nothing

• Do not assume someone understands because you ask “Do you understand what I just said” and the person answers “Yes”
QUESTIONS?