What APS Workers Need to Know about Frontotemporal, Lewy Body and Vascular Dementias

Presenter: Kim Bailey, MS Gerontology, Program & Education Specialist, Alzheimer’s Orange County
Facts About Our Aging Population:

• In 1900 the average life expectancy for a person living in the U.S. was 47.3 years. Now about 30 years longer.
• Age is the number one risk factor for developing dementia and Mild Cognitive Impairment (MCI).
• Alzheimer’s dementia and LBD typically begin after age 65.
• Frontotemporal Dementia typically develops between 45 and 65 years of age.
• Every day in this country approximately 10,000 people turn 65. About 54,000 Americans are 100 years of age or older.
Normal Age-Related Cognitive Decline

Mild Cognitive Impairment (MCI)

Dementia

Mild

Moderate

Severe
Goals

• Provide broad definition of dementia
• Define Alzheimer’s disease & discuss symptoms, progression, etc.
• Identify major subtypes of dementia including FTD, Lewy Body & Vascular dementia and their prevalence rates
• Apply this knowledge to work with APS clients & families
What is Dementia?

• An umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain (neurons) die or no longer function normally.

• Death or malfunction of neurons causes changes in memory, behavior and ability to think clearly.
Alzheimer’s Disease

Most common type of Dementia
Most common initial symptom

♦ Gradual worsening of ability to remember new information

Other common symptoms

♦ Memory loss that disrupts daily life
♦ Challenges in planning or solving problems
♦ Difficulty completing familiar tasks at home, work and leisure
Suggestive of Possible Early Dementia or MCI:

**Poor Short-term Memory:**

- Asking the same questions repeatedly
- Forgetting recent conversations
- Frequently misplacing belongings
- Not remembering names of familiar people
- Forgetting that something is cooking on the stove
- Forgetting to pay bills or paying bills more than once
- Forgetting appointments or to take medications
- Stop doing things like reading novels or playing Bridge
- Difficulty learning a new device (cell phone, TV remote)
Overview of Alzheimer’s Disease
What changes?

- Memory
- Language/Communication
- Executive Functions
- Visual-Spatial Perception
- Behavior - no longer a choice; it is a reaction
Normal Brain

Photo courtesy of The Alzheimer’s Association
Alzheimer’s Brain

Photo courtesy of The Alzheimer’s Association
Other Types of Dementia

Each type of dementia has a different cause, pattern of attack, symptoms and life expectancy.

- Alzheimer’s Disease (65 - 70%)
- Lewy Body Dementia (10 - 20%)
- Fronto-Temporal Lobe Dementia (5 - 10%)
- Vascular Dementia (5 - 10%)
- Other dementias:
  - Dementia due to Head Trauma
  - Dementia due to HIV Disease
  - Parkinson’s Disease Dementia (PDD)
  - Dementia due to Huntington’s Disease
  - Alcohol-Induced Persisting Dementia
  - Dementia due to Creutzfeldt-Jacob Disease
Lewy Body Dementia is:

A progressive brain disease and the second most common cause of a neurodegenerative dementia after Alzheimer’s disease.

It may co-exist with Alzheimer’s disease (plaques and tangles).

LBD is not rare. It accounts for up to 20% of dementia cases in the U.S. --- up to 1.3 million cases in the U.S. alone, with only 30-50% of LBD cases being accurately diagnosed, even in dementia centers.
Lewy Body Dementia:

- Features of AD (impaired short-term memory)
- Features of Parkinson’s disease (bradykinesia, rigidity, tendency to fall, shuffling gate, postural instability, akinesia)
- Fluctuating levels of consciousness (intermittent delirium; pronounced variations in attention and alertness)
- Detailed visual hallucinations (well-formed visual hallucinations early in the course of the disease) In 80%.
- Adverse reaction to neuroleptics (anti-psychotics)
- Course is more rapid than AD
REM Sleep Behavior Disorder (RBD)

- This is a common symptom of LBD.
- During periods of REM sleep the person will move, gesture and/or speak.
- The person may thrash about and even fall out of bed or strike his/her partner.
- RBD may actually be the earliest symptom of LBD in some patients and is now considered a significant risk factor for developing a degenerative brain disease such as LBD, PD, and multiple system atrophy.
Additional symptoms of LBD:

- Hallucinations other than visual such as involving smell, sound, taste, and touch.
- Transient and unexplained unresponsiveness. 81% of these patients have unexplained periods of markedly increased confusion, mimicking delirium.
- Delusions, illusions, and mood disorders.
- Visual impairment (depth perception, object orientation).
LBD symptoms that resemble AD:

- Progressive memory loss
- Decreased judgment and insight
- Loss of initiative
- Disorientation regarding time and place
- Difficulty with language and tasks
Frontotemporal Dementia (FTD) (5 -10% of all dementias)

• Frontotemporal Dementia is the 3rd leading type of dementia
• Because of the manner in which symptoms first appear and often normal performance on early testing, it is frequently misdiagnosed in it’s early stages as depression, mental illness, or Alzheimer’s disease.
• Neuropsychological testing will often show dysfunction in tests of attention, response inhibition, frontal/ executive function, and language.
Damage to the frontal lobes can produce personality & behavioral changes, difficulty performing the complex ADLs, and many other problems:

- disinhibition and poor impulse control
- poor social judgment
- apathy, loss of drive or interest
- obsessive thinking
- compulsive behaviors (hoarding objects, compulsive counting & checking, inflexibility, overeating, craving certain foods (sweets), hypersexual behaviors, etc.)
- loss of empathy, loss of awareness of others
- loss of insight, loss of self-awareness
- poor executive functioning
Executive Functions:
(involves insight, hindsight, and foresight)

Cognitive abilities necessary for complex goal-directed behavior and adaptation to a range of environmental changes and demands.

Executive functions include:

- attention, goal formulation, planning,
- organizing, prioritizing, sequencing, execution of plans,
- cognitive flexibility, self-awareness, self-correcting,
- self-monitoring, problem-solving, adapting & adjusting,
- abstract reasoning, multitasking,
- and ability to perform complex tasks (complex ADLs).
Impaired ability to perform the complex ADLs:

When individuals have problems with such tasks as:

- working
- driving or using public transportation
- cooking
- managing medications
- paying bills & managing their finances,
- shopping alone
- setting up and getting to doctors’ appointments
- traveling alone across country
- living alone without help

they are revealing a loss of executive functioning.
Vascular Dementia
Vascular Dementia

- Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients.
- **Major Stroke** – cerebral hemorrhage, thrombosis, or embolism. Also called cerebrovascular accident (CVA) (25% result in some degree of dementia)
- Multiple small strokes (formally multi-infarct dementia)
- Chronic low blood flow to the brain (vascular insufficiency), more likely to produce Vascular Cognitive Impairment
- Pure vascular dementia is not common.
- Stroke-related dementia often then follows a ‘stepped’ progression, with long periods when symptoms remain the same and short periods when they suddenly worsen (this pattern is seen because each stroke further damages the brain).
### Comparison of AD, LBD, and FTD

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<th>AD</th>
<th>LBD</th>
<th>FTD</th>
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<tbody>
<tr>
<td><strong>Age of onset:</strong></td>
<td>typically over age 65</td>
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<td>45 to 65 years of age</td>
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<td><strong>Early signs:</strong></td>
<td>memory loss, word-finding difficulty</td>
<td>motor deficits: Parkinson’s Sxs visual hallucinations sleep disturbance</td>
<td>personality and behavioral changes</td>
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<td></td>
<td>Dx: MCI</td>
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<td><strong>Cognitive:</strong></td>
<td>memory, language, visuospatial, and executive function, reasoning, and judgment</td>
<td>attention, executive function, visuospatial ability often prominent. memory may or may not be prominent initially</td>
<td>memory preserved executive function, language impaired on neuropsych testing</td>
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<tr>
<td>(deficits)</td>
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## Comparison of AD, LBD, and FTD

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<tr>
<td><strong>Language:</strong></td>
<td>word-finding and naming difficulty,</td>
<td>verbal fluency impaired</td>
<td>usually intact, aphasia may be</td>
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<tr>
<td></td>
<td>eventual aphasia</td>
<td></td>
<td>prominent feature</td>
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<td><strong>Mood:</strong></td>
<td>anxiety common; may be depression common, initially</td>
<td>depression common, also anxiety over visual hallucinations</td>
<td>no anxiety or depression, lack self-awareness</td>
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<td><strong>Conduct:</strong></td>
<td>social skills and language initially preserved</td>
<td>social skills and insight retained</td>
<td>apathy, poor social judgment &amp; impulse control</td>
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Jim was a 76 year old gentleman, who was admitted to a psychiatric hospital after being arrested for shooting his rifle at “space aliens” on his front yard. His wife said he had been seeing people for several months (that were not real).

He was evaluated and found to have:

- detailed visual hallucinations
- memory impairment and dementia
- symptoms of Parkinson’s disease
- fluctuation in consciousness (intermittent delirium)
- severe sleep disturbance (REM Sleep Behavior Disorder)
Pete’s Story

In 1998 at age 50 he began showing definite personality and behavioral changes according to his wife:

- Selfish and self-centered behavior
- Lack of empathy and emotion
- Compulsive behaviors and quirky habits
- Poor judgment; poor impulse control
- Extreme apathy

2006 he came home from work (a lucrative job he had held for over 16 years) with a 6 page letter explaining why he was being fired. The letter described all the things he had not been doing on his job. He was displaying severe apathy.
In 2006 he and his wife consulted with 16 different physicians, four of whom were neurologists, he still had no definitive diagnosis.

Pete had no memory or language problems, so it is likely that he scored normally on the MMSE, a commonly used screening test, administered by the doctors that saw him. Probably no clock drawing test was given.

In 2008 he was evaluated at the Brain and Aging Institute at UC Irvine and it was there that a correct diagnosis was made.

His condition continued to deteriorate until he was forced to move into a residential care facility. He developed difficulty walking and a progressive language disorder (aphasia), but no memory deficit.
Ruben’s Story

Ruben, a 57 year old gentleman, suffered a ruptured aneurysm in his right cerebral hemisphere in early 2013. He was in a coma for 21 days and was not expected to survive. He did eventually regain consciousness and slowly regained his ability to talk, walk, care for himself, and drive.

Neuropsychological testing showed deficits in memory, attention span, speed of information processing, verbal fluency, and executive functioning.

While his functioning at home was not significantly impaired, he was no longer able to return to his job as the head of a very successful accounting firm that he founded. In fact, he was no longer able to hold any type of job. He is now enjoying his retirement, but needs some assistance.

He has not declined or improved cognitively.
Communicating with a person who has dementia

**Principles in Communication**

- Verbal vs. non-verbal communication
  - Inability to follow verbal directions (frontal lobe loss)
  - Use visual cues to signal instructions
  - Don’t argue, don’t correct!

- Principles of treating clients with respect
  - Know how to address clients
  - Importance of always asking permission
  - All behavior has meaning
  - If they could control their behavior, they wouldn’t have this diagnosis.
Resources

In Orange County, CA:
Alzheimer’s Orange County’s
Helpline: 844-HELP-ALZ (844-435-7259)
www.alzoc.org

National Alzheimer’s Association:
24/7 HELPLINE 800-272-3900
www.alz.org
Brainstorming Questions

1. Does your agency collaborate with your local Alzheimer’s organization?

2. How can Alzheimer’s organizations work more closely with APS?

3. What kind of support would benefit you most?