Caregiving for people living with non-Alzheimer’s dementias

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Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
By the end of this presentation, attendees will be able to:

- Describe primary symptoms of Lewy body dementia, frontotemporal degeneration, and vascular dementia;

- Identify key similarities and differences of caregiving for people with Lewy body dementia, frontotemporal degeneration and vascular dementia; and

- Identify two needs of caregivers of people with Lewy body dementia and frontotemporal degeneration throughout the disease process.
What is Dementia?

“Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.”

- NIH National Institute on Aging
What Functions Can Dementia Affect?

- Memory
- Language
- Problem Solving
- Concentration
- Visual Perception
- Personality
- Emotions and Mental Health
- Motor Skills
Types of Dementia

Alzheimer’s Disease
- 60-80% of all dementias
- 5.8 million people in the U.S.
- Memory loss is the most common early symptom

Vascular Dementia
- ~10-15% of all dementias are vascular only
- ~40% of all dementias have a vascular component
- Caused by stroke(s) or other cerebrovascular damage

Lewy Body Dementia
- ~20% of all dementias
- 1.4 million people in the U.S.
- Typically involves motor symptoms in addition to cognitive and behavioral changes

Frontotemporal Degeneration
- ~50,000-60,000 people in the U.S.
- Most common forms involve changes in language or behavior
- Younger age of onset

Mixed dementia ~50%

Differences Among Dementias

- Early symptoms
  - Cognitive
  - Motor
  - Behavioral

- Progression
  - Speed
  - Symptoms

- Age of onset
  - Over 65
  - Younger onset

- Co-occurring conditions
  - Cardiovascular
  - Motor
Common Challenges Related to Other Dementias

- Delayed diagnosis
- Misdiagnosis
- Challenge locating knowledgeable medical professionals
- Lack of information
- Isolation
Vascular Dementia

- Caused by strokes or other vascular damage
  - May be minor, undetected
  - Cumulative damage
  - About 1/4 - 1/3 of people who have a stroke will develop dementia
  - Often co-occurs with Alzheimer’s disease
  - May be misdiagnosed as Alzheimer’s disease

- Risk factors
  - Diabetes
  - High blood pressure
  - Heart disease
  - Smoking
  - High cholesterol

Knopman, D., 2019; Paturel, A., 2013, February/March; UCSF Memory and Aging Center, 2010
- Symptoms depend on location of damage
  - Organization
  - Attention
  - Slowed thinking
  - Language
  - Memory
  - Similar to Alzheimer’s disease
- Symptoms may be sudden or gradual
- May progress more slowly than Alzheimer’s disease
- Strength and balance may be affected
Although Vascular Dementia is a common form of dementia, there are few specific resources.

What is the caregiver experience?
- Coordination of care related to co-occurring conditions
- Greater burden earlier in the disease?

Are Alzheimer’s disease supports and services appropriate?
Caregiving and Lewy Body Dementia

Angela Taylor
Lewy Body Dementia (LBD) is...

- A Multi-System Neurodegenerative Disorder
  - Cognition
  - Behavior and mood
  - Movement
  - Sleep
  - Autonomic nervous system
- A relative newcomer, compared to Alzheimer’s disease
  - First described in literature in the 1980s
  - Diagnostic criteria established in 1996
LBD Represents a Spectrum

Lewy body dementia (LBD) = a dementia syndrome associated with Lewy bodies in the brain

- Dementia with Lewy Bodies (DLB)
- Parkinson’s Disease Dementia (PDD)
Prevalence and etiology

• 2\textsuperscript{nd} most common form of progressive dementia after Alzheimer’s disease
  • Affects 1.4 million Americans
• The most misdiagnosed form of dementia
  • Often diagnosed first as
    • Alzheimer’s disease
    • Parkinson’s disease
    • A psychiatric disorder
• Associated with abnormal protein deposits in the brain
  • These deposits are now called \textit{Lewy bodies}, named after Dr. Friedrich Lewy, a neurologist
Why Can’t We Just Call it Lewy Body Disease?

- **Lewy body dementia**
  - Any form of dementia associated with the presence of Lewy bodies in the brain
    - Dementia with Lewy bodies (DLB)
    - Parkinson’s disease dementia (PDD)

- **Lewy body disorders**
  - Any medical disorder (with dementia or without it) associated with the presence of Lewy bodies in the brain
    - Parkinson’s disease
    - Dementia with Lewy bodies
    - Multiple system atrophy

- **Lewy body disease**
  - The actual biological process in the brain associated with Lewy body disorders
The Importance of Early Diagnosis

- Comprehensive clinical care improves quality of life
  - More responsive to cholinesterase inhibitors
- Minimize risks for medication side effects
  - Antipsychotics
  - Benzodiazepines
  - Sedatives
  - Narcotics
  - Medications for parkinsonism
  - Anesthesia
  - Certain over-the-counter medications
- Proactive caregiver education, support and referral to resources
DLB: A diagnostic challenge

- Complex to diagnose –
  - Presenting symptoms vary
  - Typically requires a specialist
  - Delirium may present prior to dementia
- Challenging to treat
  - Severe medication sensitivities
  - Treatments are prescribed off-label
- Not on the public’s radar
  - Most people first hear of LBD at the time of diagnosis
  - Caregivers must become educators and strong advocates
- LBD and its medication sensitivities are unfamiliar to many healthcare providers
  - Especially emergency room physicians, hospitalists
  - Request neurology consult if going to the ER for behavioral concerns
Strategies for Daily Life

- Cognitive Symptoms
  - Forgetfulness
  - Trouble with problem solving or analytical thinking
  - Difficulty planning or keeping track of sequences
  - Reduced attention
  - Disorganized speech and conversation
  - Difficulty with sense of direction or spatial relationships between objects

- Strategies
  - Medications developed for Alzheimer’s disease
  - Counseling may help adjust to the diagnosis
  - Plan on taking it slow
  - Adjust expectations
  - Learn to accept help
Strategies for Daily Life

• Fluctuations
  • Concentration, alertness
  • Episodes of confusion
  • Excessive daytime sleepiness

• Strategies
  • Psychostimulants may help
  • Be flexible and patient
  • Schedule in a nap
Strategies for Daily Life

- **Parkinsonism**
  - Rigidity or stiffness
  - Shuffling walk
  - Balance problems or falls
  - Tremor
  - Slowness of movement
  - Decreased facial expression
  - Change in posture
  - Reduced voice volume and eventually problems swallowing

- **Strategies**
  - Carbidopa-levodopa may help
    - NOTE: May worsen hallucinations
  - Physical therapy
  - Occupational therapy
  - Speech therapy
  - Assess the environment for safety
Strategies for Daily Life

- **Autonomic Dysfunction**
  - Dizziness or fainting
  - Temperature regulation
  - Urinary incontinence
  - Constipation
  - Unexplained blackouts or transient loss of consciousness

- **Strategies**
  - Compression stockings, add salt to the diet, adequate hydration
  - Dress in layers
  - Toileting schedule, explore alternates to medications
  - Stool softeners, added fiber
  - Monitor and call the doctor with concerns.
Strategies for Daily Life

• Sleep Disorders
  • Acting out dreams, sometimes resulting in injury
    • called REM sleep behavior disorder, or RBD
    • May predate dementia by years or even decades
  • Insomnia
  • Restless leg syndrome

• Strategies
  • Clonazepam or melatonin for RBD
  • Assess injury risks
  • Find a balance with naps in the daytime
  • Eliminate caffeine after dinner
Strategies for Daily Life

• Behavior and Mood
  • Hallucinations
  • Delusions
  • Depression
  • Apathy
  • Anxiety

• Strategies
  • Cholinesterase inhibitors are part of the long term treatment strategy
  • Accept their reality
  • Respond to their emotions
  • Redirect their attention
  • Consult the physician if behavior suddenly worsens
Driving and LBD

**Risk**
- Reduced attention
- Slowed thinking
- Visuospatial skills reduced
- Visual hallucinations
- Motor changes
  - Rigidity, slowed movements
  - Myoclonic jerks

**Strategies**
- Caregivers should trust their own judgment
- Contact the provider in advance if there are safety concerns
- Let the provider serve as ‘the bad guy’
- Use friends, family and senior transportation services
Unique Implications for Caregivers

- Activities of Daily Living
  - Early urinary incontinence
  - Visual spatial skills and executive dysfunction
  - Fluctuating cognition

- Public Awareness
  - Family and friends
  - Primary care
  - Hospitals

- Caregiver Burden
  - Moderate to severe
Closing the Gap of Unmet Needs

- Educate families about LBD symptoms and treatments
- Empower them to advocate for comprehensive and appropriate LBD care
- Make referrals to community-based services
- Point them to a community of support
- Teach them self-care and coping strategies
Contact Us

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Frontotemporal Degeneration

Sharon S. Denny, Senior Director of Programs
Aging in America Conference - April 17, 2019
Frontotemporal Degeneration (FTD)

Degeneration of the frontal and/or temporal lobes of brain

Clinical presentations:
- Behavioral variant FTD—behavior, personality, executive function
- Primary progressive aphasia (subtypes: semantic, nonfluent, logopenic)
- Progressive supranuclear palsy, corticobasal syndrome
- ALS with FTD

Age of Onset: 20s – 80s (average age @ diagnosis: 57)

Prevalence: ~ 20 per 100,000 age 45-64
Estimated 50,000 – 60,000 in the US
Neuropathology in FTD

“Frontotemporal lobar degeneration” (FTLD) - the specific pathological diseases that result in FTD syndromes.

Subtypes are based on the proteins found within neuronal inclusions. Most FTLD subtypes are either:

- FTLD-tau (Pick’s disease, some PPA, CBD and PSP)
- FTLD-TDP (some bvFTD, svPPA, ALS/FTD)
- In addition to FTLD pathology PPA can be caused by Alzheimer’s disease:

Images courtesy N. Cummings
Genetics in FTD

Genetic causes play greater role than in Alzheimer’s disease

Etiology

~ 15-20% autosomal dominant
~ 20-30% familial
~ half are sporadic

3 main genes:

MAPT, GRN, C9orf72

Other rare mutations
The Experience of FTD

Diverse Clinical Symptoms

Greater

CARE

NEEDS

Younger Onset

Less Common

Diagnostic Challenges

Family & Financial Impact

Complex pathology & genetics
FTD impacts the entire family system

Misdiagnoses -- Early confusion & hurt
- Impact of behavior (family, friends, finances)
- Coping long before diagnosed

Developmental stage of family
- Supporting children, young adults, aging parents
- Significant role changes (loss of employment; kids caring for parents; household tasks)
FTD impacts the entire family system

“No one understands”
- Symptoms not recognized as illness
- Behaviors intrusive, embarrassing
- Isolation magnifies challenges

Complex financial and legal issues

Lack of FTD-aware services
- AD care strategies & tools not sufficient
- Apathy, compulsive behavior, loss of empathy
Twelve months before an FTD diagnosis, most families reported a household income in the $75,000–$99,000 range. Twelve months after diagnosis, income fell as much as 50 percent.

Overall, families dealing with FTD face an economic burden of around $120,000 each year — roughly twice the economic burden of Alzheimer’s disease.

37% of FTD caregivers said they stopped working post-diagnosis.

58% of respondents said that FTD caused their loved ones to make poor financial decisions.

*Published in the scientific journal Neurology, 11/14/17*
Isolation and “care burden” are higher

What can we do?
Focus on quality of life

Maximize inclusion of person with FTD
Adjust expectations
Maximize engagement
Do preferred activities - differently
Assess needs of the family system
Attend to needs of each member

The best intervention is a well-informed, empowered person with FTD and care partner.
Disease Education

Education promotes empowerment for family and providers

- FTD subtypes
- Symptoms result from the disease process (not within the person’s control)
- Pathology, genetics and potential family risk
- Importance of research and emerging clinical trials.
Specialized Care

Alzheimer’s disease approaches are not sufficient in FTD

• Alzheimer’s disease meds not indicated
• Intact memory requires different approaches
• Areas of ability and impairment confuse people—“He seems fine to me.”
• Person with FTD & family equal recipients of services
Specialized Care

Non-pharmacological interventions
● Productive daily routine
● Simplified, structured environment
● Supervision

Assess for safety regularly
● Declining judgment; lack of awareness & apparent health complicate care
● Inconsistencies day to day
● Ensure safety ($$, guns, tools, roaming)
Advocate for Services

Finding appropriate services is difficult
- Many healthcare, community, legal services not familiar with FTD
- Eligibility issues under 65

Advocacy for benefits
- Retirement and disability benefits
- SSDI, Medicare

Facilitate coordination of care
- Transitions common and challenging
- Acute hospitalizations & med changes

FTD families must educate, advocate AND provide care
FTD-specific Support

Support from those who understand is critical.

- Peer-support (face to face, phone, online)
- Reframe pre-diagnostic phase (guilt, hurt)
- Reframe relationships
- Understand the impairment others don’t see

- Creative problem-solving assistance
- Identification of local resources
- Encourage use of individual, child & family counseling
Awareness of Research

Participation in the FTD Disorders Registry

www.ftdregistry.org
Supporting FTD Families Requires

- Awareness of Research
- Individualized & Coordinated Care
- Disease Education
- Advocacy
- Help & Hope
- FTD Peer Support
AFTD Resources

Behavioral Variant FTD (bvFTD)

Know the Signs...Know the Symptoms

Understanding various FTD, the most common form of FTD, is responsible for three-fourths of cases of the disease FTD is the brain disorder in which symptoms begin as early as age 40.

Signs of early-onset dementia can include:

- Dementia
- Memory problems
- Problems with language
- Problems with reasoning
- Changes in behavior

Visit www.theAFTD.org for more information.

www.theAFTD.org
HelpLine: 866-507-7222
info@theAFTD.org
www.AFTDkidsandteens.org
Questions and Discussion
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Thank you