EXPLORING OTHER FORMS OF DEMENTIA:

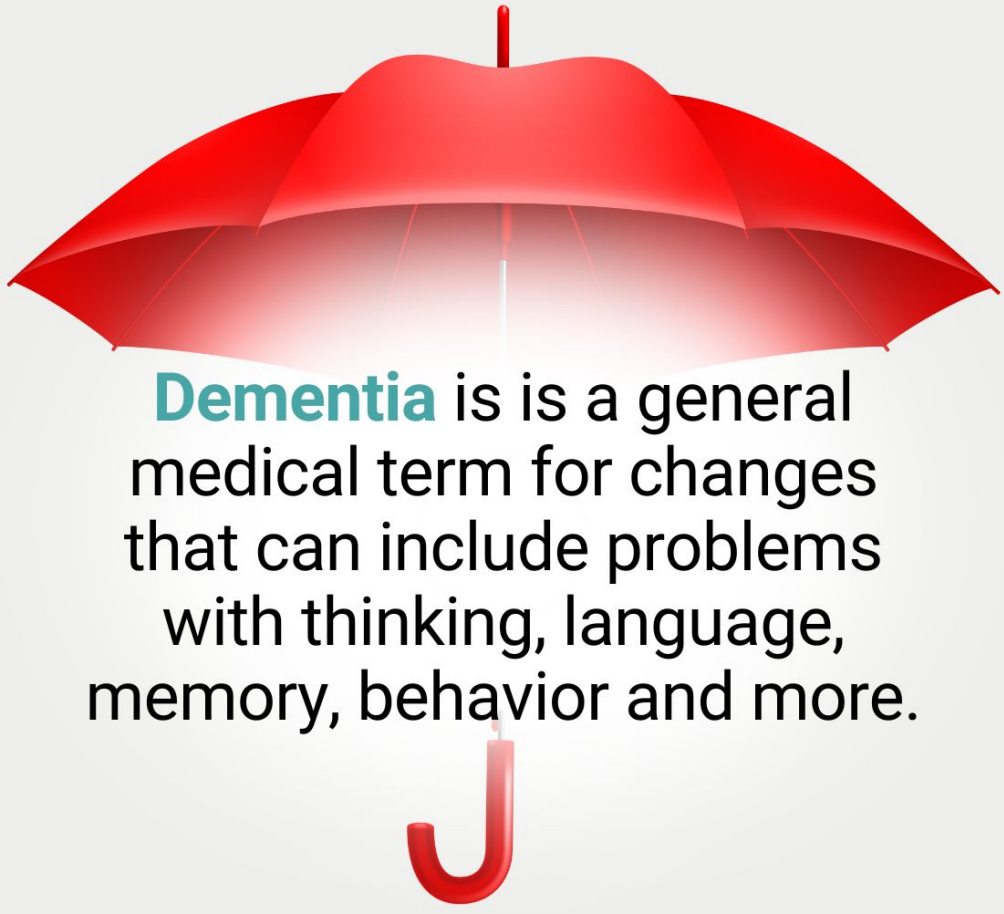
Frontotemporal Degeneration, Parkinson's Disease Dementia, and Dementia with Lewy Bodies

Spencer Cline - Georgia Ambassador with The Association of Frontotemporal Degeneration

Annie Long - Senior Director, Community Education & Outreach with the Parkinson's Foundation

Brandi Hackett - Senior Manager of Support Services with the Lewy Body Dementia Association

What is dementia?



Some of the most common causes of dementia are:

- Alzheimer's Disease
- Lewy Body Dementia
- Frontotemporal Degeneration (FTD)
- Vascular Dementia
- Mixed Dementias

Frontotemporal Degeneration

Spencer Cline, Georgia Ambassador
The Association of Frontotemporal Degeneration

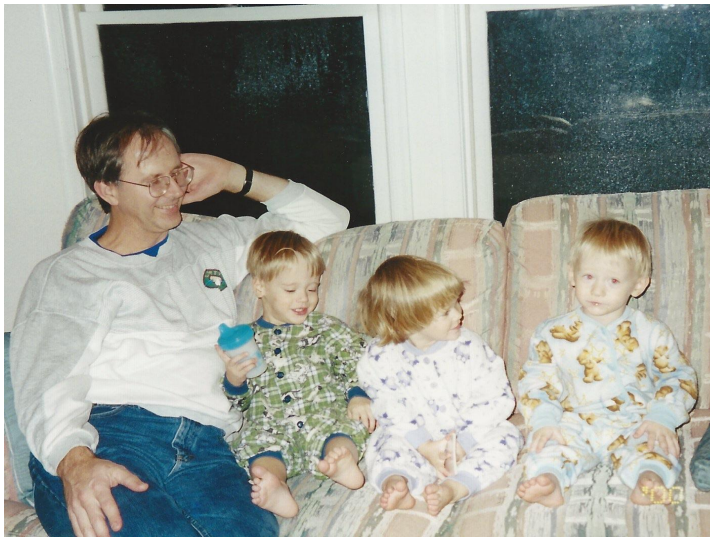
2025 DOUBLING DOWN on Dementia
DEMENTIA SYMPOSI

Understanding FTD

- FTD is not caused by a single disease but caused by a cluster of complex disorders
- Most common dementia for people under 60
- Initially impacts behavior, language or movement
- Research suggests that there are about 50,000-60,000 people who have FTD in the US

Getting Diagnosed With FTD

- FTD can take up to 3.6 years to diagnose
- Families report seeing up to 6 physicians before receiving a diagnosis
- Most common misdiagnoses are Alzheimer's or Depression
- 50% of patients with bvFTD receive a prior psychiatric diagnosis
- Tau, TDP-43 and FUS proteins can be part of the FTD disease process



Economic & Social Costs of FTD

$99K

$50K

12 months before an FTD diagnosis, most families reported a household income in the $75,000–$99,000 range

12 months after diagnosis, income fell as much as 50%

FTD VS **ALZ**

Overall, families dealing with FTD face an economic burden of approximately

$120,000

each year — roughly twice the economic burden of Alzheimer's.

37%

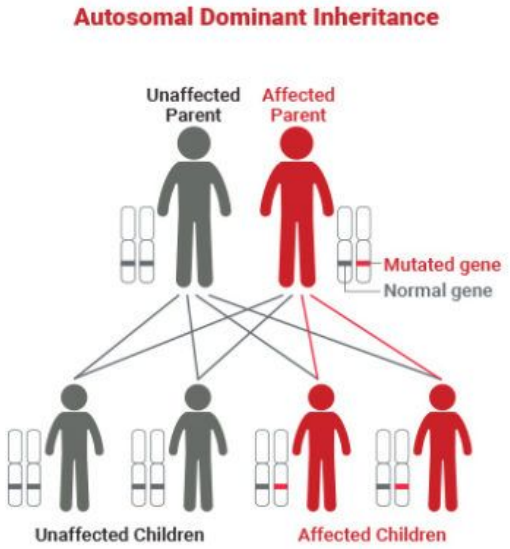
of FTD caregivers said they stopped working post-diagnosis

58%

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

Genetics and FTD

- 60% is sporadic FTD
- 40% is familial FTD
- 20% is genetic FTD
- Majority of genetic FTD is caused by three genes: *C9orf72*, *GRN*, and *MAPT*
- At least 9 more very rare variants are known to cause FTD, and more may be discovered



FTD Treatments & Therapeutic Interventions

- Currently: No disease-altering treatment to stop or slow the disease
- Active research is looking for treatments and effective therapies
- There are effective treatments that can manage symptoms
- Supportive therapies: Speech Therapy, Physical Therapy, Occupational Therapy, Support Groups, Palliative care, Dementia-friendly spaces

The Association for Frontotemporal Degeneration (AFTD)

AFTD's mission is to improve the quality of life for people affected by FTD and drive research to a cure. We work every day to advance:

- Research. We promote and fund research toward diagnosis, treatment and a cure
- Awareness. We stimulate greater public awareness and understanding
- Support. We provide information and support to those directly impacted
- Education. We promote and provide education for healthcare professionals
- Advocacy. We advocate for research and appropriate, affordable services

Resources from AFTD

HelpLine: info@theaftd.org

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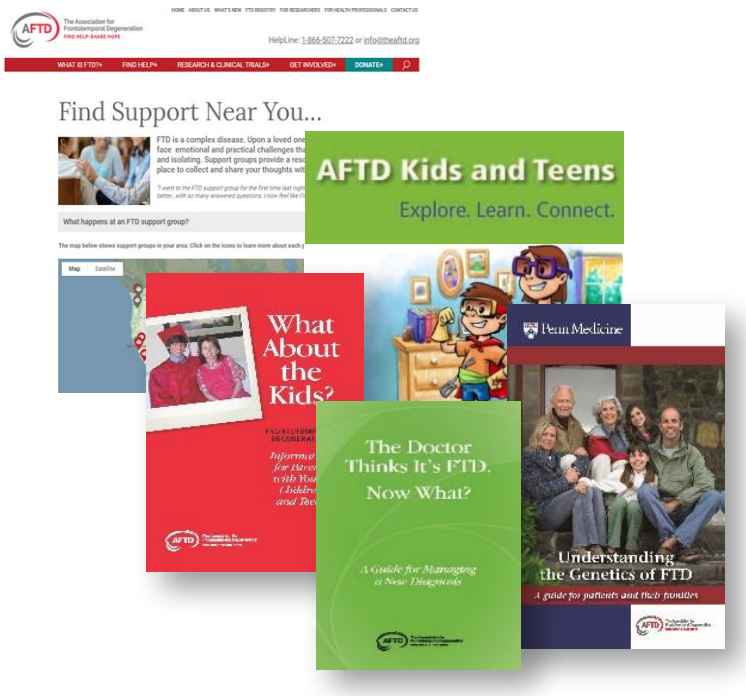


Parkinson's Disease Dementia

Annie Long
Parkinson's Foundation

Understanding Parkinson's Disease

- Chronic, progressive brain disorder that affects movement, mood, and cognition
- Caused by the loss of dopamine-producing neurons in the brain
- 90,000 new cases in the U.S. annually
- Motor and non-motor symptoms

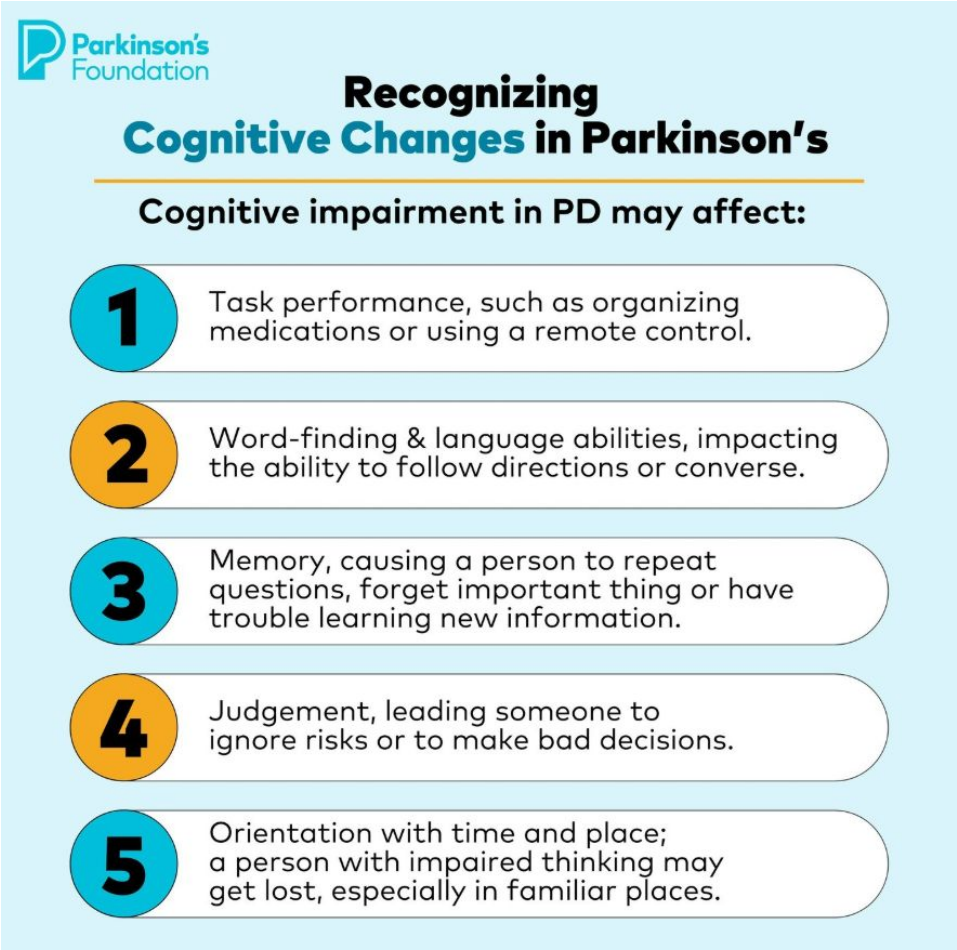
Fastest growing neurological disorder in the world – "Parkinson's Pandemic"

Getting Diagnosed with Parkinson's

- No single test to diagnose
- Clinical examination
- Response to dopaminergic medications
- Can take years to get an accurate diagnosis
- Rule out other conditions that mimic Parkinson's

Cognition Changes & Parkinson's

- Cognitive changes are common and may range from mild to more severe
- Affects memory, attention, planning, and multitasking
- Mild Cognitive Impairment (MCI) does not mean dementia
- About half of people with PD will experience MCI at some point during their illness

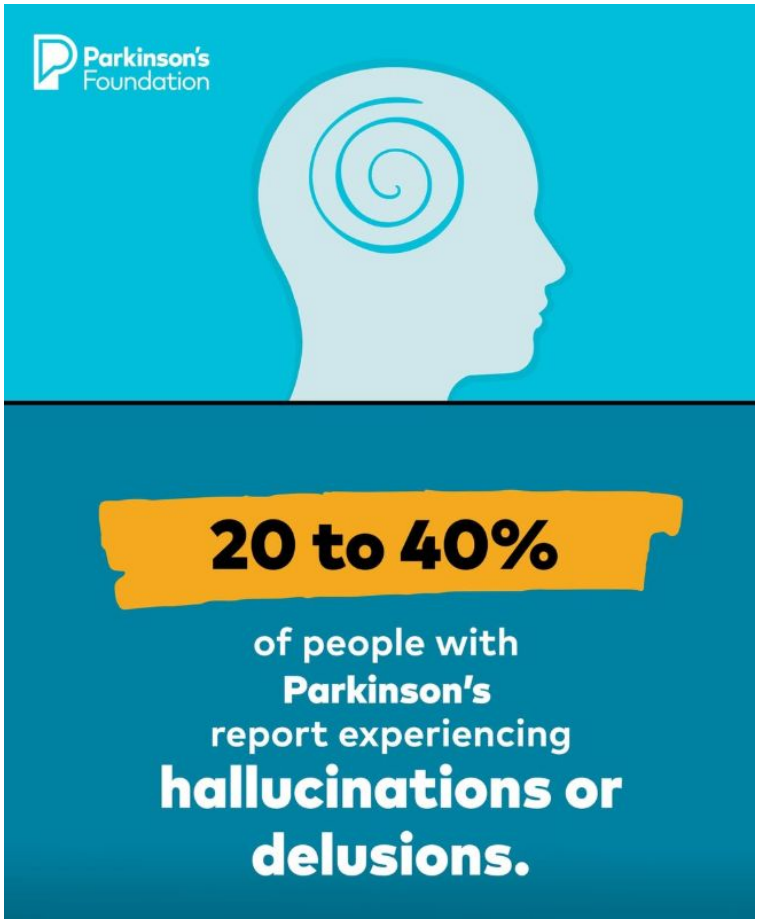


Dementia & Parkinson’s

- Permanent cognitive changes significant enough to affect daily living activities
- Sudden changes may indicate other causes like delirium or infections
- Up to 70% of people with Parkinson’s will develop dementia (usually in later stages)
- Parkinson’s disease dementia (PDD) is the most common type of dementia in Parkinson’s

Parkinson's Disease Dementia

- Changes in thinking and behavior that progress at least one year **after** motor symptoms
- Alpha-synuclein (protein central to PD) forms sticky clumps called Lewy bodies - can disrupt brain function and lead to dementia
- Symptoms include:
  - Memory changes and confusion
  - Mood changes like agitation, irritability, aggression
  - Hallucinations and delusions
  - Visual-perceptual problems
  - Language challenges like word finding difficulty, slurred speech



Treatment Options

- Parkinson's disease is treated with dopaminergic medication, surgery, exercise, rehab therapies
- Medications used for Alzheimer's have shown to benefit those with Parkinson's disease dementia
- Cognitive remediation therapy and behavior management
- Exercise supports brain health and neuroplasticity

Resources & Support

- Parkinson's Foundation offers education, support resources and community programs
- Resources in English/Spanish: Parkinson.org
- Parkinson's Foundation Toll-free Helpline: 1-800-4PD-INFO (473-4636) or Helpline@Parkinson.org

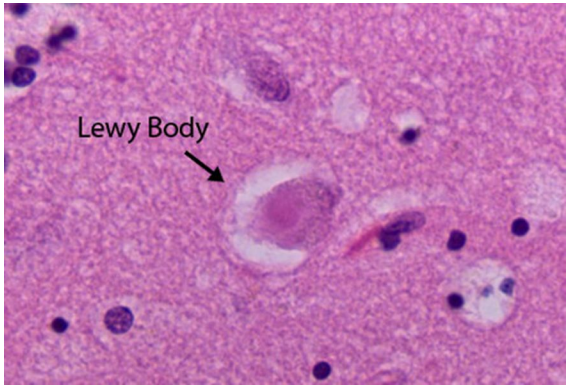
Dementia with Lewy Bodies

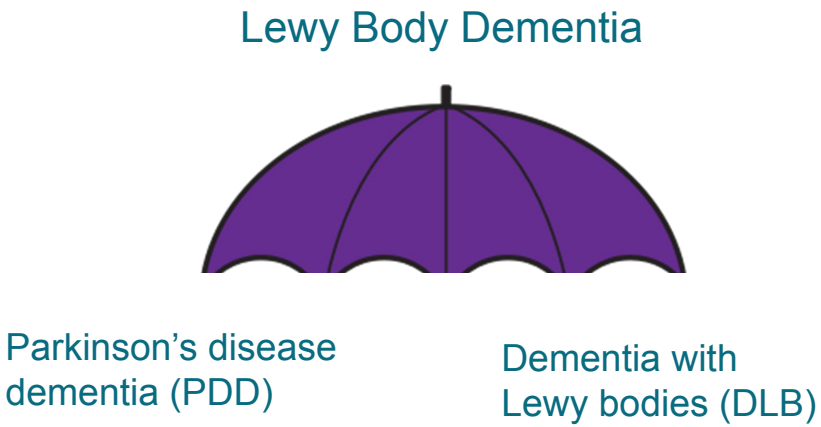
Brandi Hackett, LCSW, C-ASWCM
Senior Manager Support Services
Lewy Body Dementia Association

2025 DOUBLING DOWN on Dementia DEMENTIA SYMPOSI

Understanding Dementia with Lewy Bodies

- A progressive brain disorder
- Features abnormal protein deposits, called Lewy bodies, in the brain
- Named after Dr. Friederich Lewy, a neurologist
- Difference in diagnostic criteria based on timing of symptoms with “One Year Rule”





Diagnosing DLB

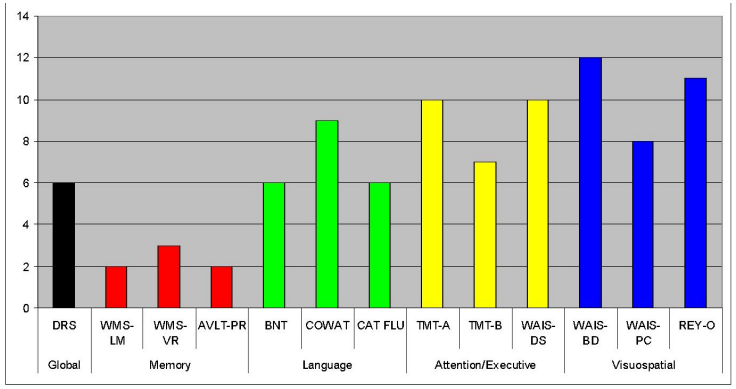
To diagnose someone with DLB, there must be enough cognitive decline to impair daily activities, plus two of the following features:

Parkinsonism	Visual Hallucinations	REM Behavior Disorder	Cognitive Fluctuations
• Slowness • Stiffness • Shakiness	• Well-formed, complex visions • People and/or animals	• Acting out dreams • Can occur decades before other symptoms	• Changes in level of alertness or arousal • "Zoning out"

All of these symptoms can also occur in Parkinson's disease

Differences in Alzheimer's Disease & Dementia with Lewy Bodies

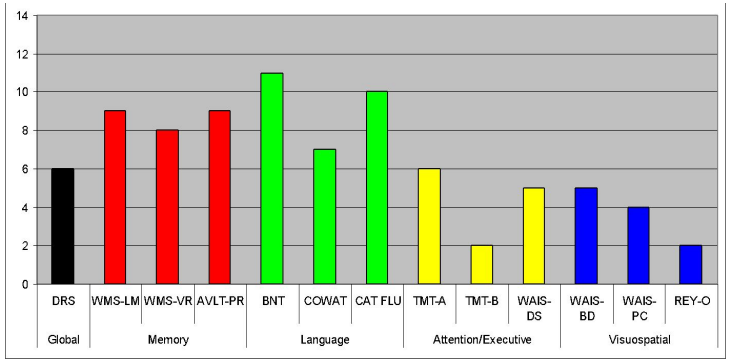
ADem



Impaired on:

- Memory measures
- Language measures

DLBs



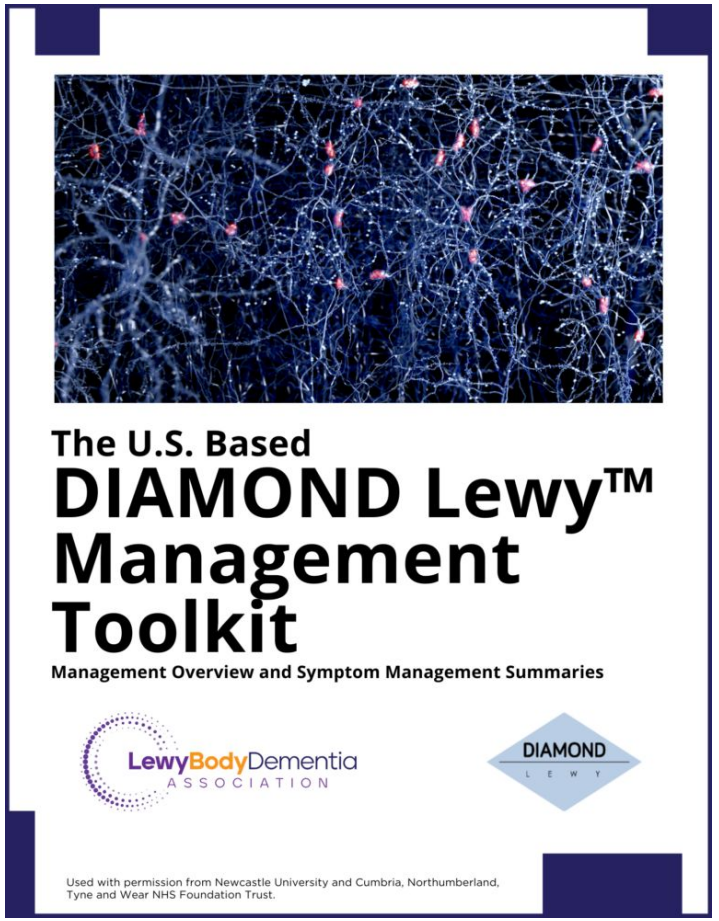
Impaired on:

- Attention/Executive measures
- Visuospatial measures

(Ferman et al, Neurology 1999)
(Ferman et al, Clin Neuropsych 2006)

Treatment and Education Options

- LBDA.org
- Lewy Digest
- LBDA community webinar series
- LBDAtv
- LBDA printed publications
- The Lewy Learning Center
- Mediflix



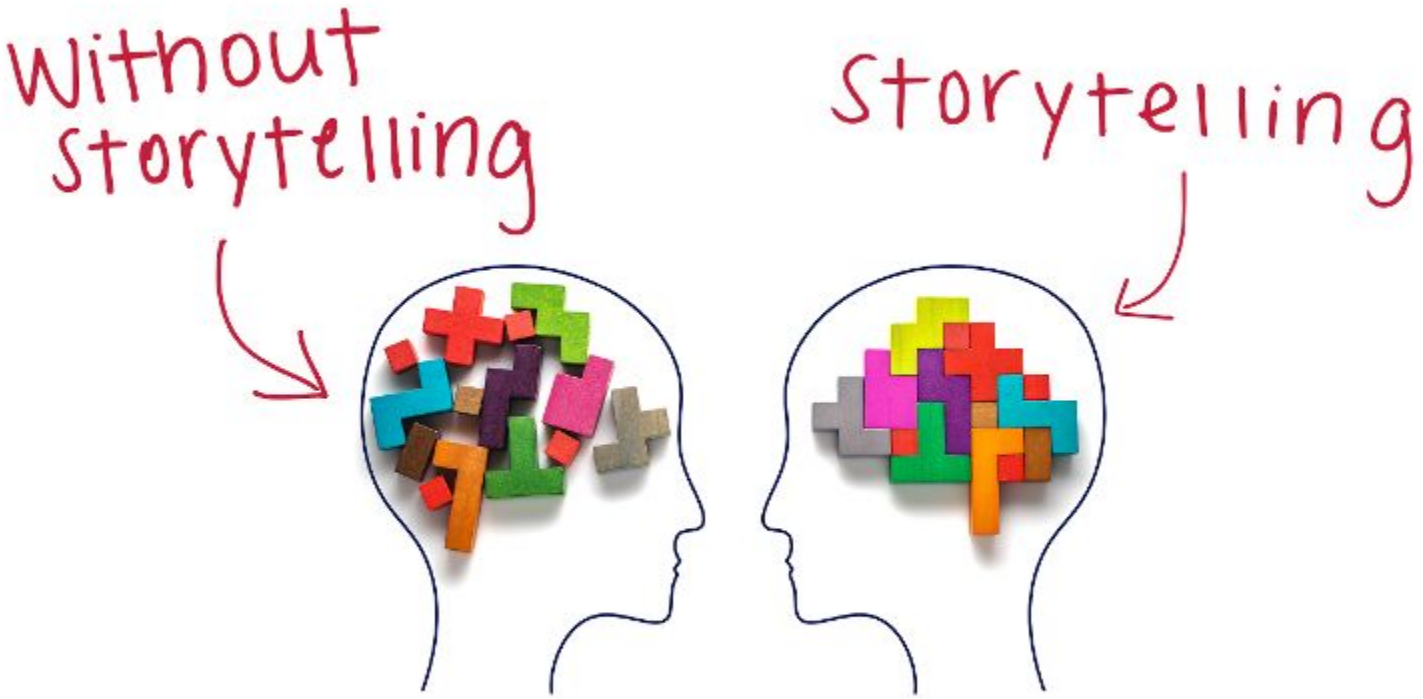
LBDA Support for Professionals and Families

LBDA Lewy Line and Support Email - Those living with symptoms or a diagnosis of LBD, care partners, and involved professionals can connect to licensed Support Services staff through the LBDA Lewy Line or Support email for guidance, information, resources, and connections.

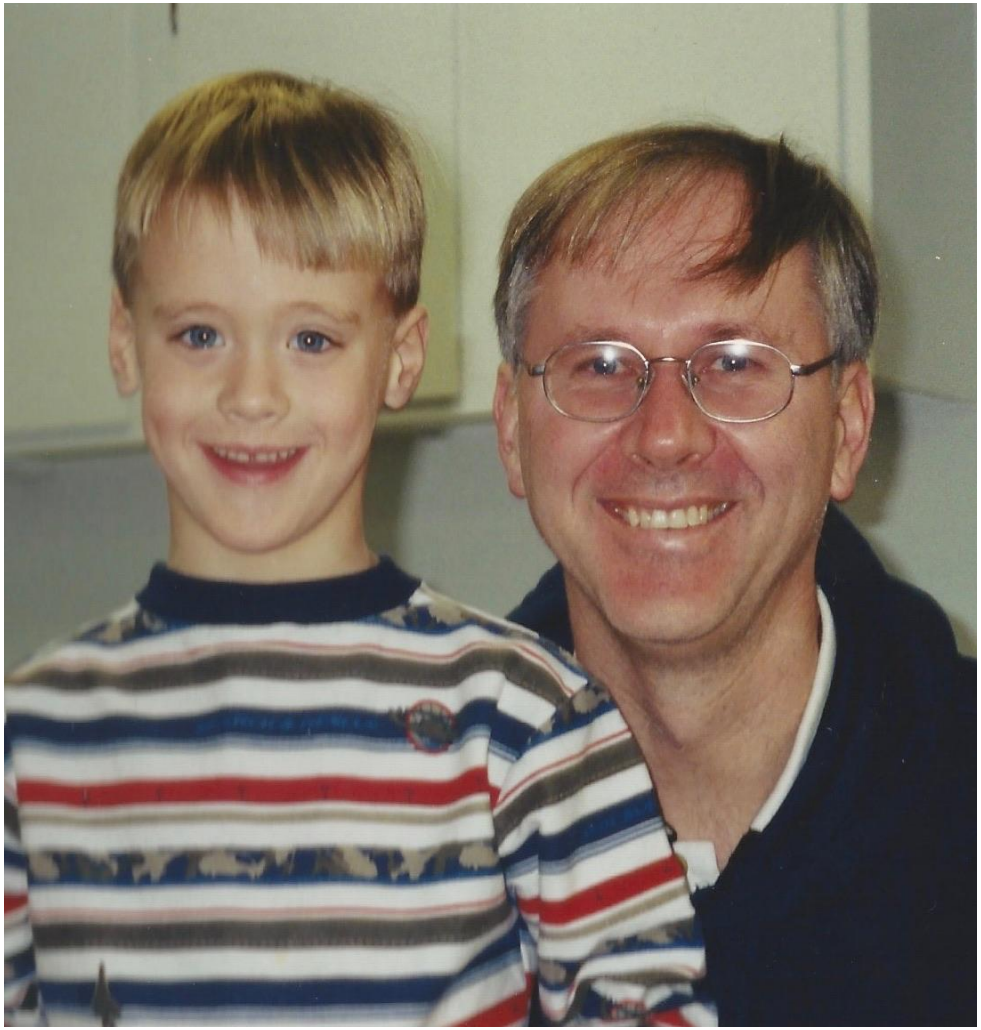
- **Lewy Line phone number** - **800-539-9767**
- **Support email –** Support@LBDA.org

We can assist individuals to connect with support groups, Lewy Buddy mentoring volunteers, Support Facebook platforms, and resources.

Exploring Real Life Stories with Other Forms of Dementia



FTD From a Child's Perspective



Panel Discussion with Annie and Brandi

- **Annie** - What similarities do you see with Parkinson's disease dementia (PDD) and my story?
- **Brandi** - What similarities do you see with dementia with Lewy bodies (DLB) and my story?
- **Annie** - What differences do you want to point out that individuals and their families may struggle with that are unique to PDD?
- **Brandi** - What differences do you want to point out that individuals and their families may struggle with that are unique to DLB?

What questions might you have?

As a reminder – there is support available!

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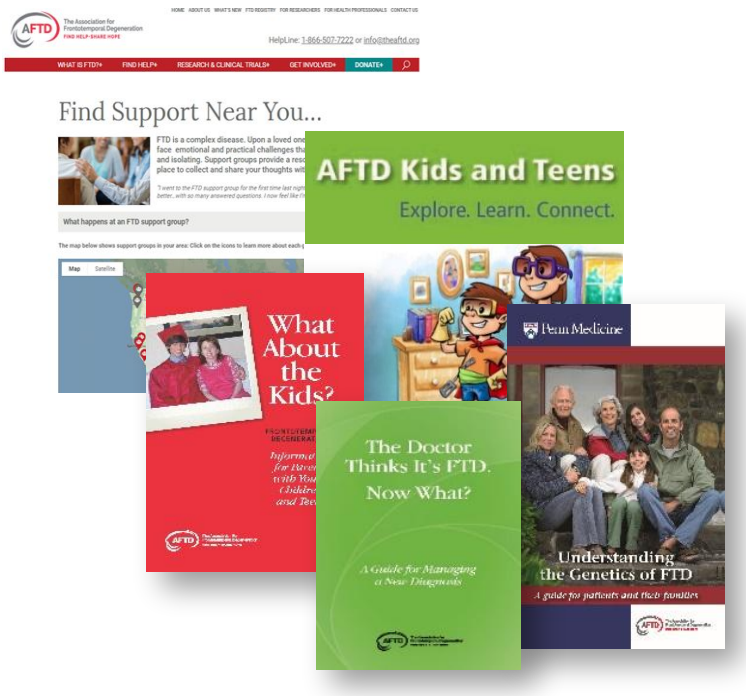

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THANK YOU FOR JOINING US TODAY!

Your donation helps us build dementia preparedness in our communities with impactful programs like this symposium.

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AND, PLEASE COMPLETE YOUR SURVEY !

ALZHEIMER'S ASSOCIATION

GEORGIA CHAPTER

Beyond Dementia Coalition