



It Takes a Team: Supporting The Person and The Care Partner in LBD

Kevin Webb-Kay, MD | Annie Adix, PT, DPT
Emily Furseth, MSW, LICSW

DRIVING AWARENESS, EDUCATION,
RESEARCH AND SUPPORT FOR THE
LEWY BODY DEMENTIA COMMUNITY

1



It Takes a Team: Medical Support

Kevin Webb-Kay, MD

DRIVING AWARENESS, EDUCATION,
RESEARCH AND SUPPORT FOR THE
LEWY BODY DEMENTIA COMMUNITY

2



The Medical Team

- Neurologist with specialization in LBD (movement disorder or cognitive neurologist)
- Primary care doctor
- Pre-existing specialists
 - May be involved at some point:
 - Psychiatry
 - Cardiology
 - Palliative Care



shutterstock.com - 2689726693

3



Lewy Neurologist

- Subspecialty in movement disorders or cognitive neurology
- Specialization and experience are important for LBD
 - Many challenges patients and families face or common in LBD but uncommon in other populations
 - Comfortable discussing trade-offs and some ambiguity
- Provide an accurate diagnosis and consider comorbidities
- Give helpful prognostic information, when desired



4



Primary Care Physician

- For all types of cognitive impairment general health care remains important
 - Blood pressure, cholesterol, sugar/diabetes, falls, head injuries, smoking, accidents, avoiding certain medications, hearing impairment all have evidence they influence cognitive impairment



5



Primary Care Physician

- Other things may come up!
- Certain paperwork, orders etc. are often done by a primary doctor and not your Lewy neurologist
- **Strongly consider having your PCP and neurologist in the same health system if possible**
- **If not possible, consider large health systems (Allina, MHealth, HealthPartners)**



6



Who else may be pulled in?

- Cardiology
- Psychiatry
- Urology
- Gastroenterology
- Palliative Care
 - Specific session after lunch on palliative care!
- Again, consider if it's possible to have these all under one roof



7



- If there is a key difficulty in your life, it may or may not be a physician who has all the answers
- Support groups, friends, social workers, rehab specialists, my mother-in-law's neighbor's friend from down the street...
- It does take a team so steady yourself and consider what's available to you



8



Key Points and Takeaways

- Experience and expertise matters in LBD
- Coordination and Communication Matters
- "Homework"
 - Find a Lewy Neurologist or at least someone you are comfortable with
 - Have a PCP and check in with them about general health screenings and care
 - Consider if you can consolidate care within one system or at least large systems



9



It Takes a Team: Rehabilitation Professionals

Annie Adix, PT, DPT

DRIVING AWARENESS, EDUCATION,
RESEARCH AND SUPPORT FOR THE
LEWY BODY DEMENTIA COMMUNITY

10



Re-habilitation? Stage-dependent



- **Restorative efforts**
 - Heal what can be healed
 - Exercise to maximize brain health and physical abilities
- **Strategies, adaptations**
 - Using tools to “stay in the game”
- **Compensations & Care partner instruction**
 - Adapt the environment to the ability level

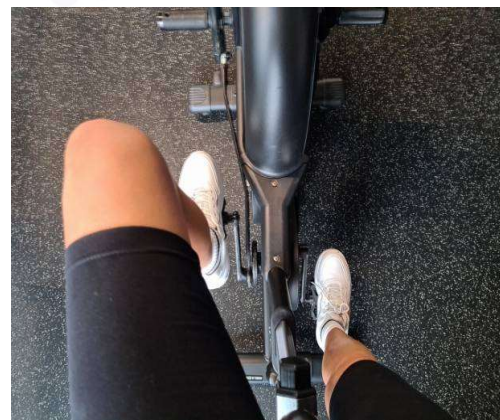


11



Q: Can Exercise Slow Progression?

- **Answer: Probably.** Research is promising in this area.
- Good for heart = good for brain
- Familiar is best – so get familiar!
 - Bike, elliptical, walk, familiar sport
- Aerobic activity recommendation:
 - 150 minutes/week of elevated heart rate
 - = 30 minutes x 5 days/week or so
- Alternate with **meaningful REST**
 - Meaning: not in front of a screen!



12



Rehabilitation Challenges in LBD

Difficulty with independent initiation

Harder to accurately report pain

Reduced dual tasking ability – “Double Burden”

Reduced perception of one’s own movements

Difficulty processing elaborate body instructions



Struthers Parkinson's Center

13



Expertise Matters: Physical Therapy



- Target specific deficits
- Address equipment concerns
- Optimize movement strategies for gait, apraxia, visual, and balance changes
- Work to find the “sweet spot” to challenge without overwhelming the nervous system
- Work with care partners to streamline cues and expectations



Struthers Parkinson's Center

14



Occupational Therapy

- Target functional cognition
- Equipment and tools for self-care and driving
- Daily life strategies for apraxia, visual changes, and fine motor & handwriting deficits
- Work with care partners to streamline cues and expectations
- Home safety & logistics assessment



 Struthers Parkinson's Center

15



Speech Therapy

- Target specific cognitive deficits and areas of concern
- Address voice volume and speech intelligibility
- Daily life strategies for changes in swallowing
- Work with care partners to streamline cues and expectations



 Struthers Parkinson's Center

16



Movement Challenge: Parkinsonism

- Smaller, slower, stiffer movements
 - Hypokinesia
 - Bradykinesia
 - Tremor (sometimes)
- Shuffling, or freezing of gait
- Reduced “autopilot” – requires focus – Double Burden
- Movement is harder with distraction
- **Strategy: Physical Therapy Specialist**



 Struthers Parkinson's Center

17



Challenge: Visual-Perceptual Changes



 Struthers Parkinson's Center

18



At home: Visual-Perceptual Changes



19



Addressing Visual-Perceptual Changes

- **Specialist might suggest:**
 - Ask what is seen
 - Higher contrast, fewer patterns
 - e.g., bright washcloths on armrests
 - Adequate lighting / night lights
- **Strategy: Occupational Therapy Specialist** – consider home assessment



 Struthers Parkinson's Center

20



Functional Challenge: Apraxia



Apraxia is the inability to execute purposeful, previously learned motor tasks, despite physical ability and willingness to do it.

(Huang & Levin, 2023)

WC brakes
Use of walker
Eating utensils
Hygiene tasks

(Image Credit: Anne Adix)



Struthers Parkinson's Center

21



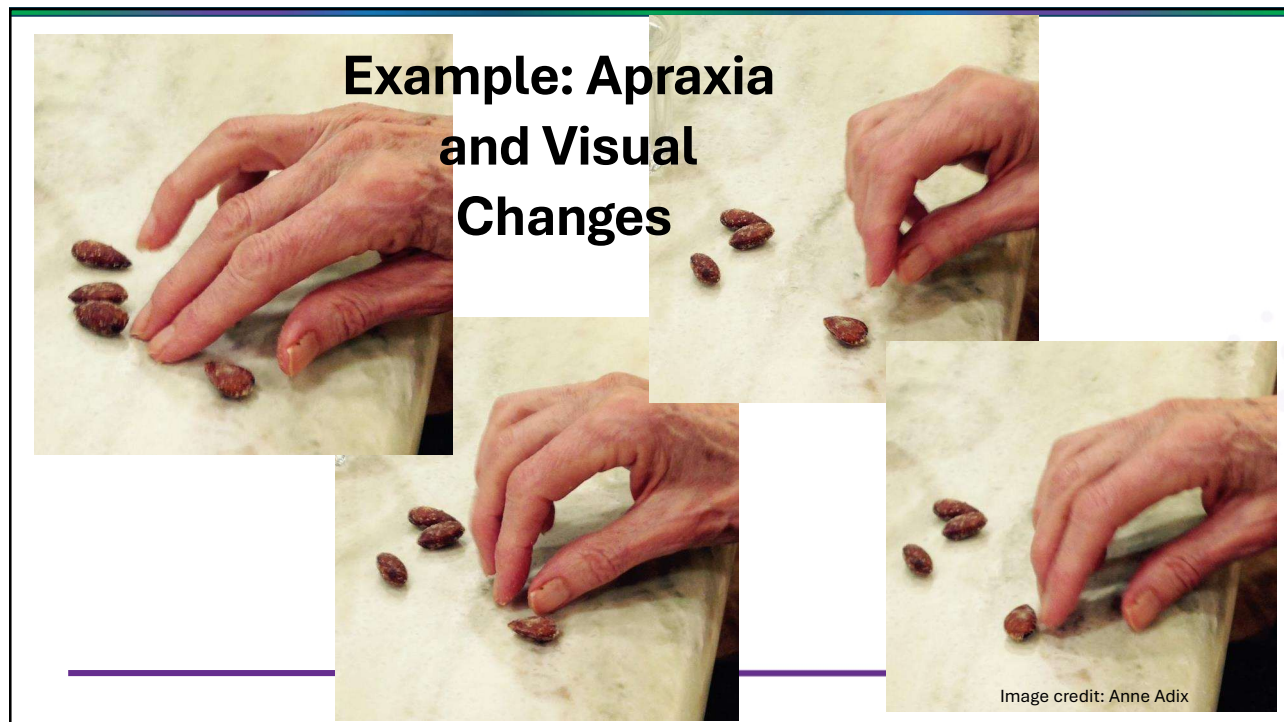
Cueing Apraxia

- **“Double Burden” of processing language cues plus body movement at the same time**
- **Fewer words = less to process**
- **Task specific cues (instead of body specific)**
 - Instead of “put your hand here,” try “touch the armrest”
 - “Here you go”
- **Examples of non-verbal cues:**
 - Patting a chair
 - Tapping a handrail
 - Hand over hand



Struthers Parkinson's Center

22



23



LewyBodyDementia
ASSOCIATION

Conclusion: Rehab Team in LBD

- When the going gets tough, use your rehab team
- Seek therapists who specialize in Lewy Body & Parkinson's
- When it comes to exercise, it does not have to be perfect to be good!
 - Change what we can
 - Accommodate what we cannot change = GRACE
 - Increase meaningful rest
- "I didn't know what you would be able to do for us. But I'm so glad we came."



Struthers Parkinson's Center

24

Find the Right Balance

Adaptations
Expertise
Accommodations

Exercise

Rest

Cues

Independence

Team

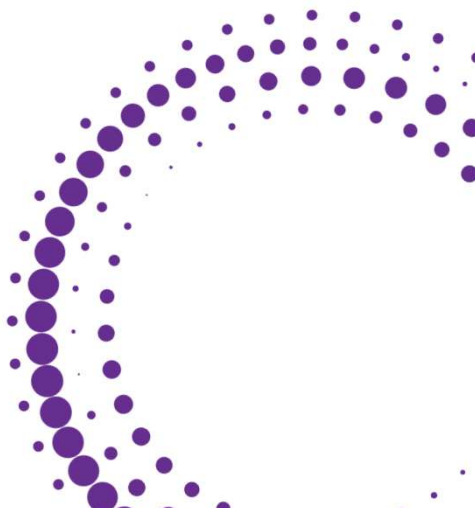
 **Struthers Parkinson's Center**

25

**It Takes a Team:
Social, Emotional, and Community
Support for the Climb**

Emily Furseth, MSW, LICSW
DRIVING AWARENESS, EDUCATION,
RESEARCH AND SUPPORT FOR THE
LEWY BODY DEMENTIA COMMUNITY

 **Struthers Parkinson's Center**



26



Climbing the Mountain Together

Living with Lewy Body Dementia is not a trek that anyone would choose...

- Unfamiliar terrain
- Unexpected changes
- Stretches that are exhausting, scary, or lonely

But living well with Lewy is possible when we make the journey together.



27



Informal Supports: Building a Ropes Team

- Care Partner(s)
- Family/adult children
- Friends/neighbors/members of faith community or place of worship
- Professional Caregivers
- *Social Workers can help you tap into your supports*



28



What Is a Ropes Team? Why Does it Matter?

- More than observers...people who experience day to day life with you...if you slip, they feel it
- Different than the experts, the guides, those who help you navigate
- These are the people who are with you day-to-day, bringing the lasagna, helping with rides, making the appointments, giving your care partner breaks



shutterstock.com · 1359558083

29



The Most Critical Support Person: Your Care Partner(s)

The ones who are there for *"the other 23 hours of the day..."*

- Most report feeling ill-prepared and having little to no support.*
- If no one has thanked you yet today – **THANK YOU.**
- We see you, we appreciate you.



*Sources: Family Caregiver Alliance, AARP Caregiving in the US Survey, 2025

30



Caregiving...It's Not a One-Person Job

- Caregiving is not a one-person job, even if you are doing it alone.
- The best ropes teams are made up of 3-5 people.
- Alpine climbers know that a ropes team of 2 is an accident waiting to happen.



Emily's brother climbing Laurel Mountain near Mammoth, California.

31



A Case for *Interdependence*

- Total independence *cannot* be the goal here
- We need each other
- **Dependence or *Interdependence* is our natural state of being, just more obvious to us with illness and disability**



32



Adult Children & Family

- Be honest with your busy children (if applicable) about what kind of help you need from them
- What if we are meant to be each other's burdens?



33



Friends, Neighbors, Faith Community



- Friendships change – grief is normal, *but don't miss the chance to forge new connections*
- Help and support from friends requires vulnerability and honesty

34



Professional Caregivers & Living Supports

- **Care in the Home:** help with tasks like meal prep, companionship, supervision...also can help with tasks like bathing, dressing, eating
- **Lean on your social worker to help understand these resources!**



35



Fellow Climbers: Support Groups

- Support Groups & peer support from others who "get it"
- Benefits of support groups
 - Shared experience
 - Shared information



36



Backpacks for the Journey: Social Workers

- What does a social worker actually do?
 - **Coping**
 - **Resources**
 - **Planning Ahead**



37



Backpacks for the Journey: Social Workers

- **Coping**
 - Support groups
 - Therapists
 - Just need to talk...
- **Resources**
 - Transportation
 - Benefits (long term care insurance, veteran's benefits, disability, county/state programs)
- Navigating leave(s) of absence from work
- Insurance questions
- Referrals to community programs
- **Planning Ahead**
 - Options for more care
 - Advance Care Planning

38



Key Takeaways

- Living Well with Lewy is possible, but it takes a team – in addition to experts, leaning into your own support network is essential.
- Consider or reconsider how you might expand your support system.
- Know that we are here to guide you.



39



Thank You

Visit us at: lbda.org

40