Finding Solutions
What I’ve learned.

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• On average it took physicians four office visits to make the diagnosis, with 33% of the respondents reporting more than six office visits.

• An initial diagnosis other than LBD was given in 78% of cases.

• 50% of LBD patients had to see two or more clinicians for symptom management.
A common refrain after an initial diagnosis when many patients return to other providers is ‘They don’t even know what Lewy body dementia is’.

77% of caregivers reported difficulty finding a physician who knew about treating LBD.

40% report feeling isolated.
LBD is Hard on Families

Day to day disease is unpredictable

Overall progression unpredictable

Physicians less knowledgeable

Sleep disorders disrupts the caregiver’s sleep
I feel like I am in quicksand and can’t find solid ground.
I struggle to adjust and adapt to so many changes. I feel so angry. Frustrated. Everything is such an endeavor. Explaining, re-explaining, and then going over it all again.

I keep reminding myself to go slow, stay calm, and take it easy.

I am not doing so great in this role. I want to run away.
Hallucinations
Delusions
Aggression
Agitation
Anger
Apathy
Depression
Anxiety
Why?
THERE'S MORE TO THE STORY
Contributing Factors

- An unsupportive environment.
- Our communication style.
- Unmet social, psychosocial, physical and emotional needs.
It’s a Fan!

It’s a Spear!

It’s a Wall!

It’s a Rope!

It’s a Snake!

It’s a Tree!
LBD: A Different World View

Perception is the interpretation of what we:
• See with our eyes
• Hear with our ears
• Feel with our skin
• Taste with our lounge
• Smell with our nose

Hallucinations
Clutter
Lighting, motion
Noise
Flooring, thresholds
Objects
Contributing Factors

• An unsupportive environment.
• Our communication style.
• Unmet social, psychosocial, physical and emotional needs.
Our Communication

• Slow down the pace of your conversation
• Pause, provide uninterrupted time to allow for recalling information.
• Be clear and concise - Keep message short
• One step requests (attention is major factor in LBD)
• Avoid drawn out explanations.
• Offer choice, but consider fewer to choose from.
• Consider tone of voice and body language.
• Your message
Paranoia—Anger—Fear—Suspiciousness

- Hallucinations or Perceptions
- Delusions (false belief/thinking)
The Imposters

- Most often people or animals.
- Is it disturbing – to whom?
- Avoid arguing, disagreeing or reasoning.
- Ignore.
- Go along with it.
- Find humor.
Delusions

I’m sorry you feel that way, because I love you.
Contributing Factors

- An unsupportive environment.
- Our communication style.
- Unmet social, psychosocial, physical and emotional needs.
Checklist for Emotional Wellbeing

- Feel understood & respected
- Feel safe (fear of abandonment and fear of the unknown common in LBD)
- Have self-esteem boosted
- Feel worthy and productive
- Have a sense of purpose
- Feel connected, a sense of belonging
The most important prescription they (doctors) should be giving people with a diagnosis such as mine is Social Engagement.

Mike
Myth: Those living with LBD can no longer learn new things.
Myth: Those living with LBD can no longer contribute in meaningful ways.
The Brain Is a Boundary

A journey in poems to the borderlines of Lewy Body Dementia

ALEXANDER DREIER
People who have been given this diagnosis can still contribute, learn, and live a meaningful life.

They also still have a voice even if they cannot communicate it in the way they could before.

Please remember that dementia is a disease not a personality trait.

Michael Belleville
For care partners, families and professionals

• Become educated about the disease.
• Be prepared to educate those around you (including physicians)
• Find support and know your community
• Visit the LBDA website