Finding Solutions

What I've learned.

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LBD Caregiver Survey

Lewy body dementia: the impact on patients and caregivers
Yael R Zweig & James E Galvin
Alzheimer's Research & Therapyvolume 6, Article number: 21 (2014)

- 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

LBD Caregiver Survey

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- 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

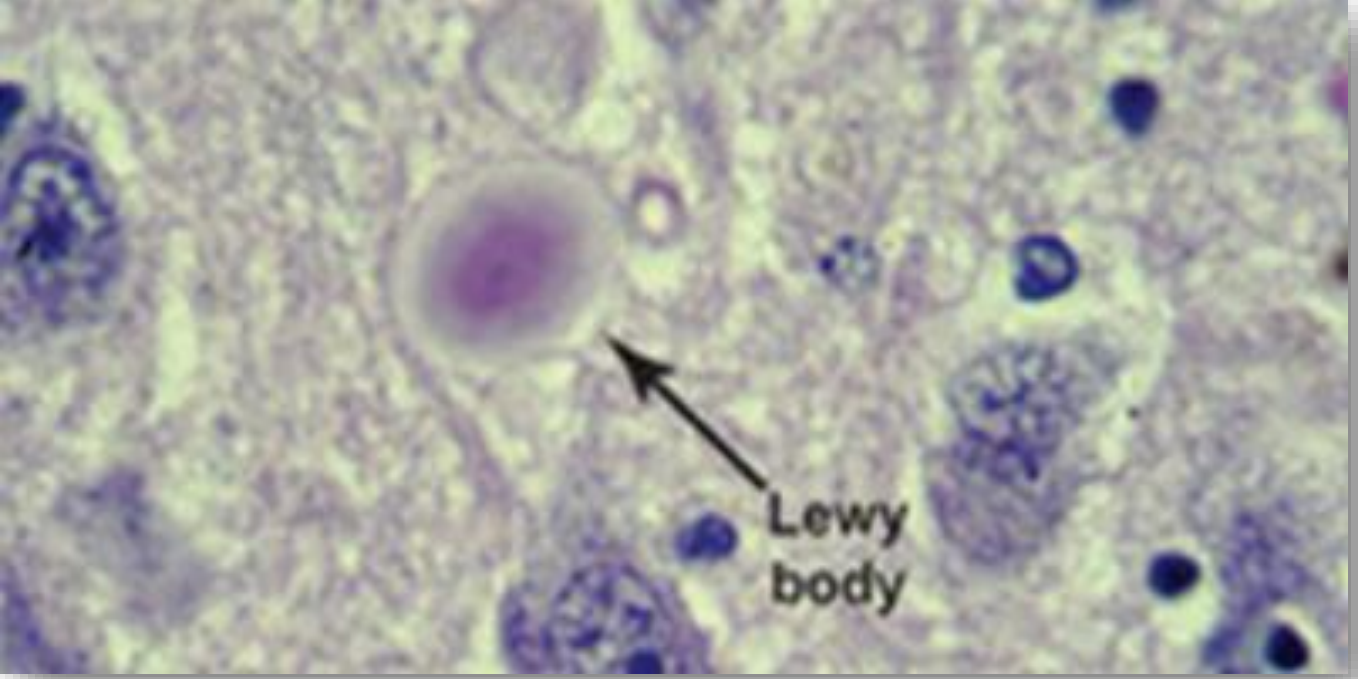
I feel like I am in quicksand and can’t find solid ground.

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

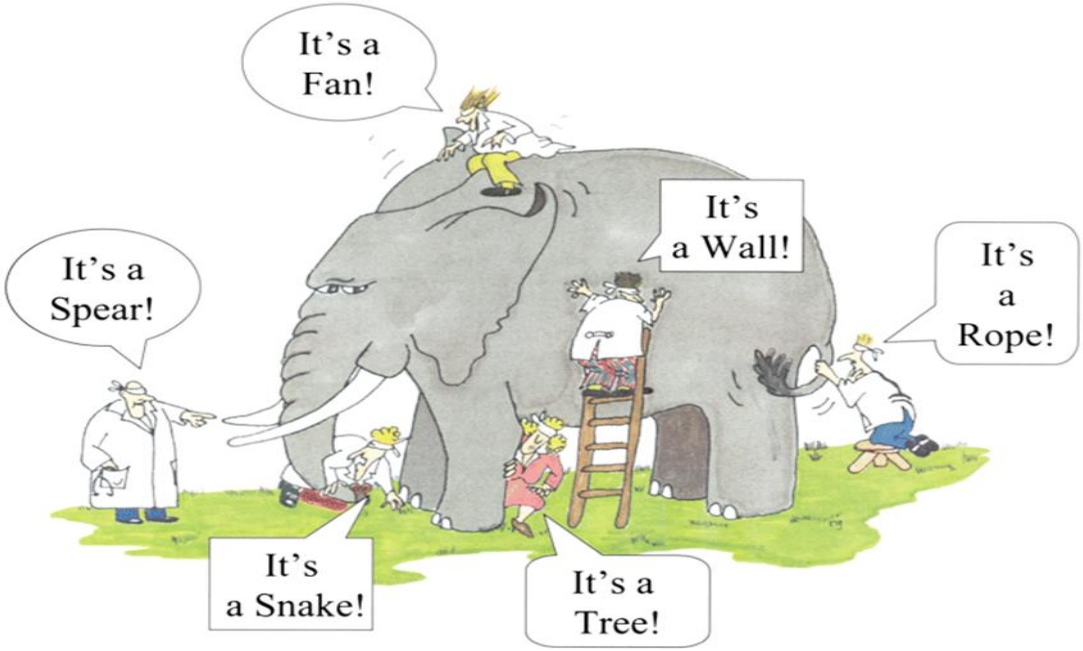


Why?

THERE'S MORE TO THE STORY

Contributing Factors

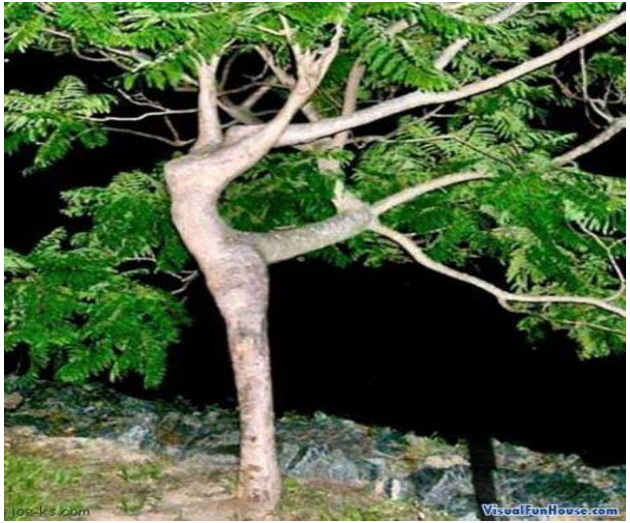
- An unsupportive environment.
- Our communication style.
- Unmet social, psychosocial, physical and emotional needs.


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


VisualFunHouse.com

Clutter
Lighting, motion
Noise
Flooring, thresholds
Objects

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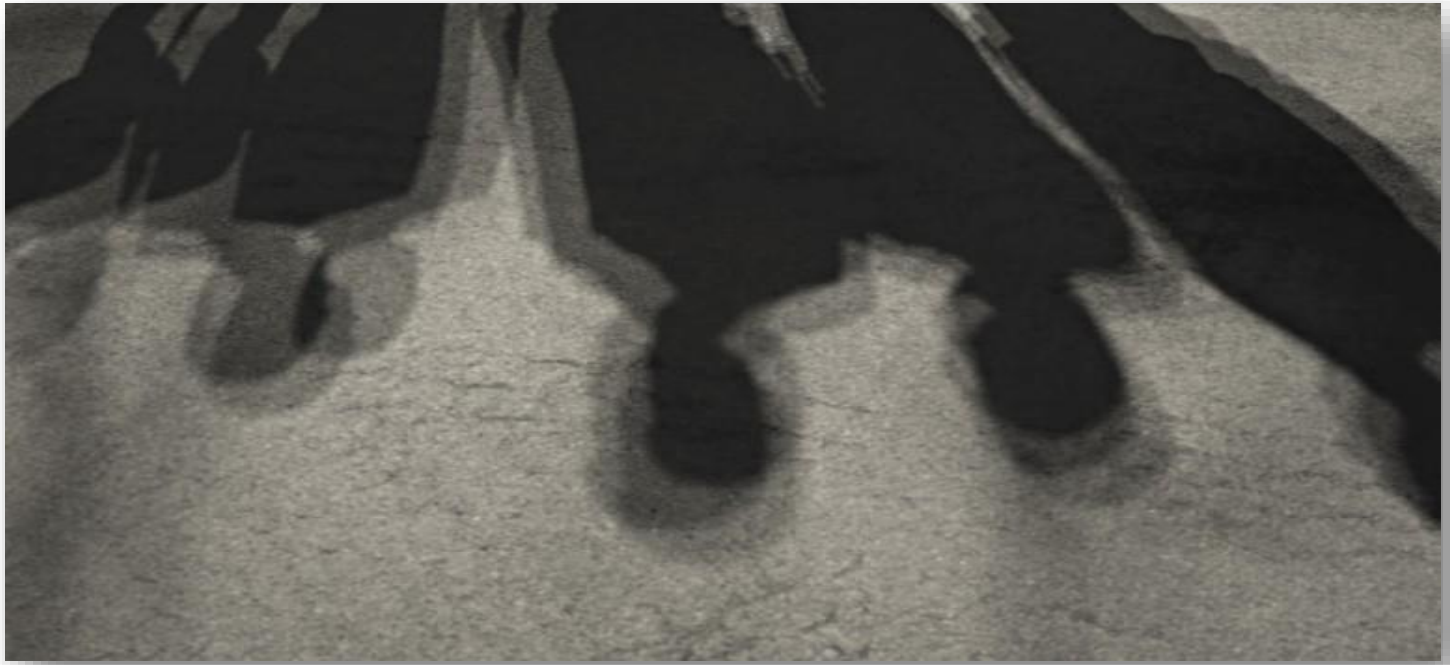
Our Communication

- 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)



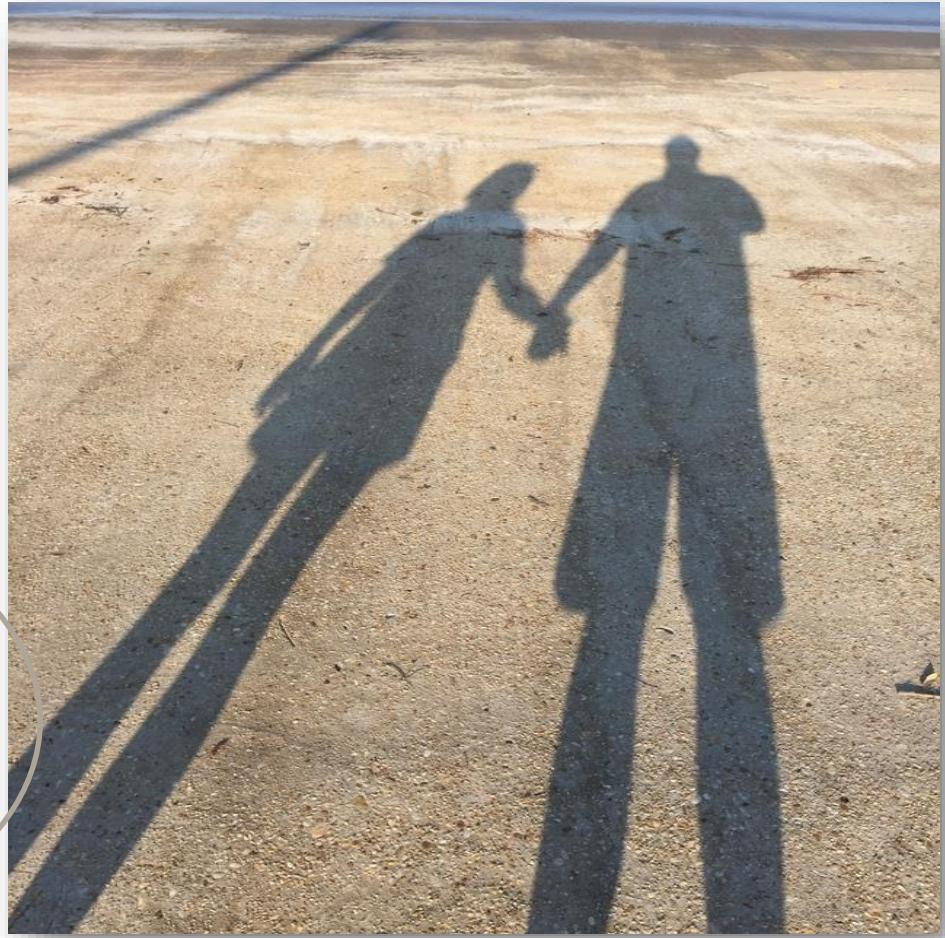
Hallucinations

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.



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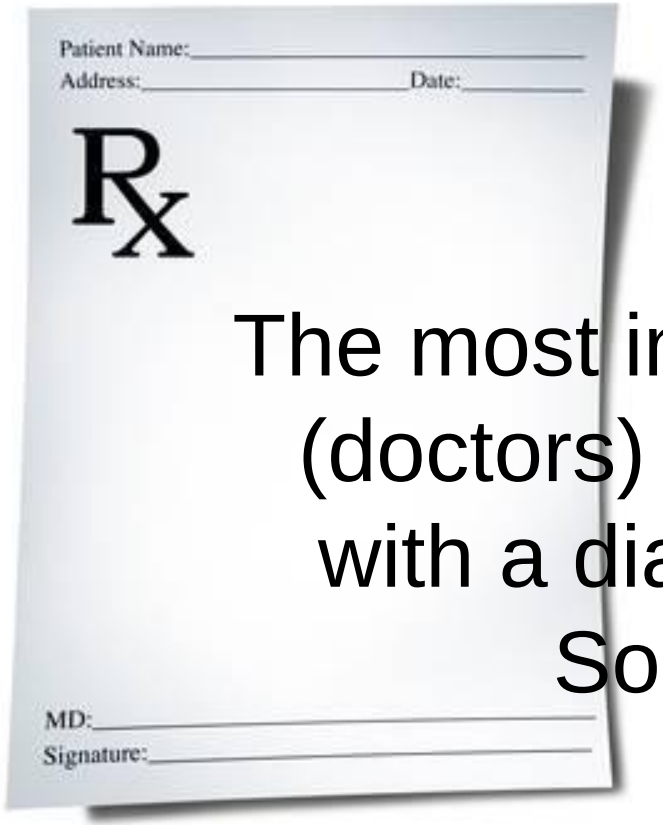
Checklist for Emotional Wellbeing

- ✓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



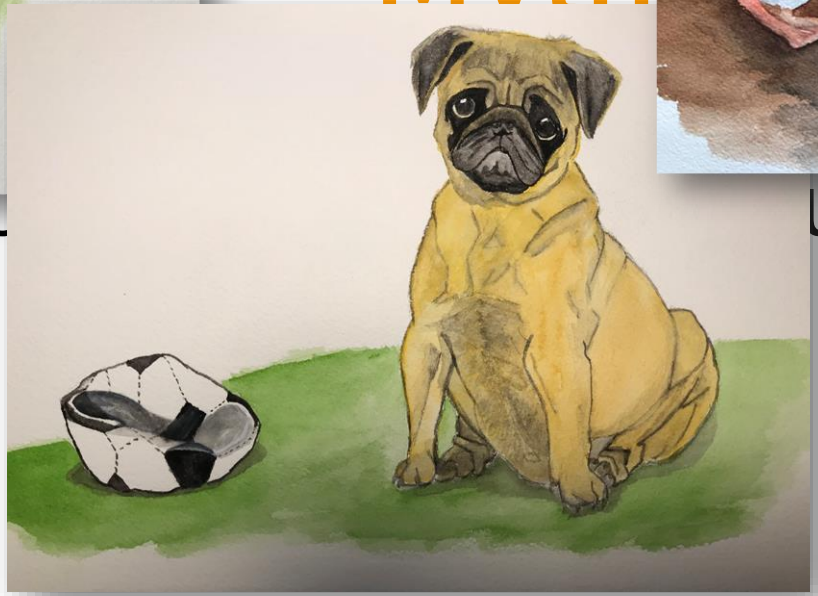
The most important prescription they (doctors) should be giving people with a diagnosis such as mine is Social Engagement.

Mike

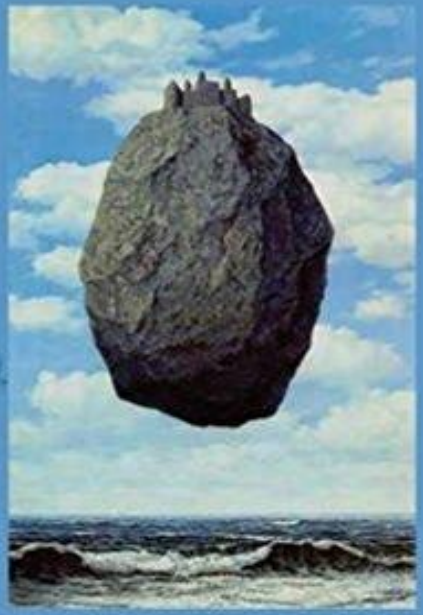

Suggested: Dessert Recipes
Let's get started

Myth

co ul 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