

Lauren With a Side of Lewy

*Perspectives of Living with Lewy Body Dementia
by Lauren U, PAC Core Team*

A few years ago, I was confident and independent. Now I cannot trust my own reality. My judgement is extremely compromised. I still have my sense of humor but find it difficult to



Lauren and Takiya at TROTR

know whether others are serious or joking. It's easier to stay quiet. If you smile, I will try to smile back. If you nod or shake your head, I will try to do the same. If I trust you, it will be completely. That's a lot of responsibility for you.

I will rely on you to properly interpret my world. Did the cashier give me the proper change? I have no idea. Do I really need a shower? Why? Do you hear that? Do you see that? Do you smell that? Are my shoes on the right feet? Are my socks on the right feet? Am I waking up or getting ready for bed? Did we already eat? Why can't I live solely on red bell peppers and Brussels sprouts?

I cannot do small talk. I lose my words and my ideas. What is the topic again? Please slow down and use fewer words. Please encourage me, but don't force me. Please tell me what I need to know, but don't expect me to remember or understand it all. Please include me, but don't give me so many details that only confuse me. Give me some time to find my words, but help if I'm lost. Please don't point out my mistakes unless it's a matter of safety or if I ask. I rely on you much more than you know.

Dementia is lonely. Friends disappear. I don't even have myself for company any more.

Lauren U is a member of the PAC Core Team. She was a registered nurse with the ANCC Board Certification in Psychiatry for 30 years. Now she is the keeper of the frolic. Lauren has been living with Lewy Body Dementia (love how they add "with behavioral disturbance") for over five years. She currently lives in Northern California with her professor husband, Eddy. She enjoys spending time with her friends (the horses) at her the TROTR equine therapy program. PAC agrees with Lauren – that she is delightful!