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Lauren With a Side of Lewy

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

I recently had a dentist appointment. The office has only known me with LBD (Lewy Body Dementia). They are a nice group of people who have adapted to and accommodated me. I casually mentioned something about a "job," referring to my creative idea for a new dental-friendly product. They heard "job" and looked at me, puzzled. Their look of surprise took me by surprise. They were appropriately and genuinely interested. "You're working now? What kind of job?" I explained no, I did not get a job, but they asked if I had ever worked. I said yes, I'm a Registered Nurse. "Really? You worked in a hospital?" I told them yes, for about 30 years. Wow. I could see that they were trying to match the woman in front of them with a nurse.

As I left the office I began to wonder if others consider me disabled or incapable of holding a job. Do people see me or do they see only dementia? I don't see anything even close to what I expect to see in the mirror. I reached out to some people who have known me before Lewy and some I have met since. People say I look "like Lauren." But this was different. It was not about my physical features. It was a statement about my competency.

They were speaking about the incongruity between their vision of a professional person and the silly and strange behavior of the woman they have only known with Lewy. The consensus from others is varied but with a clear leaning towards an appearance of "lost, haunted, and confused with a dull expression and faraway eyes." If my presence is that of someone preoccupied and incapable does that mean the core of who I am is different now?

What about my humor?

Can I hold on to it forever?

What if I can't?

Has there been a change in my soul?

Am I Lauren or am I Lauren with dementia?

Lauren U is a member of the Positive Approach™ to Care (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 TROTR equine therapy program. PAC agrees with Lauren – that she is delightful!