

# Perspectives of a Family Affected by Dementia

Edward K. Kaplan



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Thank you for the honor of participating in this urgent project. I speak as a Person first diagnosed with Lewy Body Dementia (LBD) four years ago, in the fall of 2013. At that moment, the news hit me like a death sentence: incurable, probably slow, but relentless degeneration, physical and mental. The common associations with the label “dementia” scared the hell out of me. I already imagined myself in a wheelchair, unable to speak, afflicted with nightmares and visual hallucinations.

That being said, before my diagnosis, I had already signed a five-year retirement agreement with the University, where I was an endowed professor. So, I had time to adjust.

I received superlative testing. Medications helped to alleviate some symptoms, although it took time and deliberate effort for me to accept the reality. My PCP, my physician for over twenty-five years, sent me for cognitive tests that I found humiliating, despite the kindness of the testers.

At this early stage of the illness, my limitations were mild but persistent. I began to escalate spelling errors (no spellcheck in the classroom.) In conversations, I increasingly blocked names and titles I knew profoundly. I was afraid of becoming a full-fledged Alzheimer

victim like my much older sister, or confined to a wheelchair as was a dear friend of ours, recently deceased of Parkinson's.

That brings me to my main point: We are called to this session on Recommendations of Nomenclature, as we strive to make significant changes in labeling that might do justice to the complexity of the disease, without aggravating the social stigma or provoking unnecessary fear. How can we bridge the divide between scientists, physicians, researchers and other professional caregivers – and friends, acquaintances and family caregivers.

My neurologist provided a model. When she entered the waiting room to call me for my appointment, she addressed me as “Dr. Kaplan.” At that moment, I certainly did not feel like “Dr. Kaplan,” a PhD. in French literature, widely published in the U.S. and Europe, or “Professor Kaplan,” as I was, and am still known officially in the University. The demeaning aspects of my neurocognitive deficits did not rob me of my identity, even my professional identity.

I was deeply impressed by the manner in which my neurologist conducted the intake interview, for an hour, with sympathy and understanding, and without an iota of condescension or pity. The mixture of technical and common nomenclature, which the physician explained to me, reflected her sensitivity to my essential identity as a person, Edward Kaplan, a still highly functioning human being with all the rights and responsibilities thereto. Now, my wife usually accompanies me to the neurologist, and once we also brought our daughter, a PhD candidate in clinical psychology at Temple University. I felt no humiliation in the presence of my family or my physician. Quite the contrary.

I was even fascinated with the physician write-ups of my case – as if they were literary documents: by that I mean a coherent amalgam of highly specific diagnostic terms and lucid, personal description of the whole person, of me.

On the elementary level of social conversation, if I share anything about my health, I usually say that I am doing well while living with a neuro-degenerative disease, with some loss of memory, speech hesitations, symptoms similar to an early onset Alzheimer's or Parkinson's. If people are interested, I can explain that my syndrome is named after Friedrich Lewy (1885-1950), the British neurologist who had discovered the lumps of protein (Lewy Bodies) that were eating away at my brain.

On the level of public communication, labels are important, so as not to repeat prejudices associated with “dementia”, a heavily progressed mental illness. An appropriate lexicon builds upon the true goal of “political correctness” in which human beings are deliberately given their agency; the classic example being the word “man” when we really mean all human beings, or retaining both pronouns “he and she” instead of just “he” for everyone. Ethical self-awareness can develop from such syntactical acrobatics, focusing attention on the human being. The persons we used to call “slaves” are “enslaved people.” Schizophrenics are now “people who live with mental illness.”

My initial terror at being diagnosed with Lewy Body disease or dementia (LBD could stand for both) has imagined only the end stage of the affliction. Stigma is born from such fantasies. We need to educate the public about the opportunities during the earlier stages, when people are still living very full lives.

I conclude with words of gratitude and admiration: to the “Stakeholder Group of Persons Living with Dementia”: it includes retired lay persons, medical professionals, some with mild or

moderate cognitive disorders (they all seem pretty good to me!). My Stakeholder Group looked – collectively – into the whole spectrum of powerful effects the word *dementia* produces on the person hearing it, saying it, and/or being the subject of it. We recommended to the Summit to initiate and promote new research on “implications for use of the term *cognitive impairment* or *cognitive disorder* instead of *dementia* for persons living with illness, family members, and public health.”

My final thanks go to the next speaker, Janna Kaplan, my caregiver and wife, who combines scientific objectivity and love.

Thank you very much!

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