

# Perspectives of a Family Affected by Dementia

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## **National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers**

**Presentation by Janna Kaplan, caregiver for her husband with LBD**

### **Plenary Lecture: Nomenclature – Words Matter**

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I am very grateful to the Summit organizers, and the Session Chairs, for this honor.

First, a few words about my Person with Dementia – my husband Edward, and me, his Caregiver. Ed was/is an accomplished scholar in French Literature and Religious Studies, professor (emeritus), retired 2 years ago at age 73. I am 64, and I am a research scientist in Neuropsychology; both our professional homes are at Brandeis University in the Boston Area, Massachusetts.

My husband was diagnosed with Lewy Body disease in the fall of 2013. The actual diagnosis was that of Lewy Body dementia. None of us knew at that time what LBD was, we never heard of it. So, the only information-bearing word in the diagnosis was DEMENTIA. And it hit us like a ton of bricks. Talking about “words matter”! The life as we knew it was over. I felt like that word, dementia, has redefined my husband suddenly, fully, radically, and terminally. Even worse was the pain I saw in my husband from himself feeling so redefined. It took both of us a lot of time, a huge effort, emotional and every other turmoil, to educate ourselves about the Lewy Body disease and dementia as its cognitive component, and to learn how to live with it and how talk about it to others: family, friends, colleagues, medical professionals, neighbors ... That hard journey helped us transform our agony into normalcy, our helplessness into action.

So, here are the **points I want to make today with regard to the nomenclature.**

- **Use a noun instead of an adjective.** I'd like to share with you my experience in research (NIH grant, about 10 years ago) on development of autism in children. The autism research and treatment communities trained themselves to use terminology that awards dignity and agency to research participants and to their families: *children with autism* instead of *autistic children*; *typically developing children* instead of *normal children*; etc. This made a HUGE difference! Adjective is a label, a descriptor, it is about someone; noun is a statement, which affirms the person first, with his or her full agency, in all her or his dignity, as a valid participant/stakeholder in addressing issues of his or her condition(s). Calling a person *demented* or *senile* is demeaning; *person with dementia* is not.
- **Clinical syndromes with dementia have complex and not self-evident names:** Alzheimer's disease, Parkinson's, Frontal-Temporal Dementia, Lewy Body Dementia, Vascular Dementia, etc. To a lay person, the only information-bearing word in each such diagnosis, either *disease* or *dementia*, works like a 'trigger' which instantly transports the listener into the scary realm of loss of identity, or function, or agency. So, any conversation with a lay person gets derailed into explaining what it is and thus loses time and focus, and loses track of the actual purpose the interaction had in the first place. Conversations become tense or unnecessarily oversimplified; subtle at first, the discomfort will build up and contribute to one of the worst fallouts for any PWD and the caregiver: contact avoidance and increased social isolation. PWDs' and caregivers' initiative to seek early diagnosis may also be diminished due to (misperceived!) feeling of shame and fear of stigma.
- **Key challenges with regard to terminology from my, caregiver's perspective:**
  - create diagnoses' names which do not trigger stigmatization of PWDs
  - develop lay terminology which does not evoke pity for PWD, and/or for caregiver
  - develop lay terminology which does not create/facilitate stigma for PWD, and/or for caregiver

- create a narrative/template for how to talk about PWD with lay people (to be useful for PWD, caregiver, family members, etc.)

Thank you very much for this opportunity.

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