

“It’s Not Always Alzheimer’s – My Father and Lewy Body Dementia”

This article is for elder caregivers concerned with a loved one they feel may have dementia and are in the process of educating themselves about memory loss, and the possibility of their loved one having a form of dementia other than Alzheimer’s Disease.

Having worked professionally in the elder care field for over ten years, I have met with hundreds of families who have told me their loved one has memory loss. They most often assume it is Alzheimer’s Disease, perhaps due to their familiarity with the disease through the media, their doctor, family, and friends.

I am very pleased that Alzheimer’s receives such attention and kudos is extended to The Alzheimer’s Association for their impressive work in this area. Most laypersons are not aware that The Alzheimer’s Association provides information on other forms of dementia in addition to Alzheimer’s Disease; in visiting their web site you will find a “related diseases” section:

http://www.alz.org/alzheimers_disease_related_diseases.asp

For the caregiver, knowledge leads to a better understanding of a condition, often providing them with relief in having a diagnosis. Following a treatment plan helps caregivers increase their ability to help the individual with dementia as well as improve their coping skills, and often lower their stress and frustration level.

My father Orville, a loving, patient, kind, and understanding man, had what neurologists believe was Lewy Body Dementia (LBD, also “Dementia with Lewy Body” - DLB). When I explain this disease to those outside the medical field, I tell them to imagine a combination of the symptoms of Alzheimer’s Disease and Parkinson’s Disease. According to the Lewy Body Dementia Association (<http://www.lbda.org>): “LBD is an umbrella term for two related diagnoses. It refers to both ‘Parkinson’s disease dementia’ and ‘dementia with Lewy bodies’...over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms.”

In about 2006, my sister, Mom and I began to notice my father having more difficulty with problem solving. This manifested itself as mistakes in the checkbook, as well as in anything related to the use of numbers. But we did not see any symptoms of memory impairment (for which we were on guard) which is not unusual with Lewy Body Dementia (please refer to <http://www.lbda.org>).

Another symptom noticed was Dad's attention span - it took longer for him to digest what he saw. I knew then it was time to have the talk about relinquishing his driving for his safety and the safety of others. (Fortunately for me, this was not as difficult as it is for most caregivers, as he would rather look at the scenery than drive.)

Understanding my father was experiencing these challenges, my sister Monica and Mom decided it was time to take a vacation together, driving from their Wisconsin home to Colorado. My sister drove and they stopped many times along the way, enjoying the scenery and people. It is a special memory and time for them, as they reflect back to the time before the disease began limiting my father's mobility.

Over the next few months, my mother would find my father ready to shower, shave and dress for church at inappropriate times (1 am in the morning); a normally very easy-going man, he would argue with her about whether it was 5pm or 5am. When this began to occur, my heart sank; I knew then that this would be the beginning of a disease that would be with my father until the end of his life, whether it be the cause of it or not.

We again decided to take a vacation with Dad, in part to provide my mother a respite from caregiving. My sister, Dad and I took a short trip around southern Wisconsin. We were never a family to have vacations on a consistent basis, but were blessed to have visited family in Europe on numerous occasions. My father loved Germany, and a regret I have is not stressing the importance of Dad taking one last trip to "Deutschland". To have photos of him in Germany, with brats and beer, would have been a nice addition to those photos we later reviewed with him.

During a doctor visit in 2008, neurologists at the Mayo Clinic (Rochester MN) concluded Dad most likely had Alzheimer's Disease. I, however, could not get past the fact that my father had symptoms outside what might normally occur in Alzheimer's Disease (shuffling gait and body stiffness). I brought this up to the doctor, who admitted it could also be Lewy Body Dementia.*

The fact that Dad still retained so much of his memory was baffling for us; from what did Dad really suffer? While he did have problems with problem solving and reasoning, his memory was fine. Up until his speaking ability failed, he could still communicate which baseball or football team was playing (even if it wasn't the Milwaukee Brewers or Green Bay Packers), and could recall the names of relatives and events we had long forgotten. While it is true that as time progressed, his cognition would be weaker at times, it remained. (He would call out "Becky" when he saw a former caregiver he hadn't seen in at least 6 months; and she only worked with him for ten days in October!)

Dad always had a healthy appetite, but he developed a fixation on chewing things that were not edible. He was unable to eat and chew slowly and calmly, to the point where he would place so much food into his mouth without chewing that he risked choking (which he actually did, on a few occasions, once leading to an ambulance and hospital).

Since he was increasingly unable to communicate, he began to shout and cry out for extended periods of time. We all tried, often unsuccessfully, to determine what it was that would be annoying him. We would ask him to repeat one word, for example, the name of a beloved pet, which would distract him and give him the ability to communicate a word or two to help satisfy his annoyance.

More Parkinsonism symptoms appeared and others intensified: the shuffling gait remained but slowed, the body stiffness became more apparent (which threatened more falls and reduced his physical activity level), he had greater difficulty with his speech, more frequent blank stares, and significant drooling. He then became unable to care for himself in any regard and required 24/7 care, which my mother provided for several years, until complete exhaustion forced her to look at a number of alternatives.

In the spring of 2010, Dad moved to a community based residential facility with 19 residents. My sister and I visited with him approximately every 6 weeks (she resides in Washington, DC). Dad lived only two miles from my mother; had consistent, devoted caregivers; was kept well-fed and clean, and received hospice services several times a week. My mother visited him daily, at minimum 4 hours each day, feeding and caring for him. While the facility was happy to take on the responsibilities with which she engaged with Dad, she took great satisfaction and relief in helping him herself, conversing with him, reminding him of memories, and holding his hand.

By fall of 2012, Dad became completely unable to move (with the exception of one arm), speak, or eat on his own. My mother consistently arrived daily, primarily to feed him pureed food and spend time with him. The staff transferred my Dad into a Broda** chair every morning to bring him in the living room and kitchen area for some social interactions and entertainment. He had been taking Aricept and Namenda for an extended period of time and we regularly checked with his doctors to see if we should continue to do so. I still believe that while he had not been able to communicate for some time, he was still able to understand some of our conversations.

The fact that Dad could understand communications is very important for caregivers and other family members to know and accept. I had to remind visitors not to say anything that they did not want Dad to hear as he still both heard and understood. This was evidenced to me by his various facial expressions and oral responses as well as where he would direct attention when someone was asked a question.

The experience with Dad was a good reminder that when interacting with an individual with Lewy Body Dementia, it is important to conduct oneself as one would with any other person. Communicate with them, look into their eyes, hold their hand, or perform normal actions (rubbing the back, etc). Keep your voice at the level at which you would normally speak with the individual.

Some of the things we did to connect with Dad included: reviewing old photos, dressing the Christmas tree, playing his favorite old records (German music, army band music, and big band music), interacting with my Australian Shepherd Lucy, providing him with favorite scents/smells, sharing visits by family members and friends, and, of course, watching the Brewers and Packers.

On Friday, November 9, 2012, my father died peacefully surrounded and held by my Mom, my sister Monica, and me. The three most important people in his life were there to talk to him gently, hold his hand, and stroke his back and head. "We are all with you Dad, and it's ok to go."

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* When we later received the written report from Mayo Clinic in Rochester, MN, it included Lewy Body Dementia as a probable diagnosis.

**Broda chair: designed for use by individuals who are caregiver dependent for commode and shower needs. The chair accommodates easy side transfers through swing away, removable arms. It also helps facilitate front transfers through anterior tilt and a flip up removable footrest. From <http://www.seatingisbelieving.com/chair>