

EXPERIENCES IN DEMENTIA CAREGIVING

By Hulda Bridgeman

Dementia is an umbrella term for memory loss which impairs in some way a person's ability to perform activities of daily living. Different types of dementia also have their own specific characteristics, but here I want to touch on three areas which apply to all dementias.

First of all, the journey of my husband Ken and me to find a diagnosis, in our case for Lewy body dementia.

Then, some words about dementia grief, which differs from grief in other situations, and which can have an effect even when it's not recognized.

And third, the resources which I found especially helpful as a caregiver.

A. OUR STORY

About 80% of dementias are identified as Alzheimer's. Lewy body is the second most common type. I generally describe Lewy body as having the memory loss of Alzheimer's with the motor symptoms of Parkinson's, plus a few characteristics of its own.

My husband Ken died of dementia with Lewy bodies in August 2020.

For about 35 years I had the feeling something was going on, but **he had no apparent memory loss** and dementia was not even on our radar. I used to say, to the occasional professional we consulted, "What is going on here? This is not normal." But dementia was not on their radar either.

Ken's issues were subtle and involved executive function. On office work he had trouble prioritizing and could only work at one speed - slow - so it could take him a long time to get things done. We tried different fixes - a speed reading course, different organizational aids and strategies, outside help with some tasks, but nothing made a difference for long. But he was smart, clever, very likable and quiet. He compensated and managed OK. And on other things, like remodeling projects, he appeared to be the same skilled and clever person he had always been. It hurts me now to imagine the stress he must have felt but never articulated. He just kept plugging away.

For years I kept reading and researching, trying out different hypotheses, saying that "before I die I hope I find out what's going on here."

Ken eventually became more **inattentive and easily distracted**. As an example, as soon as I started talking to him he might point out the window and say "Look, there's a bird!" I would say "Yes, but birds aren't unusual and right now I'm speaking to you." "Sorry" he would say. I would start again, and he would immediately interrupt in the same way. After the third try and interruption I would give up, but I wasn't happy! Without a diagnosis or any thought that the problem was neurological, it just seemed like really annoying behavior. Such incidents repeated over and over put stress on a relationship.

Once we got to this point I finally decided that he must be ADD - attention deficit. (Ken's neurologist, Dr. David Greeley, later told me that early dementia can look like ADD.) So we saw a psychiatrist, who sent us to a psychologist for testing, who told us that Ken was not ADD but he did have memory loss. More testing by a neuropsychologist told us that he had MCI, Mild Cognitive Impairment - that is, memory loss beyond normal aging but not yet dementia. It doesn't always proceed to dementia but does raise the risk.

Eventually Ken's memory loss became apparent. He had trouble finding his way around town, and as his functioning worsened we assumed it was Alzheimer's because that's the most common dementia. He saw Dr. Greeley to be screened for the clinical trial being run for aducanumab. Ken didn't qualify for the trial, but when I mentioned the Parkinson-like motor symptoms he was showing, Dr. Greeley said "Sounds like Lewy body." When I went home and looked it up online, it fit, even though the usual hallucinations weren't apparent.

With a diagnosis you can then advocate most effectively for your person. One example: One of Lewy body's unique features is a potentially dangerous reaction to certain drugs, so I kept a list of these in my purse. I showed the list to everyone in a position to order or administer drugs to Ken. Many people, including medical professionals, are not too familiar with Lewy body, and I found in every case they were open and interested, and helpful in discussing what would be best for him. When Ken had two surgeries I showed the list to both the surgeon and the anesthesiologist, and discussed with the anesthesiologist what type of anesthesia would be best to use. Both times I was invited to come to the recovery room as soon as he was awake, where I could lower his anxiety and aid communication between him and the nursing staff.

I gradually realized that I had become Ken's link to the world, and that his considerable anxiety was related to the fear of having to solve a problem if I weren't there.

THE TAKEAWAY: Don't be afraid to pursue a diagnosis. Knowing what you are dealing with can help in many ways:

- It can save you the stress of misunderstandings in your relationship.
- You gain the opportunity to become educated about your particular dementia, which can greatly smooth the way going forward.
- You can make necessary preparations such as legal and financial, and involve your person in decisions about the life ahead while they can give meaningful input.
- Early diagnosis allows access to some resources and clinical trials while they are available and most helpful.

All of these things help maximize your possibilities for a good life going forward.

B. DEMENTIA GRIEF

All grieving is individual, but dementia grief has unique characteristics which set it apart.

Our culture often doesn't recognize grief until a person has actually died, but in dementia the grieving starts while the person is still with you, and it starts early. It may not be recognized as grief while you are consumed with caregiving tasks, and the great sense of relief when those tasks finally end may be confusing and make you feel a little guilty.

In dementia you lose the person gradually, over and over, while they are still physically present. You can't identify a moment when it actually happened.

Dementia grief involves four kinds of loss:

There is the **COMPOUNDED LOSS** of your person's abilities, memories, identifying traits, and your shared reality. These can occur in succession over a short period of time and build up. They can weigh you down as they just seem to keep coming and piling on.

You experience **ANTICIPATORY GRIEF** as you face significant intangible losses, of companionship, of the skills and traits of the person, of what they contributed to the relationship and to your everyday life. They may be the person who took care of the car, or balanced the checkbook, or cheered you up on a bad day, and now those tasks are on your plate along with everything else.

In dementia there also occurs **DISENFRANCHISED GRIEF**, a grief not recognized by others. The compounded and anticipatory losses of dementia may be subtle and ambiguous, not easily recognized as loss by others who have not dealt personally with the disease. They may feel you still have the companionship of your person because they are physically present. This is why **it's important to have contact with people who actually share your experience**. Sharing with others who understand/share your situation is critical.

AMBIGUOUS LOSS is a significant loss which lacks clarity, finality and a normal sense of closure. Your person may be physically present but psychologically absent, sometimes called the goodbye without leaving. In this situation it can be very difficult to grieve and move forward.

All of these losses and attendant grief form an overlay to caregiving and its aftermath. The grieving may not be recognized while you are so busy, or even afterwards when the caregiving burden has been lifted. But the **unrecognized effect is worth keeping in mind as you deal with other issues in your life**.

A NOTE ON CAREGIVING

It's imperative to care for yourself. You need regular time away from caregiving, every day, every week, and occasionally for longer breaks. Totally away, doing something which sustains you personally. Caregiving is draining, and in order to serve the needs of your person you have to replenish the well before it runs dry.

I used to think of Ken and me as one unit, where **all** parts have to be sustainable for it to work.

Lots of humor helps, and quite a bit of it may be black humor. Complaining and laughing about the craziness with people who know what you're talking about is priceless.

C. RESOURCES FOR DEMENTIA CAREGIVERS

1. ALZHEIMER'S ASSOCIATION alz.org *check the menu, follow the links* **a wealth of information, good for all dementias**

get on the mailing list both local and national to know about events, both in person and online (509) 456-0456 Spokane office is currently without staff, so phone number connects you to Seattle personnel who can answer questions and send out brochures. However, the information is also available online - explore the website!

2. COACH BROYLES' PLAYBOOK FOR ALZHEIMER'S CAREGIVERS, comes with **Pocket Reference of Tips and Strategies broylesfoundation.org**

I found this book invaluable, my constant go-to source. Cost on the Broyles Foundation website is \$10, also available on Amazon but at a much higher price.

3. DEMENTIA ROAD MAP

My other indispensable reference, available through the Alzheimer's Assn. of WA office, (509) 456-0456. Also online: alz.org>Your Chapter>Washington State Chapter>*scroll to* Information and Resources>Helping You>Dementia Road Map

4. AGING & LONG TERM CARE of EASTERN WASHINGTON altcew.org altcew.org>Programs and Services>Caregiver Support

5. THE FATHER, highly recommended film, 2020 drama starring Anthony Hopkins and Olivia Coleman. How the world looks to someone with dementia, from inside their experience. Available on many streaming platforms.

6. ORGANIZED SUPPORT GROUPS alz.org (WA chapter) and altcew.org

For current local groups: alz.org>Your Chapter>Washington State Chapter>Support Groups>Click Here for a list of support groups

*Memory Cafe: alz.org>Your Chapter>Washington State Chapter>Information and Resources>Helping You>Early Stage Memory Loss Programs>*scroll down to* Memory Cafes. **Check for current information.***

7. WEBSITES FOR SPECIFIC DEMENTIAS e.g. lbd.org for Lewy body

8. INFORMAL SOCIAL CONTACTS with others who are on or have been on this journey. Past gatherings have taken the form of potluck lunches in homes or meals in restaurants, with caregivers and their people. Some individual caregivers may prefer lunch or coffee with a friend who has experienced caregiving. ***BENEFITS: Pick up valuable tips, vent, find out you aren't alone.***