Debbie's mom, Louise Gallagher, was 70 years old, just newly retired when she was diagnosed with Lewy Bodies Dementia in 2003. She died March 14, 2008. Debbie writes of the progression of Lewy Body Dementia and the heartache and sorrow that goes along with it. The journey is long, and difficult, but as she states at the end, "never let go, just hang on for the ride of your life."

My mom was a beautiful, vibrant, educated woman who worked as an accountant before serving the community for 16 years at our public library. She retired in 2003 at the age of 70. Looking back, there were probably signs of memory problems long before she retired. You tend to look beyond these problems or try not to pay too much attention to all of the “little weird things” that occur over time.

A month before mom retired, she was on her way home during her lunch hour when she was broadsided by a car. Miraculously, she didn’t suffer any serious injuries and after a series of x-rays and exams, she was released from the emergency room the same day.

I lived with my mom in New York at the time. As soon as I brought her home, I knew something wasn’t right with her. I couldn’t pinpoint exactly what it was, but she was not acting like herself. I thought she might have been depressed after the accident, but she kept insisting she was fine. She returned to work for a week and then retired. I found out later that her co-workers had noticed changes in her personality and work habits before the accident, during the weeks leading up to her retirement.

That summer, more visible signs started to occur. My sister in Georgia was already aware of mom’s symptoms, but we kept it between each other and our families. We weren’t sure what the problem was, but we were extremely worried. In fact, I was sick with worry.

Mom began buying things compulsively – something she never used to do. She began having problems balancing the checkbook and started misplacing things. She mailed bills with nothing in the envelopes. She also left the water running all the time, at times even flooding the kitchen or the bathroom. Sometimes I’d find every TV and light in the house left on, even at 2 AM. When she left the house, she’d leave the doors wide open and never lock up the house. Although she’d always been a neat freak, her house became very messy and disorganized. She would try to cook or bake and would leave out half the ingredients. She would burn pots on the stove and then burn her Formica counter tops with the burnt pots. Most days, I left for work not knowing what I'd come home to.

She'd have hallucinations, such as when she'd ask me if I heard music playing when it was silent. I later learned that hallucinations are common in Lewy body dementia. She would get confused with simple tasks and get lost in conversations. There were times I would be talking to her and she would just look right through me, as if there was nothing left inside her. Her posture changed. Her facial expressions changed. Her personality changed. I felt like I was losing my mother.

When I tried to talk to her about it, she'd get overwhelmed and yell at me, telling me to leave her alone and mind my own business. She insisted that she was fine. Friends and family started to call me out of concern, because they were noticing changes in her personality as well. Caught in the middle, I tried to minimize the situation or say that we were looking into it. Mostly, I was scared.

Finally, I got her to come with me to see a doctor. I'll never forget the first neurologist we saw. He gave her the "basic memory test" and she passed with flying colors. When he called me back into the room, he said, "Your mom is fine; perhaps you should get some counseling." It felt like someone had punched me in the stomach. Meanwhile, my mother was happy as a clam, saying, "I told you so, there's nothing wrong with me!" My sister and I weren't sure where to turn next.

A few months later, we found a new, wonderful neurologist. Dedicated, and caring, he offered us insight and information about what was happening and how to prepare for the long road ahead. We also took mom to a neuropsychologist who really pinpointed her Lewy body dementia. It was expensive, though, so be sure to check whether this kind of visit will be covered through your insurance.

After two years, mom's dementia had progressed quite a bit. We were advised to look into assisted living facilities and make necessary preparations for the future. This was devastating to my sister and me, since this wasn't supposed to happen to our mother. Lewy body dementia (like any dementia) is not a dignified disease. It strips you of who you once were. It almost felt like something took over our mom's body, and we were in some strange science fiction movie. Unfortunately, this was the reality that we lived and breathed every day.

In the summer of 2005, we decided to move our mom down to Georgia near my sister, since the cost for assisted living was much less there than what it cost in New York. It was a beautiful, well-kept, and well-run assisted living facility with a dementia unit. Although she started out in the main assisted living section, in only four months she had to be moved into the dementia unit. The next few years were the most heartbreaking because we saw the rapid progression of her disease. Bills began to increase because of all the additional care mom needed. She had a few choking incidents, and eventually she was put on a pureed and liquid diet. She couldn't write or express herself, and she eventually stopped talking and walking. She also developed Parkinsonism, where she became rigid and had restless leg syndrome. She needed care and assistance with every daily task. One small blessing was that she still knew who we were.

We were able to move her into a double room, which helped a little with the monthly expenses. Still, the cost of care continued to increase. I called the management when mom's money was almost gone, and they asked if we'd ever inquired about hospice care. No one had told us anything about hospice. The agency we found was more than happy to help us and explained that given our mom's diagnosis, she was entitled to hospice services that were covered by insurance. I highly recommend that anyone caring for a terminally ill parent, either at home or in an assisted living facility, look into hospice. If we had learned about it sooner, our mother wouldn't have run out of money in only a few years. This forced us to move our mom to a less expensive facility in December of 2007.

During the last few months of mom's life, the hospice agency cared for her. They gave us information and support during her final weeks. When I visited her on March 1, 2008 I knew in my heart that she wasn't doing well. She had lost almost 80 pounds in less than a year and had developed a bed sore. Things just started to shut down; as the hospice nurse said, "Your mom's little body and little heart just couldn't fight it anymore, she was tired."

Soon after my visit, our mom declined so much that we moved her into a 24-hour hospice facility so she'd be more comfortable. The day after she was moved, my sister called and told me I needed to come back, "right now." On Friday, March 14, 2008 our mom died. I was blessed that I was able to be there with my sister when it happened. Mom's long struggle with Lewy body dementia was finally over.

In those final hours, the hospice staff was wonderful. I cannot say enough about their dedication and about the loving care their patients receive. Hospice care was one of the good parts of our experience. I wish I could have written more about hope and goodness rather than despair and sadness, but Lewy body dementia is a difficult, progressive disease. Here’s what I’ve learned from the experience:

- Learn as much as you can about your loved one’s disease. Be aware of all the stages you might encounter during your loved one’s struggle.
- Make sure you have a good support team and good doctors that know about the disease.
- Don’t be surprised if you feel misunderstood while you’re dealing with something like Lewy body dementia. People will say, “Oh, I’ve never heard of that,” or, “Lewy what?” Bear with them and explain it to them.
- Take care of yourself. Find a support group, because dementia is an exhausting disease, not only for your loved one but also for you. If you can’t find a support group, start one and build a support system.
- Cherish the memories and the moments. Take pictures. Remember all you can about them. Love them for who they were as well as for who they are now.
- Take advantage of touch, hugs, and gentle kisses on their cheeks. Touch and rub their hair. Look at them, and tell them you love them. One day, you will no longer have this chance. Above all, be patient and kind.

If you do these things, you will know in the end that you did all you could and that you did the best you could. Good luck in your journey, and hang on for the ride of your life.