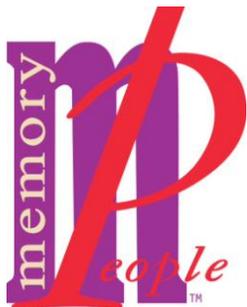


bringing awareness...



...one person at a time

The Memory People Page

"The Reluctant Good Daughter"

An Interview with Diane Hoover, caregiver to her 'Little Mama' during her journey with Alzheimer's Disease.

Diane, can you describe the first signs when you and/or Little Mama began to realize that there was a problem?

Looking back at the things we didn't know how to recognize is a sad part of this journey.

I am quite sure our little mama knew something was wrong for several years before we understood the warning signs. She was a remarkable lady. She learned how to prepare tax returns at the age of 62 and worked full-time until she was 82.

She was an Enrolled Agent for IRS. About the age of 80 she made a pretty significant error on my sister's tax return. She was able to explain it away, but it left a little seed in our minds. During the next two years she developed a system of notes and reminders to help her through her life. All her kids, except her brother, lived out of state.

At 82 she lost her job and was devastated. She wanted to file an age discrimination suit and I helped her with some of that research and paperwork. She would get lost in some of the legal wording and that took me by surprise. She also became much less social.

I tried every trick in the book to get her to the local senior center to take advantage of their day trips, their dances, exercise classes. She absolutely refused because she did not want to be around old people.

By 2007 it was very apparent something was amiss. My husband and I were living in Oregon and trying to sell our home and get to her. That took over a year. In the meantime, I called her every day, sometimes twice a day. I wanted to know if she was eating, did she get dressed that day, etc. At this point in time the boy who would become her brother was only involved with her by dropping off tortillas and cheese when she asked and picking her up for breakfast on Saturday mornings. I discovered she was only eating cheese quesadillas --- 3 x a day!



We finally arrived in late 2008. Living in her house was the worst seven months of my life. I could see some of my mother in her, but the mean Bessie had really taken hold. While she was still capable of getting up, getting dressed up, getting something to eat, it was in your face evident she was not capable of making good decisions for herself.

She had a massive infection in her big toe and had ignored it. She could not follow doctor instructions. We discovered she had not kept a heart doctor appointment for two years. When she showed the doctor her pills box it was full of black jelly beans. And so the long journey began.

As the situation became apparent, did any of you struggle with denial? If you did, how did you get yourself to a place of acceptance?

Denial. One word. So powerful. Even though I knew there was "something" wrong, I still struggled with accepting it was a disease, THE disease.

Little mama always wanted to be in control. She could be quite insistent, but she had never been mean. Well, the mean Bessie came to reside in her house. She would not even let me have one drawer in a chest for my underwear. I had to keep my clothes in the garage and dress out there. She told my husband that if he brought something into her house it meant it was hers. She went through our belongings every day and she took things. She threw his clothes in the swimming pool.

My son, his wife and my grandsons came for a visit and stayed with us at her house. She would not let us have our coffee pot in the house (she liked decaf, we liked full throttle) so we kept it out in the garage. My husband set the pneumatic opener to OPEN while he and Shiloh went out to bring in coffee for the four of us. My son could hear her upset about something.

She drug a chair over to the door, climbed up and proceeded to literally rip the heavy duty screen door off its hinges.....and then turned around and asked my son if he had seen what Hoover did. My son said he was totally entranced by the whole affair. He said, "mom, on one hand you are appalled, but on the other you gotta give it to her. She is a little 86 year old woman who can rip a door off!"

I never ever minded the incessant repeating. She could ask me the same question 50 times in 10 minutes. But I was completely "unhinged" at how mean she could be. After the door incident I spent more time researching THE disease. I decided I needed to be more tolerant. I needed to learn how to let it go. That does not mean it was easy.

There is nothing about this journey that is easy. And it doesn't mean I didn't walk up and down that hallway saying bad words to myself – I did. But I became more aware of how to say things to her, how to approach getting her in the shower, how to place 3-4 outfits on the bed to let her choose, how to get her to help in preparing a meal.

And before I joined Memory People, I vented like crazy via email to my sisters. At one point one of them said, "You know, this is your choice." And I said, you are right, it is. And I don't like any bit of it, but I would not be anywhere else. I am the reluctant good daughter. And because you are not here, you get to be the listening good daughter. She got it. And so the journey continued.



At some point did Little Mama soften to you and to her situation?

I don't think Little Mama ever consciously consented to the idea she had the disease. I think Alzheimer's just kept on its relentless progression until it consumed her.

She was a force to be reckoned with in every aspect of her life.

I think she believed she could just overcome this just as she had overcome so much in her amazing life.

In the early years I am certain she knew something was wrong but she never mentioned it to anyone.

As we began to be aware and stepped in to help her, she became angry. She usually took out that anger on me, but once her brother was trying to help her sort out her medication and she just yelled at him, "Why are you here? Do you think I am stupid?" He put them all down and walked out the door. She was not stupid, but she did not know what to take or how to take them. As I have stated before, brother is right – this is not really an anger stage, it is a terrified stage.

At this point I was the main care warrior. Jim would stop by after work to say hello and then head on home. I was on the front lines....and we all know it is not fun. I would vent to Jim and he would tell me, "these are the easy days." And I would say, "yes, for you they are."

As we continued down the path, Angry Little Mama became Sweet Little Mama and there were some very special moments when she recognized me and even thanked me. Once she said, "I know who you are and I know what you do for me and I thank you for being here when you could be with your husband." Astonishing! During the last year Jim said, "I was wrong, *these* are the easy days."

Just because she was not so nice did not mean I could abdicate responsibility for her. It just meant I had to get tough, tougher, toughest. I fibbed to her even before I heard the term fiblet. Whatever was necessary to keep her safe, clean, comfortable, well fed, pain free and well loved – the principles that guided me and kept me on track. There is nothing easy about this journey and I never ever expected it would be me. I am the quintessential reluctant good daughter.

Diane, where are you at now that Little Mama has found her Eternal Home, and you and hero brother and your family are now finding your new normal?

In the two weeks before Thanksgiving I noticed a change... barely perceptible, but definitely different. I told the other girls and two of them came to see her the weekend before the holiday. They are thankful they did. Little Mama was lifted up to heaven on December 4, 2013. In the previous 6 months, brother and I had the same prayer....asking the good Lord above to shine His grace upon her and take her home. Our prayers were answered and we are grateful. The end of the journey seems so long and lonely – for everyone.

For hero brother and I, December seems like a puff of smoke. Decisions about the service. Where does everyone sleep? Who is hungry? What time is your flight? Husband went back to PA and his parental vigil on 12/25... we wondered if we had misplaced Christmas.

The new year brought new challenges. Legal notices and papers, I moved into the house, two girls came back for a long weekend.....who wants what? Who is going to sort out a lifetime of memories and stuff? Still working full-time, working on house on weekends, stumbling across treasures, weeping when least expected. Brother sits in Little Mama's recliner every night...falls asleep and snores just like she did. It is strangely comforting.

Grieving takes time and it is best to just let it sweep over you and revisit the memories, the fun stuff, the bad times, the sadness, the love and let the tears fall.

And even though I am free to roam, I feel tethered to that house. I have come to understand that tether will probably not be broken until everything is in a new home and the house is sold.



Hero Brother reading to Little Mama

The three girls are coming for a week in March to start claiming the items that rekindle their memories. The girls already call me Mama Diane and the process takes us one step at a time to our new normal where I become the family matriarch.

We are doing ok and that is as good as we can expect. More than anything else, we are so blessed to know she is once again that beautiful girl, Bessie Evelyn Baldwin, reunited with her beloved Howard and they are dancing with the angels.

Thank you, Diane, for sharing your beautiful Little Mama with us. May you all be blessed as you remember her in love.





Join Rick Phelps and Leanne Chames each Friday at 1pm Eastern time, 10am Pacific, as we discuss all things dementia.

Memory People Talks are informal conversations that give us an opportunity to share about our journeys as patients and caregivers, ask questions and find encouragement and help.

The Talks are held in our Memory People Talks group on Facebook. You can access the group by pasting this URL in your browser.

<https://www.facebook.com/groups/554631627956006/>

Plan to join us as we share and learn together!



If you or someone you know needs support and encouragement for this journey of dementia, please join us at Memory People™, a closed support group on Facebook.

Through sharing our stories we find help and hope, together.

We don't have a cure, but we do have each other, and that means the world.

Join us today!!

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