

## **The Guilt**

Guilt can often weigh a ton and keep you down. Keeping you down so you don't act, you're afraid to act or take any action whatsoever. Guilt makes you freeze.

When your elderly parents can no longer live alone and need help, one of the things that can impair your doing the "right thing" is "the guilt" you have. Why guilt - because you're not asking them to move in with you and your family. Or you're not getting a 24-7 caregiver to live in with them.

I suffered from severe guilt for over 3 years when my mom suffered a stroke at the age of 91 and I was told she should no longer live alone. Keep in mind this was a woman who lived in her own home alone (as her husband had died two years previously), and still washed her own floors and refused any help whatsoever. The stroke brought on a serious dementia and left her wheelchair bound. Location played a big factor in the steps I took for her care – she was in Buffalo and I lived in New Jersey.

As the doctors advised in rehab – I moved her into an Advanced Assisted Living Facility. At that time she was not on Medicaid so we paid for everything and as most of you know, is fairly costly. That was the first leg of my guilt – I was not close by to oversee her care. I made arrangements to fly up every 3 weeks or so to stay a day or so, then return. I worked full time and my husband at home was a cancer patient, not doing very well. So I was getting hit by guilt from both sides.

But that was all in my own mind, I created my guilt.

I was blessed to have a husband of 40 years who was an amazing human being. He's the one who convinced me to move my Mom down to NJ to be closer to me. She was 91 at the time and it was not an easy task, however I cleaned out her house and her 1-bedroom at the Assisted Living in Buffalo, and moved her down in our mini-van to an Assisted Living in NJ. I couldn't get a room for her close to me, so I would drive down to her every Saturday and spend the day with her. I would bring her coffee and donuts, then we'd go out for lunch every Saturday. She enjoyed it. After 1 year, I found another facility, only a 4-minute drive from my house and a private room and moved her there. She's been in this facility for 2 years now.

Throughout all of this, I suffered great guilt – primarily am I doing the right thing for her? Am I being selfish as I didn't move her in with us. However, my husband who was a cancer patient was not doing well at the time so that was not a possibility. I was also his caregiver and working full-time.

Moving my Mom to a facility so close to me was the answer. I stop by every day after work for an hour or so to make sure all is well, she's doing OK and not lacking for anything. The facility is a very good one where the nursing staff is very professional and experienced dealing with the elderly. The benefits to her are way more than I could have provided having her at home with

me. In fact, I didn't even realize initially that moving her there was the best thing for her. In these situations, where we're trying to help our parents who are very precious to us, it's important you focus on what is the best situation for them. You often times have to remove yourself from the emotion which is difficult but necessary. Had I brought her to live with me, I would have had to hire someone to be with her for 9-10 hours a day. That person would have to be someone I could trust, which is very difficult to find. And what would they do – probably after dressing her and feeding her, they would just sit her in front of the TV all day. My Mom would not have interaction with anyone else.

I've discovered that an Assisted Living Facility provides many benefits to her well-being, in particular her mental well-being which is often overlooked in dementia patients:

- I pay extra for a private room; psychologically I think this is so important as it's her own space which is manageable to her with her own bath. She spends a lot of time organizing her things and then reorganizing. It's hers.
- Someone looks in on her every 2 hours or so at minimum. She is able to communicate with many different people in one day. The aids remind her when to go to meals and she is able to see other people in the dining room and lounge area and in the hall. Wherever she goes, everyone waves to her and says hello. So there is a flurry of people around her whenever she leaves her room. They record that she is eating meals and if she doesn't feel well, they immediately check her out and if need be, send her to the ER. In fact, they are very cautious about anything that could possibly be serious and send her to the ER immediately. They won't take any chances which is something I feel is invaluable.
- Any nursing services that are required will also be taken care of, to an extent as it's not a nursing home. My mother does not require 24-7 care yet. She dresses herself, uses the bathroom herself and feeds herself. She has difficulty with time which is why the aids come to get her for meals.
- She feels safe there and feels it's her home now. In fact, she used to stay overnight at my house on holidays but now asks me to take her back in the evening.

I stop by every day after work for an hour or so to make sure her chocolate bin is filled, she has enough apple juice, she's clean and take her to the dining room for dinner. On Saturdays I bring her to my house for the day where she relaxes in an easy chair and watches my cats.

The guilt has never gone away completely. I still worry about the little things – is she picking out the right clothes for herself, is she eating her snacks, is she staying alone in her room all day long, etc. But all in all, I do know now she is much better off in the Assisted Living than she would be with me. And that has to do with the exposure to all the other people – a very important factor that is often overlooked and that I could not have given her at my house.

My Mom is the one woman in my life that I respect the most. She has led an incredible difficult life and is now 95. Our job, our duty as children is to make sure our parents have the best possible care in their later years. And to also address the mental health of their well-being which is too often overlooked. So the guilt I think never completely disappears; however it is manageable if you stop thinking of yourself but think more about your parents and what they need.