

Wish You Were Here

One wife shares coping strategies as she navigates Early Stage Alzheimer's Disease with her husband.



I am sitting in the restaurant having lunch with my husband, Howard. But Howard's not here.

We ordered our lunch; Minestrone soup (Howard's favorite), Caesar salad, a nice panini bread, and tea. Howard excused himself, "I have to go to the bathroom Dear."

"Alright," I responded. The soup came; I didn't want to start without Howard, but I was hungry. I finished my soup, still no sign of my husband. The salads arrived, still no Howard. The food items have taken on a secondary importance.

By now, I'm beginning to wonder. I asked our waiter, "Excuse me, would you please check on my husband? He's been in the men's room for a very long time."

The young man complied, and reported back to me, "your husband says to tell you that he has to wait for his friend. In fact, the two of them are engaged in conversation."

"I don't understand," I replied. "Howard went to the bathroom alone."

By now, the young man could see that I was becoming anxious. With a sigh, he said, "Okay, Madam, I'll check on him once again if you like."

And he did so. When he reported back to me, it was the most confusing and frightening message I have ever received.

"Your husband is talking to his friend in the mirror. He told me to tell you he can't join you for lunch until his friend is ready."

Peggy and Howard met nearly 45 years ago at a University dance. Peggy was studying Nursing, and Howard, Civil Engineering. Peggy said, "I knew I was going to marry that guy, when he offered to take me home from the dance, with a bus ticket he found on the dance floor." They married three years later; two children followed, a son and a daughter.

"Wish You Were Here" is a true story. Howard is in early stage Alzheimer disease. From the moment of diagnosis, his wife, Peggy, family members and friends are thrown into a state of turmoil, attempting to understand and attach meaning to what is happening to this person, Howard, they once knew.

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The interview with Peggy, the wife follows:

Talk about how it was for you when Howard was diagnosed with Alzheimer disease.

The first thought I had was fear, but then, as strange as this may sound, the diagnosis almost came as a relief. I now can understand what has been causing Howard's strange behavior. And, to empathize with some of his fears.

Can you offer suggestions for other families who are passing through a similar journey?

The scary part of Alzheimer disease is I don't know from one day to the next how Howard is going to react to different things. He said to me one day, 'Peg, I can't remember from one minute to the next what I've done and what I haven't done.'

What has really been most helpful is to draw closer with family and friends. We always have been a close knit family and now I feel the children are even closer. I feel blessed to have them. The best thing for us has been to take one day at a time. Some days, Howard is really himself again, and this gives me hope.

Do you communicate with Howard any differently since the diagnosis of Alzheimer disease?

After 39 years of marriage, Howard and I are sensitive to one another's body language. I know when Howard is happy, sad, glad, mad. I don't talk to him any differently, but I find Howard now communicates with feelings, not words. This happened when we were in the restaurant that day. Howard seemed to be getting agitated as soon as we arrived and needed to excuse him.

Are there times you have difficulty understanding what Howard is saying?

I find I must be real sensitive to his body language and anticipate his needs. One day Howard wanted a glass of water and couldn't articulate the word glass. This frustrated him a great deal. We played guessing games for a bit until I figured it out. Even that day in the restaurant, he was trying to tell me he didn't want to be there.

How do you make the transition from being the wife of Howard to being his caregiver?

It's difficult. This disease is not about me. I know that, and yet some days I feel, 'hey, my needs aren't being met.' Howard and I have always been very close, and we still are. Alzheimer disease has changed our lives, but Howard is still Howard and I love him, whatever my role is. I will always be here for him.

What made you choose this particular restaurant to have lunch?

I have been told that the person with Alzheimer disease needs an environment that is non-threatening, familiar, and simplified. Howard and I have been to this restaurant many times. This visit, he no longer recognized the place or the waiter. I guess that means we are onto the next stage.

Do you find that social situations have become awkward?

Howard and I never have been social butterflies. We have a small circle of friends. However, I do find that we stay at home more now. That day in the restaurant was awkward; I guess because the 'mirror dilemma' was so shocking for me. I had a difficult time encouraging Howard to get to the car following. He didn't even eat his lunch.

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How did you manage to get Howard to the car?

Good question. As hard as I try not to be embarrassed or humiliated by these 'public scenes,' I am. I know that Howard doesn't function well with noise or outside distractions. I really should have been more sensitive to his body language at that moment. The waiter was terrific and so helpful in encouraging Howard to 'excuse himself from his friend,' and return to the table.

On the car ride home, we found humor in the situation. I find that it works really well to change the subject

Talk about some things in your home environment that you have changed?

Howard is down to basics. I have simplified the environment as much as possible. I find that this eliminates a lot of confusion for him. The fact that Howard was engaged in conversation with 'a friend in the mirror' is an indicator that he no longer recognizes himself or others around him. Interesting that Howard isn't bothered by the mirrors in our home.

When do you pause in your busy day to take care of Peggy?

I only give Howard so much of my time. I take good care of me. I maintain a healthy diet for both of us and we take walks together. I love that Howard still likes to hold hands when we are walking.

Howard loves to garden; he finds great joy in pruning the shrubs. I join him outside and we both enjoy the fresh air and nature.

Talk about how Alzheimer disease has changed your family relationship and interactions with your children and grand-children.

The children focus on Howard, their Dad and their Grampa, and not the tragedy of Alzheimer disease. Some days, Howard doesn't remember our children's names. This hurts. Never mind; we keep our love strong and our family strong. I do try to keep family gatherings smaller now; Howard enjoys this much more.

What lessons have you learned from caring for your husband?

Alzheimer disease has robbed Howard of our memories. However, one can still be someone without memories. We can still have a life without our memories.

Howard is lacking in judgment. The other day, he had his best suit jacket on to go out and wash the car. I have resolved that if the behavior isn't hurting him or others, then I let it go.

Howard gets upset with me when I try to do too much for him. So, I focus on what he still does really well. Howard makes a 'dynamite pasta sauce,' and when we work together in the kitchen, I make sure that I chop the veggies.

I find that Howard lives in the moment. I know that Howard 'is still in there.' And I know Howard is still a beautiful human being.

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Getting Started

This is a time of chaos and confusion for this family. This is a time for understanding the needs of the person with dementia, and also for understanding the needs of the family caregiver. Peggy's family is attempting to understand and attach meaning to what is happening to this person, Howard, they once knew.

One of the greatest challenges in caring for persons with dementia is that family and friends maintain unrealistic expectations. They may hold the one they love to the standard of who they were before the diagnosis. This can be extremely frustrating for both the person with dementia and their family and friends. Howard lives in the moment. Family and friends are constantly playing catch-up. As quickly as they may adjust to a new dimension or loss of function, there is another change. As Peggy realized, on this visit to the restaurant, Howard no longer recognized the place or the waiter. This means that they may be on to the next stage.

Adding Flavor

As Peggy is coping with her husband's early stage Alzheimer's, she may be wondering, "Will we ever be normal again?" Family and friends caring for Howard, don't understand what is happening. Although Howard is lacking in judgment, Peggy realizes that there are many things that he still does really well. And this is what she focuses on. They enjoy gardening together. Peggy loves that Howard still likes to hold hands when walking. And they work together in the kitchen, Howard making his "dynamite pasta sauce," and Peggy chopping the veggies.

Putting It All Together

Alzheimer's disease has robbed Howard of his memories. Peggy is discovering that they still can have a life without their memories. Howard is living in the moment. She knows in her heart that Howard "is still in there." And she knows that Howard is still a beautiful human being. As Peggy says, "Howard is still Howard, and I love him."

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What Works

- Communicate with feelings
- Find humor in the situation
- Focus on strengths
- Simplify environment

What Doesn't Work

- Environment that is unfamiliar
- Logical reasoning
- Overcompensating for person

Suggested Readings

- There's Still a Person in There; Michael Castleman, Dolores Gallagher-Thompson, Matthew Naythons; 1999
- Best Friend's Approach; Virginia Bell, David Troxel; 2002
- Learning to Speak Alzheimer's; Joanne Koenig Coste; 2004