

For Better, For Worse...In Sickness and In Health

*by Laura Case
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As I decided to write this article about early onset dementia, two remarkable men came to my mind who were on this journey together with their wives. I met Roger and Mark when I worked at an assisted living community a few years ago. I was amazed at their dedication to their wives: daily visits, participating in activities such as exercises, singing, and outings, and spending time with their families during the holiday events. I recently sat down with Roger and Mark and asked them some questions about their journey and was in awe by their devotion to their wives. The words in the forefront of my mind, “for better, for worse...in sickness and in health” took on a whole new level of commitment.

Let me introduce you to Roger and Jeanne:

Married 44 years with two children and one granddaughter, Jeanne was a secretary, a stay at home mom, and then after her kids grew up she became a bookkeeper until retirement. She was diagnosed with dementia at the age of 56 before passing away recently at 64.

Now meet Mark and Ruth:

Married for 40 years with two sons, Ruth was a pastry chef and involved with the Boy Scouts before she was diagnosed with dementia at the age of 55. Now 59, she currently lives in memory care at an Assisted Living community.

During Jeanne’s and Ruth’s transition from home to assisted living, Roger and Mark became friends. They started encouraging and leaning on each other and eventually joined the same support group. It wasn’t long before they began to encourage other spouses and family members going through the same journey. They are still both actively involved in a couple of support groups.

Question: In the beginning what were some symptoms you noticed to seek out medical attention prior to the diagnosis?

Roger: After a bad fall requiring surgery, I noticed during recovery Jeanne wasn’t quite understanding what PT was asking her to do. Her hand-eye coordination wasn’t the same, balancing the checkbook was difficult, and then following verbal directions and feeding herself became difficult.

Mark: Ruth was having difficulty finding words, repeating herself a lot - mostly numbers. She was having trouble sleeping and even had a sleep study done. She started to wander away from the house.

Question: How did Jeanne and Ruth respond when they were told of their diagnosis?

Roger: We were on a cruise in 2010 and she wasn't herself so upon our return her doctor figured out she was dehydrated and may have had a stroke so he ordered a CT scan. The doctor noticed her brain was older than her actual age. Her first workup with a neurologist diagnosed her with Frontal Temporal Lobe Dementia (FTD) in 2012. We went for a second opinion and was were she had Posterior Cortical Atrophy (PCA). PCA made more sense to me after doing my own research and the symptoms fell in line.

Mark: In 2014 Ruth's MRI resulted in a Frontal Temporal Lobe Dementia (FTD) diagnosis. She claimed to be perfectly fine and refused to get a second opinion. Eventually I was able to get Ruth to another doctor and he confirmed she had FTD. Her verbal and interactions with others started to decline. Ruth had some denial in the process, but we were able to get her to agree that changes were occurring.

Question: How was it living with Jeanne and Ruth while their dementia progressed?

Roger: The two of us began attending Alzheimer support groups together to learn more and help with some home environment challenges like stairs. We decided to install a stair lift after she had trouble remembering what to do with her feet while walking up the stairs. Her personal care became more and more difficult for me to do. Ruth attended an adult day center so I could have some time to myself but as her dementia progressed the continuous care was too much so I decided to look into assisted living communities.

Mark: It was very hard. Ruth would wonder off and neighbors down the street would bring her back. She refused to take her medicine and began showing more challenging behaviors - especially during sundowning hours. Her best friend was about the only one able to calm her down and to get her to take her medicine. She no longer recognized me but instead thought I was the handyman coming and going each day doing chores. Realizing I needed more assistance with her care and a safe environment where she couldn't wander off, I started looking into facilities.

Question: How was getting some extra help at a memory care community a blessing to you?

Roger: Jeanne continued to fall so I was glad to get her professional assistance and in a friendlier environment. With her now living in a community I was able to address my own health issues and take more time for myself. Jeanne's last few months in hospice had its ups and downs, but knowing she was in great hands, I was at peace and embraced by our family who were with her until her final days.

Mark: Caring for Ruth at home was becoming too hard for me and the boys. Knowing she was being cared for at the memory care community was comforting. I still visit many times a week and we participate in some activities. However, going out in public is now too challenging since she's restricted to her wheelchair and keeping her seated is their biggest concern these days along with the behaviors that still surface due to sundowning.

You will not find two finer, more committed spouses who have found a way to cope with their situation. I still go by the community for visits and I loved seeing Jeanne with Roger and their granddaughter and family. The look in her eyes and the smile on her face speaks volumes. Recently, I volunteered and saw Mark and Ruth participating in the activities and joy overwhelmed me. Seeing Mark helping Ruth with the balloon volleyball or her exercises was very heartfelt. How lucky these two ladies are for this is not the journey either couple could have imaged they'd be on when they married 40 years ago. If you ask me, I truly think the words "for better, for worse...in sickness and in health" was exemplified by these two men. Words they held onto in their journey together.

Laura lives in Atlanta, GA with her family. She joined PAC in 2016 after working at an Assisted Living community in which she still visits and volunteers to see her friends. In her teenage years, her grandparents moved in with their family. She enjoyed spending time with them and helping them in many ways until they became sick. That is when she realized how much the older generation has to offer with their wisdom, their stories from years past, and valuing the time to share with others in this busy world we live in...take time to smell the roses.

Laura enjoys spending time with her family, boating, cheering on her favorite sports teams, playing with her dogs, and she loves baking and cooking.