

# My Spouse has Aphasia PPA: How We Cope

Written by Charles Walker

May I set the stage with a little background information? We met in Atlanta in 1948. She is the most openly honest and direct person I have ever known; it was not love at first sight. She had another boyfriend but I lived nearby, called often and since she was brave, fun-loving and trusting, we saw each other often and our love for each other grew. We became engaged at Christmas and married in the spring 1949.

Three weeks later, I was commissioned in the US Navy, a major change in plans, as we had contemplated our life together. With no reservations, she accepted this very different lifestyle. During the next 28 years, we lived in 9 different states and 3 foreign countries. She was mother and sometimes, father to 4 children. Never a complaint or a criticism was heard. We are a very adaptable couple and she was a true partner in my success as a Naval Officer and aviator.

Then at age 50, I retire from the US Navy, we settle down and our lifestyle changes again. For the next 16 years, my employer is a private university. During these years, our offspring produce 14 wonderful grandchildren; she attends the university, earns a BS degree, and is diagnosed with cardiomyopathy and diverticulosis. We are adaptable and these events have only minor effect on our lifestyle. We love to travel by motorhome, take ocean cruises, and enjoy camping and boating the Suwannee River, as we watch our grandkids grow. Basically, we were in good health in spite of these troubling diagnoses; we take our pills and cope actively.

I first noticed symptoms about five years ago; she began to have difficulty finishing sentences in normal conversation. She would

say, "I know what I want to say, I can see the word in my mind, but I can't say it." I thought, "OK. We are getting old at 74, maybe this normal." We share the symptoms with our Mayo primary care physician; he sends her to a Mayo Clinic neurologist. An MRI revealed a very small, very old stroke; neither of us can remember when it may have occurred. After numerous physical and psychological exams/tests, she is invited and agrees to participate in a Mayo Clinic study with the diagnosis suspected to be aphasia PPA; the study lasts 2 years with an MRI and blood tests given as required. Final diagnosis is primary progressive aphasia,

Though in general good health, my shapely 130 pound wife gradually lost weight, without changing her diet or eating habits. We added calories to her diet with a daily milkshake made with ice cream and supplements, such as Ensure Plus and Boost; her weight leveled off temporarily at 105 but has since very slowly decreased to 92. Her appetite is good and she eats virtually the same as I do at 185.

My agile fun loving bride has lost most of her sense of Balance. She is strong willed and independent, will not stay in a chair; she has fallen 5 times; thus far she bruises easily but never breaks anything. I assist her when she will let me; she needs help to get in/out of the car, in/out of bed or chair, on/off toilet, in/out of the shower. We have showered together for the past 3 years to keep her from falling and I have carpeted the bathroom.

We will never become hermits. While she no longer enjoys shopping, an earlier joy, I take her somewhere everyday; grocery shopping, to the bank, post office etc. She likes to get out of the house; we use our golf cart for many of our errands or just to cruise the neighborhood.

My gourmet chef, who could produce a fancy meal for 20 with sterling and china, or an outdoor BBQ for 40 around our pool or for a football tailgate, no longer touches anything related to the kitchen or food except to eat what is served; she eats anything. I am learning from her collection of recipes.

Our ability to communicate has deteriorated slowly. I estimate that I understand about 30% of her oral messages; it's more difficult to estimate her ability to comprehend what I say, probably about the same. Body Language saves the day. After nearly 59 years together, we should understand each other, a look or gesture is usually all I need.

She is getting less tolerant of me and others. A daytime caregiver is with her several days each week, when I need to attend to business, or get exercise. The caregiver gives her 100% attention; my wife loves her and the attention. When I am her caregiver, I can't give her 100% since the cooking, laundry, vacuuming etc must be done. She doesn't understand that at 80 years, I can't jump as high or move as fast as in my youth. Often I remind her that I'm not her servant, rather her husband and can't/won't do everything she wishes. Usually she accepts my explanation but sometimes she doesn't and gets angry with me.

She tries to ask many simple questions such as: where are we going, when will we get there? And she asks them over and over and often. After a few times, I usually satisfy her by saying, "It's a surprise and I know you like surprises."

She is incontinent and wears protective panties at all times; yet she usually can communicate when she needs to urinate. If a rest room is convenient, accidents are avoided. I usually survey stores

and restaurants for a family facility to be prepared, when necessary. To avoid changing sheets, in addition to Depends, she sleeps on a large fitted full bed pad. I set the alarm clock for about 1am and 4 am each night rather than risk accidents.

She no longer brushes her teeth effectively. We try; I help, but the results are not satisfactory. We have quarterly dental appointments for thorough cleanings but lately she resists the dental technician by refusing to follow her directions such as refusing to open her mouth. I'm uncertain whether she is being uncooperative or perhaps doesn't comprehend. I have consulted with the dentist to determine if she may need to be sedated to provide the necessary care. He suggests a dose of Valium or Atavan in advance.

I am not a natural chef but I'm not afraid to experiment and learn. Good nutrition is as important as her medication for cardiomyopathy and diverticulosis; she has no medication for aphasia PPA. My goal is to keep her on a high fiber, high calorie, low red meat, whole grain diet. For breakfast, she usually has hot oatmeal and fruit or a high fiber whole grain cereal with banana, raisins, peaches and milk. Also, she loves pancakes with fruit and syrup. For lunch or dinner, I use a lot of different types of dried beans and ground poultry (turkey) seasoned well, with onions, garlic, potatoes, carrots, celery cooked in a crock pot, served in a bowl with a tossed salad and whole grain or corn bread. Usually we have one meal each day in a restaurant of seafood, Chinese, Mexican or fast food.

I will never commit her to a nursing home. She does not have Alzheimer's disease; she is aware of a large part of her life and our life together. If she needs a care facility, I would need to be with her and continue to be involved with every part of her life.

Therefore, I have made the decision to keep her at home and employ those Health Care Professionals that she needs; and I will stay healthy for her.