

When the Words Won't Come: One Couple's journey to a PPA Diagnosis

By Mary Beth Riedner

I was sitting at my home computer when I first learned about Primary Progressive Aphasia. It was the fall of 2006 just after returning from a visit to a neurologist with my then 58-year-old husband Steve. The doctor had mentioned "brain disease" as a possible reason for Steve's speech difficulties. Of course he wanted additional testing (e.g., EEG, MRI, neuropsychological testing) before making a diagnosis. But he had also said that Steve's aphasia shouldn't be getting worse over time if the cause was a stroke, which was a previous diagnosis. I entered "brain disease" and "aphasia" into the search box and was quickly directed to articles on Primary Progressive Aphasia. I remember the awful sinking feeling in the pit of my stomach as I read about this disease and its insidious progressive nature leading to the loss of all language abilities and worse. Everything seemed to fit my husband – the early onset, prevalence among men, difficulties with speaking, reading, writing, and arithmetic. I knew right away that this was probably the name that would be given to my husband's condition and I immediately felt a great sense of loss and grief. How could this be my husband's future...my future? A feeling of numbness set in. I didn't share any of this information with my husband, but I wasn't shocked at the next visit to the neurologist, after all the test results were in, to hear the diagnosis of PPA.

Our journey to this diagnosis goes back to 2002 when Steve first had difficulty with his job as a tool and die maker. Tool and die making is a high-precision job that requires great attention to detail and uses sophisticated math. While he was still able to make accurate calculations using a calculator, he noticed that by the time he walked a few feet to the appropriate machine he had forgotten what numbers should be entered. He found that he had to write down the numbers and take them to the machine. He knew that something was wrong and that he was making mistakes that he never would have done before. He discovered ways to adapt and was actually fortunate that the company had little work at that time. His boss was happy if everyone in the shop "looked busy", so he often spent his days doing meaningless tasks.

Over the years, Steve had been an active participant in local government and often went to village board meetings to express his concerns about current issues. He was an eloquent speaker and could make logical arguments with ease, often extemporaneously. However, he has vivid memories of the embarrassment of giving a faltering speech at one board meeting in the summer of 2002, even though he had written out his comments.

At his annual physical the next year, the doctor noticed his speech difficulties. He directed him to a neurologist and ordered a number of tests to see he had had a stroke. An echocardiogram came back negative. A neuropsychologist observed speech and language problems but indicated that "naming and comprehension skills were intact".

Although an MRI came back negative for stroke, both the neurologist and internist decided to treat him as if he had had a stroke anyway. Cholesterol lowering medications and a daily aspirin were prescribed.

In July, 2003, Steve lost his job as part of a larger company wide layoff. The plant was closed and production was moved off shore to China. Steve made some efforts to find a new job, but outsourcing was eliminating tool and die jobs everywhere. He knew that he could not present himself well at interviews due to his speech difficulties. As I had a full time position that provided us with health care insurance and an adequate income, Steve eventually gave up looking for work and declared himself "retired". You may well imagine my raised eyebrows at this decision, but what options did a man in his mid-50's have when his high level skills were no longer valued by the marketplace.

Fortune smiled upon us in a strange way when my employer changed health insurance providers in 2006 and Steve had to change doctors. At his initial physical, he casually mentioned his speech problems towards the end of the visit. The doctor then directed him to the neurologist who made the PPA diagnosis.

Just over two years later, I am sitting at the same computer typing out this article. We have since learned that our four year journey to a PPA was much shorter than many others have experienced. While the diagnosis is extremely painful, both Steve and I feel that we now know something about the enemy we are facing and can take some steps to deal with the future. We are lucky to live in the Chicago area so that Steve can be seen by one of the top PPA researchers, Dr. Marsel Mesulam of Northwestern University. Participation in research opportunities at the university has given us a sense of empowerment and the opportunity to make a difference in combating this disease. We have also benefited greatly from the informational sessions and support groups available through Northwestern and other agencies in the Chicago area. The annual PPA conferences sponsored by Northwestern armed us with information so that we could start making financial and legal plans for the future. We applied for and received Social Security Disability and Steve is now eligible for Medicare. This made it possible for me to retire from my job and we are now spending more time enjoying each other's company and doing some traveling.

The feelings of numbness and grief have not abated. Now that I am no longer working, I can see the almost daily losses that are occurring. But I take a lot of encouragement and hope from my husband's strength, courage and sense of humor. We just try to make the best of each day and concentrate on the bright spots that still shine through.