

Primary Progressive Aphasia (PPA): A Caregiver's Perspective on a Different Kind of Aphasia

A fuzzy starting point and feelings of concern

It is hard to know exactly when it began. My husband started having trouble with word recall. Maybe a couple times a day. I ignored it for a while, but then it got more noticeable. Was it stress from work, not getting enough sleep, not eating enough? All these thoughts went thru my mind. I asked him if he noticed it. He did, but did not think it was interfering with anything.

After a year or so, I talked to my daughter to see if she noticed anything. She began to pay attention and did see some changes. He also began to have trouble problem solving. After some worry and a few more months passed, I suggested to my husband that he should have a physical. He agreed, but he did not want to discuss some of his symptoms with the doctor. So I insisted that I go with him. He reluctantly agreed. But how would I bring this up to the PCP without my husband's knowledge? I called the doctor's nurse and told her of my concerns. I also went on MyCharts and emailed the doctor directly. When we arrived at the doctor's office I did not know what to expect. I was able to go back with my husband to the exam room. The doctor was great in asking probing questions during the exam to get to the heart of the matter without my input.

The Unexpected Diagnosis

OK - so now we have his Primary Care doctor on board - let's get a diagnosis. He ordered a Neuropsych test which was done in 2 phases, along with an MRI. First diagnosis was a stroke. His left frontal lobe showed degeneration. Ok - that made me feel a little better. His symptoms can improve after a stroke - - but they weren't. We then went to a neurologist. He ran further tests on his heart and blood flow to make sure they weren't the causes. Some additional cognitive tests were run. The final diagnosis was a rare form of dementia called **Primary Progressive Aphasia**. He has the *Logopenic variant* that will slowly cripple his ability to talk, write, and even recognize people in his own family. The amount of time from when we went to his PCP to the final diagnosis was 9 months.

Terrifying news with no guidance or support

Ok - Where do we go from here? There is no cure or medicine to take. The only thing that the doctor suggested was that Speech therapy may help. That's it. The doctors offered no guidance or support. We were on our own to find out what this all means and how to live with it.



Taking matters into our own hands

Time for a game plan. These are my suggestions:

1. Find out all the information you can on PPA. Some places to start:
 - a. National Aphasia Association ([Home - National Aphasia Association](#))
 - b. The Association of Frontotemporal Degeneration ([AFTD - The Association for Frontotemporal Degeneration \(theaftd.org\)](#))
 - c. Local universities with Speech and Language disorders as a major (In Pittsburgh, consider Duquesne University or University of Pittsburgh)
 - d. [alzheimer.org](#)
 - e. Aphasia Recovery Connection ([Home | ARC \(aphasiarecoveryconnection.org\)](#))
 - f. Tactus Therapy ([Tactus Therapy: Speech Therapy Apps for Adults with Aphasia after Stroke](#))
2. Find a support group or two. I belong to two - FTD disorders and Alzheimer's.
3. Enlist a Speech Therapist (Brooke Lang, M.A., CCC-SLP is our current speech therapist - [www.iraphasiatherapy.com](#))
4. Seek moral support - family and friends. They will be life savers.

Grieving process, children to the rescue, and important preparations

My daughter helped me with this game plan. Actually she started the ball rolling while I dealt with my emotions of the diagnosis. Anger - This isn't what I planned for our retirement. Why is this happening to him? Depression - What am I going to do? Grief - Mourning the loss of my brilliant and confident husband. It helped so much for my daughter to gather these resources. Once I found my footing I began dealing with some practical matters that I think many folks forget to plan for.

- Review or prepare wills, trusts, power of attorney, medical directives
- Plan for the cost of home care and long term care. It is not ever too early to gather names of good home care individuals and nursing homes. Not all are the same.
- Review your finances with your executor of your will. Our executor is our son. Remember to plan if something happens to you - the caretaker. My husband does not have any idea what our bills are, medical insurance contacts, social security, investment accounts, etc. I do all the finances. I have made a list of all our assets, passwords, and contacts for our accounts, medical insurance, pension, etc and have reviewed it with our son. He can step right in if I am unable.

So you see, my children have come to the rescue. Our daughter is more the emotional support and our son deals with the money end of things. A good team!!

Also, I have extended family and friends that are supportive. My mother had Alzheimers so I know it is important to have support and to take care of myself. It is very emotional and stressful. I walk with several friends to share my burdens when I need to. My sister-in-laws



call frequently and take me out to lunch. And the horrible part is knowing that it is only going to get much much worse. It helps to have the support to surround us.

My husband's current situation

My husband is now retired. Unfortunately, I am not sure if he understands his diagnosis or if he is in denial. He refuses to tell his family (other than our children) or his friends. His condition is obvious, so I have told everyone that needs to know without his knowledge. His speech is slowly going downhill. He particularly has trouble with finding nouns and verbs. Sometimes we have to play guessing games to figure out what he is saying.

He is still active. He boxes 2 times a week and volunteers with Rock Steady Boxing for individuals with Parkinson's disease. He goes with me to babysit our grandchildren. Although I do not let him alone at all with the children, he enjoys observing them. We love to travel to the national parks and will continue to do so as long as possible. I find giving him daily tasks helps him have a sense of accomplishment - vacuuming, mowing the grass, cleaning the cars, cutting up vegetables while I cook. I realize I will have to adjust to these tasks as the disease takes its toll.

Changing roles and accepting our new normal

The hardest part for me has been accepting my new role. I am a caretaker now. I have lost my best friend and my confidant. His personality has changed. He used to be confident and the life of the party. Now he relies on me to fill in the blanks when he is speaking and asks for directions. He is very quiet in groups even with family.

I have found I can not confide in him with anything going on in my life or others around me. He tends to blurt out these secrets in public. I also watch what I say about money or schedules as he worries excessively when it is not necessary. Sometimes he does socially unacceptable things in public. It used to embarrass me but most of the time it is in front of strangers - so I figure I will never see them again. Other times it is with our friends. And since they know about his condition, we have a good laugh afterwards.

I am getting to know this new person. - what makes him tick, what makes him worry, what makes him happy. I know it will be an endless process as his condition worsens. I will continue to read and connect with people to help us through this process.

