

## Unpacking the Layers in Life with PPA

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### **“Three Voices at the Table” in The Journal of Humanities in Rehabilitation; Fall, 2018. (Open Access)**

#### 1. We need you to look, rather than look away.

- Grief & Resilience exist together—degrees of each change moment to moment, day to day.  
Learning to live with both of them simultaneously.
- A balance between
  - (a) Enjoying life to the fullest, and
  - (b) Planning realistically for progressive losses (e.g., decreased ability to describe health symptoms; POAs; online Primary Progressive Aphasia Support Group)
- Feel guilty & embarrassed  
Cover-up our abilities & activities when interacting w/ other families w/ PPA who are more disabled
- What to give up? What to grasp dearly?
- “Curative Therapies” Does “Curative” exclude us??
- Married to PPA (that happens to live in my husband)  
vs.  
Married to Wayne (who happens to have PPA)

#### 2. We have not stopped living.

- Need help w/ daily, routine activities  
(e.g., using credit card in payment terminal; navigating TSA at airport, using commands w/ our pet dog; Int'l Host Family; reading menu/ordering in a restaurant)
- Help us to learn, plan for, & do new things, take risks, explore new adventures
- Offer, teach, support us w/ various communication tools & strategies (iPad whiteboard, speak function, photos w/ captions); Do not develop a fetish with a single strategy; Help us “stretch” to use new/different strategies; Strategies are most helpful if grounded in our social/cultural context

3. We are in relationship with others.

- Help in identifying & describing PPA to others—how & when to do this (e.g., aphasia card, verbally); Sometimes it's helpful & needed, other times not necessary
- How to “hold” PPA in close relationships—a balance btw being direct & honest and yet not letting PPA become the sole & often grim/tragic focus. How might we respond to others when they tell us: “You’re so inspiring.” “Your husband is so lucky to have you.” “It’s great you’re a nurse.” “I’ll be praying for you” (when that is not consistent w/ our beliefs)
- How to manage others who “walk away” (literally or otherwise; e.g., change the subject)

4. We are two unique individuals who need time and lives apart.

- At the same time, we also value time and lives together
- Need help to learn how to balance independence and interdependence; That balance is changing

5. We have benefitted from our local aphasia community and its many & varied organized activities  
The significance of this has been immense!

- SLPs, students, and individuals w/ aphasia from various causes & their families have grown to know, understand, and advocate for us; Learning together; All our comfort w/ PPA is increasing
- Learn & practice communication strategies; social connections; feel support; enjoy meaningful activities

6. We cherish what we have, but what about individuals & families who are not as fortunate?

- We know how to navigate the HC system & are familiar w/ the language in HC; familiar w/ & able to use community resources; able to establish and maintain relationships, we’re Caucasian, speak English, financially comfortable, well-educated, linked w/ the university, and generally healthy (physically and mentally); we have adequate health insurance
- What about others who have PPA and have significant needs in some or many of these areas?

7. I wonder if holding both an ANALYSIS approach and a SYNTHESIS approach would be helpful?

- Analysis (break down into parts): Can she drive? Does he use yes/no reliably? How much can she comprehend? More of a Western model
- Synthesis (put the parts together): What is a typical day like? Please tell me about a typical week for you. More of an Eastern model