

## **Communication Strategies That Other People Can Use to Help a Person in the Early Stage of PPA**

*by Joanne Douglas*

I have nonfluent/agrammatic variant primary progressive aphasia (also known as progressive nonfluent aphasia, PNFA). I am fortunate to have received an early diagnosis and to be receiving excellent medical care. People often ask what they can do to help a person in the early stage of PPA communicate. I would like to share some of the approaches I have found to be of use when people are interacting with me, together with a brief explanation of why they are helpful. I hope these strategies will also help other people communicate with people in the early stage of nonfluent/agrammatic variant PPA or other variants of PPA. I will be adding new tips and strategies when I learn them in the course of adaptation to my progressive loss of language.

### **Strategies to Help a Person with PPA When Speaking**

- *If the person with PPA is searching for a word, please do not interrupt to suggest a word or try to complete their sentence unless they specifically ask for help.*

I know there is a strong temptation to try to help out in this way, and it might seem that being given a word would be beneficial the person with aphasia. In fact, it only makes it more difficult. Let me try to explain why. If I am searching for a word, then I am focusing on that. If a word is suggested, it means that I also have to think about whether that word is correct. So, in effect, it's doubled the number of words I have to struggle with.

- *Minimize background noise and distractions.*

Normal everyday sounds from the environment now seem much louder and more intrusive than they did before I had this condition. This background noise can overwhelm my ability to hear and understand the words of the person I am speaking with, and also displace the words from my brain so that it is very hard for me to speak. I have found several ways to minimize the distraction in different situations.

- Eat at a restaurant during off-peak hours and choose a table in the corner or against the wall, with the person with PPA facing away from the center of the room.
- In a social gathering, I find that communication is facilitated by stepping to one side of the room, rather than trying to speak when surrounded by other conversations.
- Turn off the sound on the television before talking to a person with aphasia.
- Talk on the phone with a person with PPA from a quiet place, because the voice of the caller will be drowned out by any background sounds such as the television, music or the general noise of other people talking in a coffee shop.

- *Try to speak one-on-one.*

It is much easier for me to speak with one person at a time, rather than speak to several people in a group.

- *Speak loudly and clearly.*  
It is easiest for me to understand someone when they are speaking loudly, although it is not necessary for them to shout. It is also better when they do not speak too quickly.
- *Make sure you have the person's attention before speaking.*  
It can also be helpful to start the conversation by stating what you'll be talking about.
- *Let the person with PPA guide the conversation.*  
While all speech is quite difficult, I find it particularly hard when the person I am speaking with switches topics rapidly. It can be very difficult to recover from being caught unawares in this way. Similarly, I find it hard when someone says something quite unexpected.
- *Please be patient and understanding.*  
The person with PPA may look just as they have always looked, which can make it difficult to remember that they have a degenerative brain disorder. There are several situations in which it is particularly difficult for me to speak, so I am always grateful when people realize that I am doing my best to communicate and am not deliberately being rude.
  - If I am not expecting someone to speak to me, I can be caught without an appropriate vocabulary for that situation, even for something as simple as being asked how I am. I am grateful when I am allowed to ease my way into a conversation.
  - Likewise, if someone says something I am not expecting, I will flounder and find it hard to recover and achieve a normal conversation. It is particularly hard for me to switch topics in a conversation or to speak to successive people.
  - I have a "quota" of functional speech each day. This means that I might need to conserve my speech early in the day if I need to be functional for an important appointment, such as a doctor's visit, later on. I always explain this because I do not want anyone to be offended if I cannot speak to them at any given time.
- *If the person with PPA starts to struggle in the conversation, it is best to stop talking at that time and then resume on another occasion when they have had a chance to rest.*  
My ability to speak coherently declines over the course of a conversation. When my speech starts to be noticeably less fluent or I am stammering, it is best to end the conversation because it will continue to worsen. The conversation can then be picked up again at a later date.

### **Strategies to Help a Person with PPA When Writing**

- Please understand that a person with PPA finds writing very difficult. Therefore, avoid sending letters or emails that require a long response. Don't be offended if the person with PPA writes just a couple of sentences by way of reply or doesn't respond at all.