

Communication Strategies That I Find Helpful in the Early Stage of PPA

About six months have passed since I first described some communication strategies that I have found helpful in the early stages of nonfluent/agrammatic variant primary progressive aphasia (also known as progressive nonfluent aphasia, PNFA). In that time, I have continued to experience a decline in my ability to speak, read and, especially, to write. I am finding that the tips I learned earlier still serve me well in my ongoing adaptation to the progressive loss of language, and so I am continuing to implement those approaches on a daily basis. And I have managed to devise some additional strategies which make meaningful improvements to my quality of life as my condition progresses. I would now like to share some of these new approaches in the hope that they might be beneficial to other people with nonfluent/agrammatic variant PPA or other variants of PPA.

I would like to make clear that I've written this piece incrementally, working on it for no more than 15 minutes a day, which is the limit of my writing ability.

General Strategies That I Find Helpful

- *Prioritize language activities on a daily basis.*

Now that I have nonfluent/agrammatic variant PPA, it is as though I have a “quota” of words available for use each day. Whereas a few months ago I felt as though I had one quota of words for speaking, a separate quota for writing and another for reading, as my condition progresses it now appears that I have a single common bank of words which I can use for speaking, writing or reading on a given day. For example, I find that I can no longer both have an important conversation and produce even a short piece of high-quality writing on the same day. Therefore I have to decide how best to use my available quota of words on a given day. And so, if I have a major activity involving speech, such as a doctor's appointment or a phone call to a family member celebrating a birthday, I will not attempt to write anything important that day.

- *Have realistic expectations in keeping with current level of ability.*

I can feel my ability with language slipping away, which is only to be expected as I have primary progressive aphasia. The daily quota of words available for my use is shrinking over time, although the absolute size can vary slightly from day to day. Whereas six months ago I could still manage to write three or four sentences on a bad day, I now consider it a good day when I am able to write three or four high-quality sentences. In recognition of this inevitable progressive decline, I am finding it important to set realistic goals and have realistic expectations of myself. For example, my revised goal for writing is that every day I will produce as much good quality writing as I can. And I accept that some days my writing output will be zero.

Strategies That I Find Helpful When Writing

- *Focus on one writing activity at a time.*

It is very hard for me to speak with people in a group or one after another, and I also find it hard to keep up with changing topics in a conversation. It feels like I can only hold one group of

related words in my brain at a time, and I struggle to make the switch. I experience similar difficulties when writing. Therefore I now focus on one writing project per session. This project could be a short e-mail to a friend, a letter, part of a longer piece, or maybe a form I have to fill in. When I have completed that activity I will stop and take a break before attempting my next writing session. In this way, I give each piece my full attention and can assemble some relevant vocabulary in my mind beforehand, so that I can maximize my output.

- *Use voice recognition software.*

Over the past six months, my ability to write has been declining more rapidly than my ability to speak. My neurologist recommended speech recognition software to improve my productivity and I have therefore started using Dragon NaturallySpeaking. I've been using the program to dictate e-mails, letters and other pieces, and have been very impressed by the accuracy with which Dragon converts my speech into text. A major benefit is that I know that all words will be spelled correctly, so I no longer have to spend time wondering about words looking strange.

- *Create an outline before starting to write.*

Although I am finding it increasingly hard to write, I still understand the process of good writing. When working on a piece that I know will take me several days, weeks or possibly even a couple of months, I now find it essential to have a very clear outline from the beginning. With this structure in place I can tackle the piece in “bite-sized chunks,” adding a few sentences at a time as my ability allows. For example, I've written the beginning, middle and end of a single paragraph on separate days. I find it helpful to remind myself that no-one ever sits down and writes a whole article in a single instant—all of us write word by word, sentence by sentence, to craft the piece. Therefore my limitations can be viewed as an extreme version of the way I have always written.

- *Make note of useful words and phrases.*

As my daily time available for writing continues to shrink I'm finding it absolutely essential to plan what I intend to say so that when I sit down to write I'll be able to make the best possible use of my time. I'm now finding it helpful to make a note of useful words or phrases as they come to mind during the day, either by jotting them down on paper or by recording a voice note on my smartphone (with Evernote being my app of choice). I then have these key words at hand and available for incorporation into the piece when I'm ready to write, thereby saving valuable time.