

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

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. As a result, I have found that there are a number of communication strategies that can make meaningful improvements to my quality of life in these early stages. I would like to share some of these, in the hope that they might also be beneficial to other people with 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.

I would like to make clear that I've written this piece incrementally, working on it for 20 minutes a day, which is the limit of my writing ability.

Strategies That I Find Helpful When Speaking

- *Visit a speech and language therapist.*

I have benefited greatly from the knowledge of a speech therapist. Since PPA is by definition progressive, I have found it important to be referred for speech therapy every six to eight months so that I can learn adaptation strategies tailored to my current level of ability.

- *Undertake Lee Silverman Voice Training.*

To my great surprise, I learned that the volume of my voice had dropped significantly, even though I thought I was speaking just as loudly as I did before I had nonfluent/agrammatic variant PPA. After undertaking a course of Lee Silverman voice treatment (<http://www.lsvtglobal.com/>) with a specially trained speech therapist I regained my loud voice, which I now maintain by daily exercises and monitor with a sound level meter. An additional benefit of regaining my louder voice is that speech is rather less effortful. And using less energy in speech means that I am more able to show personality when I talk, rather than having all my personality drained by the mere act of speaking.

- *Now that I have nonfluent/agrammatic variant PPA, it is as if I have a “quota” of words available for use each day.*

After I have spoken for a given length of time (currently around 40 minutes, although this is continuing to decrease) there is a rapid and noticeable decline in my ability to speak coherently. When I sense that I have used up my quota of words for the day I stop speaking and spend time in silence to “replenish my word banks.” It is rather like a battery that needs to be recharged when the available power has been depleted.

- *Stop speaking as soon as speech declines.*
When I feel that my speech is slipping for the day, I *have* to stop speaking. This is not like running a marathon in which participants “hit the wall” but can then push through to the finish line. I have found that it is just not possible to recover coherent speech by pushing on when I have started to decline in a conversation.
- *Prioritize speaking activities.*
The daily quota of words means that I have to prioritize and plan my speaking activities each day. For example, if I am meeting someone for lunch or have a doctor’s appointment in the afternoon, I will refrain from speaking that morning so that I will still have some words available for use.
- *Schedule activities for the most functional time of day.*
I find that my ability to speak varies according to the time of day, with the late morning and early afternoon being the times at which I am most functional. Therefore I schedule any important activities for these times.
- *Prioritize topics for speech.*
The act of speaking now takes a huge amount of energy. I am frequently left feeling physically exhausted after speech. However, I find it less tiring to talk about subjects that are meaningful to me, and I have therefore learned that it’s not necessary to have an opinion on everything or to have something to say about every topic.
- *Silence is restorative.*
Whether I’m recovering from speaking or planning to speak later in the day, I find it most helpful to spend time in silence. And by this I mean complete silence – no television, radio, music, or any other background noise.
- *Minimize background noise and distractions.*
Normal everyday sounds from the environment now seem much louder and more intrusive than they did before I had nonfluent/agrammatic variant PPA. 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. This makes it hard to speak in social settings, such as coffee shops, restaurants, meetings or parties, so I try to avoid these situations if at all possible. However, participation in social activities is important to maintain a good quality of life and there are several ways to help minimize distractions:
 - I entertain at my home, where I can influence the environment.
 - I eat in a restaurant during off-peak hours and choose a table in the corner or against the wall. I sit 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.
- *Speak one-on-one if possible.*
It is very difficult to me to speak with people in a group. Whenever possible I try to speak one-on-one, so that I can then focus on a single person. It is also hard to speak to people one after another, such as speaking to a receptionist, nurse and then a doctor. Sometimes the need to speak to successive people is unavoidable, so I try to make plenty of time between each conversation to allow for some recovery.
- *Make notes before important conversations or appointments.*
I find it helpful to write an outline of the key points I want to discuss, and also to assemble some vocabulary relevant to the topic at hand. I then refer to my notes during the conversation.
- *Rehearse individual sentences.*
In certain situations I find it helpful to plan exactly what I'm going to say and then rehearse that sentence mentally before I need to speak it. For example, I use this approach to place an order in a grocery store, or to start a conversation.
- *Remember that it's not always necessary to use the perfect word.*
Instead of using precious time and energy searching for the *perfect* word, it is acceptable to use an *adequate* word instead.
- *Explain to other people that I have PPA.*
Now that it is becoming increasingly obvious to other people that my speech is declining, I explain my condition. I tell them that I have a progressive neurological disorder, a form of frontotemporal degeneration, in which the region of my brain that controls speech is atrophying. I then say that this is why I am speaking slowly, closing my eyes and moving my hands a lot when I speak, and ask them to please be patient and bear with me. I have never been met with anything other than kindness from anyone I have said this to.
- *Remember that other people are kind and want to help.*
I have never met anyone else with nonfluent/agrammatic variant PPA. No-one I know has ever met anyone with any form of PPA. This means that they will not automatically know the best way to help me in conversation. However, I find that people are kind and very willing to learn how they can facilitate my speech so that I can interact with them in a meaningful way. I have written a few of these tips in another piece for others

communicating with someone who has PPA. Also, I find it helpful to remember that no-one is deliberately going to say something hurtful to me about my condition. On those rare occasions when another person's lack of awareness of PPA leads them to inadvertently say something hurtful, I immediately explain the situation to them. By making a conscious effort to address these hurts at the time they occur I can maintain a good quality of life.

Strategies That I Find Helpful When Writing

- *Stop writing at first sign of decline.*
Just as I have a “quota” of words available for speech each day, I also have a quota of words available for writing. On a good day, I can write for about 20 minutes, after which my ability markedly declines. On a bad day, I can manage no more than three or four sentences. At that point, words begin to look “strange” and I start to wonder if they are spelled properly and if my sentences are grammatically correct – even when there are no errors. Basically I start to second-guess myself. This is an indication that I should stop writing immediately because if I continue I will only undo much of whatever I've written. And once my writing ability in a given session starts to decline, it is not going to recover at that time. However, the result of many daily 20-minute writing sessions can still be quite substantial.
- I want to make the maximum use of my daily time available for writing. Therefore I keep a list of things I need to write and a list of people I have to write to. I also spend some time planning what I intend to say and rehearsing some sentences in my brain, so that when I actually sit down to write I'll be able to start straight away.
- *Speak out loud while writing.*
When I am having trouble selecting the correct word when writing, I now find it helpful to run through the choices by speaking out loud. For example, I am having increasing difficulty in deciding the correct preposition to use, so I go through a number of options aloud and decide which sounds best: should it be “congratulations *on* ...” or congratulations *for* ...” or “congratulations *about* ...” ?
- If I am writing an important letter or email, then I will start work on it one day and then review it the following day before sending it. I find this is a helpful way to check that it still makes sense.
- I never start writing important emails from within the email program, but use a word processing program and then paste them into the email once I'm sure they're correct. This avoids the possibility of accidentally hitting the send button too soon.

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

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.