

HELP & SUPPORT

Communicating with Persons Living with PPA – Tips and Strategies



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Primary progressive aphasia (PPA) is characterized by a gradual loss of one's ability to speak, read, write, and understand speech. The inability to communicate is troublesome for the person living with FTD, as well for those caring for and supporting them.

Adapting how one communicates with persons living with FTD can increase their understanding. Below are some tips and tools that may help you do just that. Please note that many of these tips will require trial and error. Experimentation is the key to see what works best for you.

Simplify your speech without dumbing it down.

- Use simple, direct sentence structures. For example, "I am going to the store to buy fruit" is better than "At the store, I am going to buy fruit."
- Use "high frequency" words. These are words that are more commonly used in everyday conversation (ex. "give" instead of "donate").
- Think of each word as part of a hierarchy. If a specific "level" of the word is not understood, move down to a simpler level. For example, if the person diagnosed does not understand "basset hound," move to "dog," and if they do not understand that, try "animal."
- If you are presenting a choice or a decision to the person with PPA, ask yourself: Can this be narrowed down into fewer options? Can this be broken down into a yes/no question?

If there are barriers to understanding, be creative.

- Use pictures or written words.
- Act out what you are trying to say.
- Try different words or phrasing.
- It may help to pretend you are trying to talk to someone who speaks a different language.
- How would you get your point across?

Use communication aids that the person living with PPA is enthusiastic about using, such as:

- Your smartphone (it's always with you!). Create custom photo albums, take notes, and download apps designed to help people with aphasia (SmallTalk and CommunicAide are two free ones).
- A custom picture book with useful and meaningful photos.
- A "cheat sheet" containing their most common phrases, restaurant orders, loved one's names, or anything else that they want support for.
- Cue cards with responses (yes, no, maybe, I don't know, etc.) that they can point to.
- Ask a speech language therapist for help identifying other tools that will meet your specific needs and abilities.

When using written language (for example, emails) to communicate to someone living with PPA, consider the following:

- Use bullet points instead of sentences.
- **Bold** important words or phrases.
- Pare back information to that which is truly essential.
- Read written information aloud.
- Add age-appropriate pictures to boost comprehension. The website [ParticiPics](#) has free pictures that are geared toward people with aphasia, and includes images for medical and everyday settings.

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When in a conversation with a person living with PPA:

- **Don't correct, but do clarify.** If you understood the person living with PPA, then it doesn't really matter if they mispronounced a word. But if you didn't understand them, ask them to repeat themselves, or paraphrase what you heard and ask if that is correct.
- **Keep it positive.** People with PPA will say the wrong word. Just try to keep the dialogue going in a non-judgmental, supportive way.
- **Develop a plan for "filling in the blank."** If the person living with PPA cannot express a word, do they want you to supply the word for them? Give them more time to think of it? Write it down? Maybe there are situations where they want their communication partner to do most of the talking.

Other tips:

- **Follow the lead of the person living with PPA.** How do they wish to be spoken to? Talked about? Supported? Included in conversations?
- **Utilize the improv principle of "yes, and."** Accept what was said, no matter how imperfectly, and add to it to build conversation.
- **Be flexible.** If one word doesn't work, try another. If a conversation just isn't working, take a break, or try having it in smaller mini-conversations over time.
- **Change your mindset.** PPA is progressive; language skills will continue to deteriorate. Adaptability is key. What worked today may not work tomorrow.
- **Plan ahead.** Look at restaurant menus online and choose meals ahead of time. Review goals for a doctor's visit in advance. Strategize how to engage at a family reunion.
- **Include others.** Develop a small group of people who will graciously accept communication faux pas. Children tend to be really good at this. Isolation is common in PPA; foster connection.
- **Determine the goal of your communication.** If your goal is for the individual to comprehend information (like legal or financial records), accuracy is important. If your goal is connection (for example, saying "I love you"), you will have more flexibility.
- **Get regular eye and hearing appointments** to ensure that visual and/or hearing challenges aren't getting in the way.
- **Miscommunication happens to everyone.** Laugh when you can, mourn when you need to, and exercise patience.

Some reminders:

- You are communicating with an adult who likely understands your tone and facial expressions. Be respectful and age-appropriate.
- Communication is physical. We communicate through movement (pointing, shrugging), tone of voice, eye contact (interest versus disinterest), touch (or lack thereof), etc. Make sure your body language matches your spoken language.
- All communication strategies and aids should build on the strengths of the person with living PPA. If they weren't technologically savvy before their diagnosis, that probably won't change.



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