

My loved one has Aphasia....now what?

Often as Speech-Language Pathologists, we hear caregivers tell us, “I wish someone told me this sooner,” or “I was so overwhelmed, I don’t remember what they told me.” Our goal is to avoid these feelings of stress and frustration as much as possible and provide support for some of these issues that may arise early on. We are hoping this can serve as a printed resource for caregivers of individuals with Aphasia. Below are some of our most frequently asked questions and challenges that individuals are faced with when Aphasia becomes a part of their lives.

“What can I do to help my loved one? They get very frustrated with the doctor, especially when he talks to me (the caregiver) and not my husband (PWA)”

Doctors often buzz in and out of a patient’s room, quickly presented verbal information is muddled with jargon and technical terms, and there is not a lot of time left for questions or clarifications. The most important thing you can do is be an **ADVOCATE**. Unfortunately, **YOU** may need to actually be the person who provides education to the doctor. Below are a few steps you can take to improve communication between a Person with Aphasia (PWA) and their doctor (or any medical professional):

1. **ENCOURAGE THE MEDICAL PROFESSIONAL TO TREAT THE PWA AS AN ADULT.** Your loved one’s intelligence is intact. They did not lose their language. Instead, they are now having trouble accessing the words they need to express themselves or understand language. They also did not lose their hearing, and speaking to them in a loud voice will not assist with comprehension. Therefore, it is important for you to encourage others to **maintain an adult tone** and **use short and direct sentences**. Doctors and medical professionals should be **including the PWA** in all conversations about their care. They should be looking at **THEM**, talking to **THEM**, and using you, the loved one, to help provide support for communication breakdowns as needed. It is important that the medical professional address the PWA directly, regardless of how much they are able to process.
2. **SET UP FOR COMMUNICATIVE SUCCESS.** It is likely that at some point, you may need to leave your loved one alone for a period of time, whether it’s to go home to take a shower, grab some lunch, or take phone calls with family and friends. Therefore, it is important that you provide the PWA with written information that he/she can use to communicate basic needs and emergency information. They should have an Aphasia card displayed on their tray table or message board that says their name, that they have Aphasia, what Aphasia is, and an emergency contact name and number. It is also important to include a few communication tips that seem to be most beneficial to your loved one. See our list below for some ideas and examples of these. It might also be nice to include a few lines about your loved one so the nurses and other medical professionals have some background information for when they attempt to communicate with your loved one and no one is available to help interpret their message or provide communicative support. Finally, make sure your loved one has some way to communicate basic needs, such as having picture icons and words available for pointing responses, for things like bathroom, pain, or water.



3. **GIVE THE PWA EVERY OPPORTUNITY TO COMMUNICATE SUCCESSFULLY.** The goal is to COMMUNICATE, regardless of whether or not the message was communicated VERBALLY. You want to encourage any method of communication that can be helpful.
 - a. Expression:
 - i. **Give the PWA time to respond.** Patience is especially important.
 - ii. Offer the PWA a **piece of paper and pencil** or a whiteboard so that they can write or draw.
 - iii. Create a **simple page of pictures** that represent basic needs so that they can communicate these with the nursing staff (i.e. hungry, bathroom, pain, etc.) Sometimes, these are already available on the medical units and utilized by nursing staff.
 - iv. Encourage the PWA to **use gestures** to communicate their needs and wants.
 - v. **Ask yes/no questions** to confirm your understanding.
 - b. Comprehension
 - i. **Write down key words** of the conversation or request printed material from medical professionals.
 - ii. Speak in **simple, direct sentences.**
 - iii. Speak at a **normal volume.**
4. **REMOVE AUDITORY AND VISUAL DISTRACTIONS**, such as the TV or radio.

“The doctor told me my loved one is confused and doesn’t know what day it is, but I think he seems to understand what is going on.”

There can be a period of confusion that comes with a stroke or traumatic brain injury (TBI). However, orientation questions (where are you?; what day is it?) are often presented verbally and the PWA is not given sufficient time to process the questions or respond to them, and are often not provided with opportunities to use other methods of response. **Try providing picture options representing WHERE (i.e. picture of a hospital, home, or school) or a calendar for WHAT DAY it is to allow them to respond by POINTING.** By allowing the PWA other methods of responding, the doctors may see a different cognitive picture.

“My loved one with Aphasia is not as intelligent as they used to be.”

Aphasia does NOT affect intelligence. Aphasia does impact one’s ability to speak, process language, write and read. It may also affect one’s ability to say or use numbers. Although it seems they may no longer be able to describe how to do something that they used to be very good at (i.e. change a tire), if all physical limitations were put aside, they would likely have no trouble carrying out the task. However, they are unable to access their language in order to produce the words and formulate the sentences to describe such a procedural task.



“My loved one has been diagnosed with Aphasia and Apraxia of Speech. What is the difference?”

Aphasia is a **LANGUAGE DISORDER**. It results in difficulty accessing language, causing impairments in verbal expression, processing language, reading, and writing. Difficulties with word retrieval and sentence formulation are often challenging.

Apraxia is a **SPEECH DISORDER**. It affects the motor planning and programming involved in speech. Apraxia affects how someone can direct the movement of their lips, tongue, and jaw to make the sounds they want. In other words, our brain typically communicates with our articulators, and would signal our tongue to tap the roof of our mouth and turn on our voice in order to produce the /d/ sound. That connection is impaired in someone with Apraxia, making it difficult to produce and combine sounds to formulate words and sentences.

“We’ve never heard of Aphasia. Is Aphasia rare?”

No! It is estimated that **at least 2,000,00 people in the USA have Aphasia**. That means more people have Aphasia than other well-known conditions such as Cerebral Palsy, Multiple Sclerosis, Parkinson’s disease, or Muscular Dystrophy. However, a recent study conducted by the National Aphasia Association showed that about 85% of people surveyed have never heard the term “Aphasia.”

“When will my loved one be able to communicate normally again?”

Aphasia is different for each person. Additionally, **there is no cure for Aphasia**. Therefore, while some PWA make close to a full recovery, others are faced with accepting “a new normal.” **Multiple factors impact a patient’s progress, the recovery trajectory is often quite variable, and it is not something that can be well-predicted at this time.**

“The doctors said my loved one only has 6 months, or at most up to 1 year, to make progress, and that will be as much progress as they will make.”

False! Do not ever accept this statement as true. PWA can continue to make progress with effective therapy for years following stroke or brain injury. However, the period of SPONTANEOUS brain recovery often lasts 6 months to 1 year. It is not uncommon for a PWA to make the most and quickest amount of recovery during this window of time. **While progress might slow down after this period, a PWA can ALWAYS continue to make progress.**



“My loved one wants to sleep a lot and gets tired more easily than before his stroke.”

This is expected. **The brain and body need a lot of rest to recover from a stroke or traumatic brain injury.** Additionally, speech therapy can be mentally exhausting. We often have clients tell us they take a nap after a speech session. Rest is good and encouraged. However, if you are concerned with the amount your loved one is sleeping, don't hesitate to **discuss it with his/her doctor.**

“Why can my loved one with Aphasia say my name sometimes but other times can't seem to remember it?”

Aphasia is not an issue with remembering words. **You do not LOSE your language or have memory loss for words.** However, PWA have difficulty **ACCESSING** their language. Therefore, accessing the word they want to use can demonstrate inconsistent results. PWA often describe it as feeling like “I know what I want to say, but I can't get the word out.”

“Insurance is about to stop covering more speech sessions and we cannot afford private pay therapy. What do we do?”

There are a lot of other low or no cost ways to participate in therapy, groups, or communicative activities. **The important thing is to keep communicating.** Many **Aphasia centers** or **online support groups** offer free online groups and activity sessions. **Research** is also another way to participate in therapy as a low or no cost option. Many research studies offer free therapy. Lastly, **apps can be a good way to support progress.** A few of the bigger app companies for Aphasia are Constant Therapy and Tactus Therapy. Ask your Speech Language Pathologist to trial these apps with the PWA prior to purchasing or consider using the free trial first. It is important to ensure that these apps are a good fit before purchasing. **Check out the resource section on our website for additional information about Aphasia centers and research programs.**

“My loved one won't let me help with therapy. What do I do?”

Boundaries can be important. Each PWA is different. Some prefer to work with family and friends on speech and language tasks, whereas others prefer their family and friends do not take on that role. It is important to respect their preferences. Roles can change quite a bit after a stroke or traumatic brain injury. Taking on the responsibility of a Speech Language Pathologist might not be one of the roles a PWA wants their family to play.



“He says ‘table’ when he means ‘chair’ and ‘orange’ when he means ‘apple’.”

This is known as a **Semantic Paraphasia**. This means that when a PWA attempts to access the target word of “table,” they instead may choose a related word, or one in the same semantic category (i.e. furniture), such as “chair”. Semantics is a fancy word for the meanings of words. This can sometimes become fuzzy when you have Aphasia, and those concepts and relationships need to be re-strengthened in order for your loved one to have improved word access.

“She says things like ‘hen’ or ‘ben’ when she wants to say ‘pen’.”

This is known as a **Phonemic Paraphasia**. This means that when a PWA attempts to access the target word of “pen,” they instead may choose a word that sounds similar, such as “hen”. This is likely a result of their Phonology (a fancy word for one’s sound system) being affected by their stroke or brain injury. The PWA may have trouble accessing the word form (i.e. the number of letters associated with the word, the number of syllables, the correct letters, and/or the correct sounds), causing them to produce an inaccurate target.

