

The Importance of Aphasia Advocacy: Perspectives from our Aphasia Caretakers

Advocating for Aphasia Awareness is extremely important. According to a survey done by the National Aphasia Association (NAA), 86.2% of participants reported that they have never heard of “Aphasia.” Why are we having such a hard time educating the world about “Aphasia,” or even getting people to recognize the word itself? Perhaps the act of advocating presents a challenge when the person affected by the disorder has limitations with communicative expression. This is why it is crucial for family members and professionals to get involved with Aphasia advocacy, especially early on when it might be particularly challenging for the person with Aphasia to advocate for themselves.

For National Aphasia Awareness month, we reached out to some of our caregivers to ask how they advocate for their loved ones with Aphasia. These are just a few examples portraying the challenges of advocating for someone with Aphasia:

Caregiver: My husband, John, was in the hospital. They **wouldn't let him get out of bed, to even go to the bathroom by himself.** When he pushed the call button for help to get up, the call center would ask him what he wanted...of course **he couldn't answer, so they would just keep restarting their question.** I tried to get the nurses to tell the call center that if the phone for his bed called them, they needed to send someone right away and not ask questions. The bottom line bottom line was that the person answering the call was **always changing and they had no way to post a notice** for all the people taking calls to know John's needs. I tried but it **didn't get very far to help him.**

Caregiver: Initially, Bryn (age 26) had Global Aphasia and made very few sounds and had very little speech (just one word!). **We had to do all of the talking for her.** The beginning days in the ICU were so very hard because **we did not have a Power of Attorney.** We had to do **a lot of advocating for her to obtain one** and once it was determined that she could understand what was being asked, she was able to make an "X" to sign one. It's so difficult without a Power of Attorney because **we couldn't handle her banking, car insurance, employer human resources, health insurance, disability insurance for her. Nobody will talk with you** since your child is now a young adult and has been handling her own affairs very effectively. Once we obtained one, we handled all of that for her.

Caregiver: Ken's speech pathologists while in the ICU, step down floors in hospital, as well as the LTAC, then onto Craig rehabilitation hospital, were wonderful. They all worked in Neuro. They helped both Ken and I understand Apraxia and Aphasia. When **our insurance changed,** Ken began outpatient therapy with speech, OT and PT. **Unfortunately his speech teacher lacked the**



skills Ken needed with his Aphasia. She only spoke to me. This *wasn't working well for us*, so we left and found another speech pathologist, and all went well.

Advocating presents a challenge even within our own medical system, which again, is best explained by our caregivers:

Caregiver: In 2020-2021 we had a **misdiagnosis in the ER** and at a physician's office, resulting in a change of hospital and provider; and an ***office refused entry to me as caregiver even though I had advance permission*** prior to arriving at the appointment. The nurse loudly asked in the waiting room why John needed assistance, an ***obvious HIPPA violation***. Now I use a [document provided by a group on Facebook](#) for when entry is denied.

Caregiver: As an observation from my short time as an Aphasia care partner, **our disability "system" does not do enough to recognize and meet the needs of those with communication differences**. For example, try navigating an SSDI form with Aphasia. ***There are many words and nobody who understands what Aphasia is***, not to mention having to **navigate a complex phone tree**, being on hold for (sometimes) hours. **We have provisions and compassionate allowances for other disabilities, but not Aphasia.** I have been asked multiple times *"Why isn't Ms. Bryn calling us herself?"*

Additionally, unlike many other disabilities, Aphasia is an "invisible" disability. If a person does not have any residual physical limitations from their stroke or brain injury, people do not "see" a disability. It makes it extremely hard to advocate for a disability when someone doesn't understand that it's there.

Caregiver: When Bryn handed her ***"aphasia information" card*** to a TSA agent, she replied "ma'am, you don't need to show us that, we just need you to tell us what is going on with you." It's a great example of the **need for awareness and to accept ALL forms of communication as valid.**

Caregiver: We have had ***a lot of difficulties, especially during COVID.*** Because John looks like every other patient and often has no speech or cognitive issues, the medical teams do not seem to understand ***why persons with Aphasia need support.*** Especially **when he is ill, the stroke sequelae present and he needs assistance.**

Alternatively, sometimes family, friends, and medical professionals know a person has Aphasia, but do not know how to best communicate with that person. Unfortunately, this can result in them talking to the carepartner as if the PWA is not even in the room.

Caregiver: When we came home from being gone for ten months, friends came to visit. The issues we encountered were that ***many of Ken's friends***



didn't speak to him. Instead they **spoke to me in front of Ken**, asking questions etc, ***as if he were not there.*** This was ***difficult for everyone.*** I find this to be a ***normal reaction for many people*** who encounter Aphasia. As time moves through the years, living with Aphasia is better. It is difficult, yes, but better.

Advocating can be difficult but it is extremely important to help improve the lives of Persons with Aphasia. Advocacy helps increase awareness to not only improve daily interactions for PWA with the general public and medical system, but also to encourage insurance to fund ongoing therapy. As one caregiver put it “While research provides evidentiary support and data that intensive Aphasia programs are most effective for treating Aphasia, our insurance companies do not recognize or cover it.” Caregivers play a major role in helping to promote awareness of Aphasia. However, it is important to encourage and allow a PWA to advocate for themselves as well. As caregivers, your role as advocate can continually change as your loved one progresses through therapy. Sometimes the best way to advocate is to step back and allow the PWA to communicate in their own way.

Caregiver: If you think about it, ***you cannot accomplish much in our world without the ability to communicate.*** Aphasia affects every aspect of communication (speaking, reading, writing, sometimes understanding) so that makes life challenging! Today, Bryn's diagnosis is Broca's Aphasia. She is very independent and really knows exactly what she needs to do, keeps her own schedule, handles her own meds, and cares for Margie (her chihuahua). ***We now advocate for her by communicating to schedule appointments, and speaking with healthcare providers and SLPs.*** Numbers can be difficult, so we assist by calling for prescription refills, banking. **Bryn's judgment, thought processes, and intelligence are all intact**, but sometimes *we have to "loan" her some words.* She likes to write meaningful notes to others and we will help her with sentence structure and grammar when she asks. ***Aphasia is very isolating and sometimes friends can fall away without help in communicating with them.*** Initially, it was really hard to send anything to friends except emojis. We are very thankful to speech and language pathologists who have helped us with creative ways to advocate for Bryn. Many times, this ***means stepping back and allowing her to do things on her own***, such as ordering at a restaurant, using a Boogie Board, etc. ***Advocating is sometimes giving someone with aphasia more time and not interrupting or finishing sentences and helping others understand that too.*** Bryn is really working hard to regain communication so that she can advocate for those with aphasia. Watching her work is truly inspiring to us and we are proud to stand beside her!



Thanks to all of our amazing caregivers who contributed to this article, and shared so many valuable observations that we can all learn from. If you would like to see how some of our PWA have advocated for themselves, [watch the video they made as part of their advocacy project](#) on our website.

