



Helping Aphasia Caregivers Overcome Their Biggest Challenges



A Guide for Speech-Language Pathologists

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A Story That May Sound Familiar

The morning Lucy had her stroke I was laid up in bed with the flu and my wife was babysitting our grandchildren. The phone was ringing, and she wasn't picking it up, so I got out of bed to answer it. The call was from my daughter. Apparently, the grandchildren called her and asked why Lucy wasn't speaking to them. I said I did not know but would find out what was going on.

I found my wife lying on the couch and I asked her what was happening, and I got no reply – only a blank stare. After trying to get her to say something and get up from the couch, I realized something was wrong. I called 911. The police and first aid arrived within minutes.

We were in the ER for about 30 minutes when the doctor told me that my wife had suffered a very bad stroke. By the next day she was in the Intensive Care Unit (ICU) and was paralyzed on her right side and could not speak. After three days in the ICU she was transferred to another hospital and for the next three months she received physical, occupational, and speech therapy.

The day I was told she was being sent home I was in shock. Other than repeating some words, she couldn't speak or write, and had no use of her right arm and leg. She was not even able to control her bowels or urine flow. I knew then I was going to be a 24/7 caregiver.

It's not easy to be a caregiver – ask any of us. But for me, my role as a caregiver is quite simple. I just remember these words: “In sickness and in health, until death do us part.”

-Ed, Spouse and Caregiver.



About the Challenges Aphasia Caregivers Face

We knew that caring for someone with aphasia can be stressful — but we wanted to know more. So, we surveyed more than 700 caregivers to get a better understanding of their experiences.

The result was our 2020 Aphasia Caregiver Report. It offered a never-before-seen look at the individuals who care for someone with aphasia.

These individuals go by several names and titles: caregiver, care partner, communication partner, co-survivor, wife, husband, child, sibling, and so on.

They come from all different walks of life, reside in different geographic regions, and have diverse backgrounds.

Yet, they are all bound together by this common thread: their lives were irreversibly changed when someone close to them acquired aphasia.

In this eBook, we discuss the **biggest challenges aphasia caregivers face, and how SLPs can help.**



The Critical Role That SLPs Play

Caregivers play a pivotal role in the life of a loved one with aphasia. They often bear the most responsibility for their loved one, spending a great deal of time caring for them and communicating on their behalf. Over 90% of caregivers said that their biggest motivation for doing what they do is that they are invested in their loved one's quality of life.

That's why clinicians need to include caregivers in the treatment of the person with aphasia. SLPs need to make sure that caregivers understand their loved one's diagnosis, how that impacts their communication, and what they can do to ensure their loved one continues to make progress.

But it's not easy. Aphasia can have far-reaching effects on caregivers' mental, physical, and emotional states as well as their relationships with others.

Caregivers report a worsening in all of the following since their loved one acquired aphasia



90%
stress level



79%
emotional
well-being



69%
sleep quality



68%
energy level



67%
life outlook



43%
physical
discomfort

It is clear that unless caregivers overcome these challenges, they are likely to experience a serious decline in their own personal health. Ironically, this may leave them unable to care for the person with aphasia.



Challenge No. 1: Communication

Over 93% of caregivers say that the inability to communicate or converse with the person with aphasia is a challenge.

Aphasia affects individuals differently based on the parts of the brain that were damaged following a stroke or traumatic brain injury, and the severity of that damage.

Individuals with aphasia commonly struggle with spoken language. However, aphasia can also affect language comprehension, written expression, and reading comprehension.

No matter what symptoms a person presents with, it's important to remember that aphasia does NOT affect intellect.

But that doesn't make traditional communication any easier between persons with aphasia and their caregivers.

In fact, it appears as though few caregivers receive proper communication training or know how to properly employ communication aids like alphabet boards, communication charts, erasable whiteboards, or a communication app or device.

Over 58% of caregivers note that their loved one does NOT have a communication aid.

**APHASIA
DOES NOT
AFFECT
INTELLECT.**





Challenge No. 2: Dependence

Nearly 80% say that adjusting to the person with aphasia's dependence on them is a challenge.

As noted earlier, aphasia can cause serious language impairments. As a result, the person may become dependent on their caregiver for help communicating with others. Over 91% of caregivers said communication assistance is an activity they helped with.

Additionally, because aphasia typically occurs as a result of a stroke or traumatic brain injury, physical impairments may increase the individual's dependence on their caregiver.

In addition to communication assistance, approximately 2 out of 3 caregivers spend up to one-third of their waking day assisting loved ones with activities that may be more indicative of physical impairments such as transportation assistance, food preparation, and providing medication.

Activities Aphasia Caregivers Help With



91%
communication
assistance



79%
transportation



77%
food preparation



74%
providing
medication



69%
technology
assistance



Challenge No. 3: Motivation

Nearly 79% say that motivating the person with aphasia is a big challenge.

Because aphasia can cause serious impairments with spoken language, language comprehension, written expression, and reading comprehension, individuals with aphasia can quickly become cut off from the life they once knew.

The special connections they once shared with a spouse, family, friends, and loved ones can essentially vanish overnight. That can easily leave the person feeling isolated, depressed, and unable to find the motivation to work on improving their communication or any other conditions they may be dealing with.

It is clear to see the impact that the loss of communication can have on one's life.

- Nearly **98%** of people with aphasia were not employed
- Higher than **95%** report the person spends most of their time watching TV or listening to the radio
- Over **56%** of caregivers say the person is more withdrawn or isolated
- About **51%** of caregivers say the person is more worried and anxious
- More than **50%** say relationships with friends have worsened

Only **8% say their loved one is pursuing a new hobby or activity**





Challenge No. 4: Self-Care

Over 77% say that finding time for self-care and personal activities is a major challenge.

According to the report, over 63% of caregivers spend as much as one third of their waking day providing care to the person with aphasia. For close to 45% of caregivers, that figure is as much as half of their waking day.

As we noted earlier, caregivers most commonly help with communication assistance, transportation, food preparation, providing medication, and technology assistance.

However, caregivers whose loved ones more recently suffered a stroke or traumatic brain injury may provide assistance with bathing or hygiene, dressing and grooming, walking, bathroom assistance, and feeding.





Challenge No. 5: Household Activities

More than 69% say that keeping up with household activities and chores is a major challenge.

Given how much time aphasia caregivers spend providing care and assistance to loved ones, it should come as no surprise that household chores and activities can quickly fall by the wayside.

Additionally, their worsening stress level, emotional well-being, sleep quality, energy level, life outlook, and physical discomfort can all be contributing factors in their inability to keep up with household activities.

Another critical thing to note is that 82% of caregivers are age 55 or older. This means that just around the time when our bodies naturally begin to slow, caregivers are taking on double the responsibilities they had in their youth.





Challenge No. 6: Finances

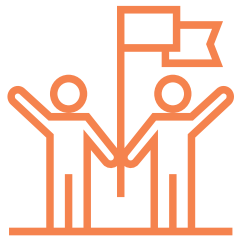
Nearly 45% of caregivers say that lack of income or financial resources is a major challenge.

As we already learned, most aphasia caregivers tend to be older adults. In fact, over half of all respondents indicated that they were 65 years of age or older, meaning that most will be of retirement age. Indeed, when asked about their employment status, nearly 55% of all caregivers indicated that they were retired.

When combined with the information that some 98% of people with aphasia are not employed, it becomes easier to understand how finances can be a major challenge.

It's easy to see how ongoing medical expenses for their loved ones can have an impact on finances.





6 Steps to Helping Caregivers **Conquer** Their Biggest Challenges

Now that we've seen the top challenges facing aphasia caregivers, let's discuss six steps that SLPs can take to help caregivers overcome these common challenges. Over the next few pages, we'll learn how SLPs can ensure caregivers become knowledgeable about their loved one's condition, can communicate more easily and effectively, and can continue to help their loved one improve long after your sessions together end.

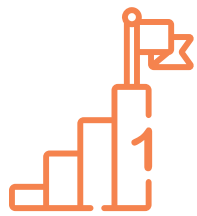
The foundation for these six steps, lies in the **Life Participation Approach to Aphasia (LPAA)**. LPAA is a mindset or approach to aphasia therapy where the person with aphasia, their family, and the SLP are a team with the goal of increasing life participation and improving quality of life for anyone affected by the condition.

According to the American Speech-Language-Hearing Association (ASHA)¹:

LPAA supports all those affected directly by aphasia, including immediate family and close associates of the adult with aphasia. The LPAA approach holds that it is essential to build protected communities within society where persons with aphasia are not only able to participate but are valued as participants. Therefore, intervention may involve changing broader social systems to make them more accessible to those affected by aphasia.



¹ Life Participation Approach to Aphasia: A Statement of Values for the Future. (2020). Retrieved 31 January 2020, from <https://leader.pubs.asha.org/doi/10.1044/leader.FTR.05032000.4>



Step No. 1: Make Attendance Required

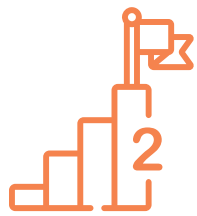
The first step to helping a caregiver overcome their challenges is to inform them that their attendance at each session is required. Even if you aren't able to hold them to this, it's important to demonstrate how critical they are in this process.

Unfortunately, too many caregivers take their loved one's therapy sessions as an opportunity to run errands or simply have free time. They may drop off and pick up their loved one without ever taking the time to speak to the SLP to learn how he/she is progressing or help answer questions about communication goals and challenges.

While it's certainly understandable given how stressed and strapped for time caregivers are, be sure to set the stage.

Let your patients' caregivers know how critical their presence is to their loved one's long-term success.





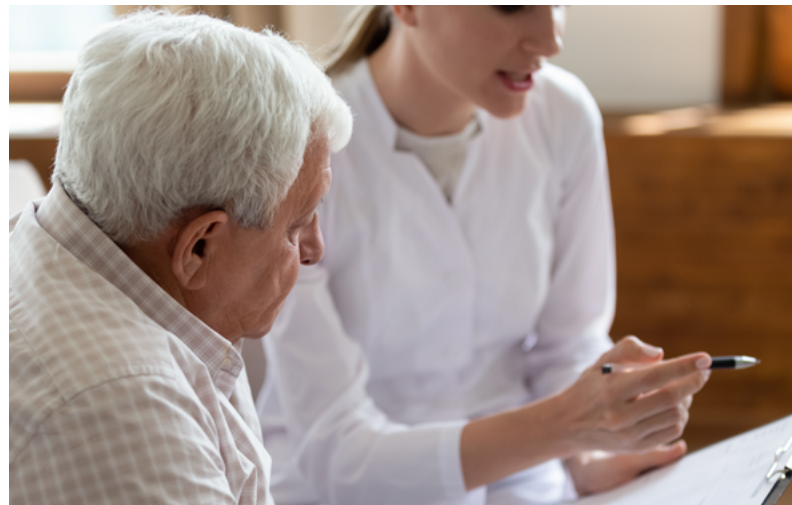
Step No. 2: Educate the Caregiver on Their Loved One's Condition

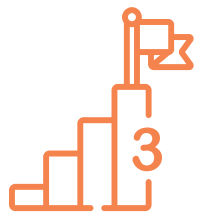
The second step is to educate the caregiver about their loved one's condition.

In the days and weeks following a stroke or traumatic brain injury, the focus is seldomly on the individual's communication impairment. Instead, most concern goes toward the physical impairments that often accompany those events. But as the patient stabilizes, and often long after they've returned home, new worries rise when caregivers realize their loved one isn't able to communicate as they once could.

For this reason, we recommend you take the time to:

- Ask the caregiver what they've been told about their loved one's diagnosis, and how well they understand it.
- Explain how their loved one's type of aphasia and severity might impact their ability to communicate with others.
- Learn how they are currently communicating with their loved one, and show them how it could be more effective
- Help caregivers learn and implement strategies for supporting communication, and make sure they understand how that can alleviate challenges.





Step No. 3: Offer Them Emotional Support, Referrals, and Resources

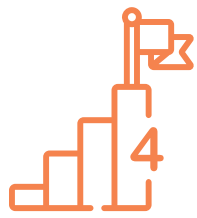
The third step is to offer them emotional support, referrals, and resources.

As we learned earlier, being the caregiver of someone with aphasia is not easy. The majority of caregivers feel stressed-out, are emotionally drained, running on little sleep, and may have a poor life outlook. Although counseling related to emotional reactions and feelings related to the communication disorder are within the scope of practice as an SLP, some caregivers will need additional support and resources.

For example, you may refer caregivers to counselors, psychologists, psychiatrists, or social workers as and when appropriate. Alternatively, you might consider referring them to a local aphasia support group where they might connect with other caregivers and people with aphasia who are living through the same experiences.

Finally, remember people with aphasia and their caregivers tend to be older adults who may be financially stressed. Keeping up with therapies and medication can be an enormous burden. Be sure to provide them with information around financial aid, and community resources for health, transportation, senior care.





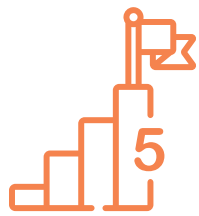
Step No. 4: Teach Them Some Basic Communication Principles

The fourth step is to teach caregivers some basic communication principles.

As we know, aphasia affects everyone a little differently. Some will struggle to speak, others may struggle to understand, and so on. Many will have a combination of several impairments. Nonetheless, by using some fundamental communication principles, caregivers can improve the odds of communicating their message properly as well as helping their loved one to convey theirs. Some of these key principles include:

- Using yes or no questions
- Sticking to one thought per question
- Eliminating distractions
- Use thumbs up or down
- Nodding your head
- Pointing up or down
- Pointing to things around you
- Mimicking common actions
- Extending your hand in a “stop” motion
- Speaking in a normal voice and volume
- Being patient





Step No. 5: Provide Supported Conversation Training

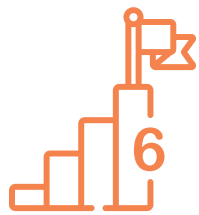
The fifth step is to offer them Supported Conversation Training.

Supported Conversation for Adults with Aphasia or simply SCA™ is a multi-modal communication approach developed by the Aphasia Institute. It teaches caregivers how to support the person with aphasia.

SCA can be helpful for people with all types of aphasia. Its goal is to improve conversation for people who have trouble speaking or understanding language. It is based on the idea that conversation is an important part of actively engaging in life. It encourages communication in many forms, such as speaking, writing and drawing, alongside the use of communication aids like alphabet boards, communication charts, writing keywords on paper, or using pictures or drawings to express ideas.

Examples of strategies that are taught include:

- Speaking in a normal tone of voice
- Acknowledging communication difficulties and trying to fix them
- Writing key words
- Using drawing or gestures, focusing on one word at a time
- Keeping a written “log” of the conversation that can be reviewed
- Asking yes/no questions to confirm understanding
- Summarizing what the person with aphasia has communicated



Step No. 6: Determine Whether an AAC Device Can Help

The sixth step is to determine whether an AAC device can help the person with aphasia and their caregiver.

Communication tips and techniques can make communication easier for many caregivers and people with aphasia. However, some still struggle despite using the recommended techniques. If there is a gap between what someone wants to say and what they are able to say, AAC devices can prove invaluable.

AAC devices allow people to participate in activities that are important to them. They use a combination of customizable pictures, written words, and spoken language to help people with aphasia more easily express what it is they'd like to communicate.

In addition to helping people with aphasia to better communicate, the devices offer therapeutic benefits that can demonstrably improve users' language abilities.

By using an AAC device, people with aphasia are afforded the opportunity to continue to participate in activities like engaging with loved ones, being part of a community, or pursuing a hobby or activity they might enjoy.

By helping them to communicate more effectively and independently, SLPs can help alleviate many of the biggest challenges caregivers face.

Finally, AAC devices are often fully covered by insurance providers, meaning there's little to no burden on families who are on a tight budget.



How Lingraphica Can Help

Lingraphica is the only company in the world that is dedicated entirely to helping adults with aphasia improve their communication and quality of life through educational resources, communication training, applications, and communication devices.

“After seeing him use the device in various ways now, I see where it is helping him regain speech. He’ll pull words out of his hat that he hasn’t said in years. **I feel like we aren’t playing charades anymore.**”

– Julie Barron, Spouse and Caregiver

“It keeps him involved with the activities of daily living, and he’s getting better with the device each day. **He diligently strives to improve his communication skills and takes a lot of initiative...**”

– Diana Brunetti, Spouse and Caregiver

“I am happy that Sally has the opportunity to use technology again in her life. **I see that she can continue to keep improving...and get to a level where she will be satisfied with her life again.**”

– Gloria McCormick, Sibling and Caregiver



Take the Next Step

Lingraphica offers free one-on-one consultations for SLPs who have someone on caseload who might be a good fit for an AAC device but aren't entirely sure where to start.

To learn how Lingraphica can help, schedule a free one-on-one consultation at:

www.aphasia.com/aac-consult

