



# Overcoming Aphasia Caregivers' Biggest Challenges

A Guide for Caregivers of  
People with Aphasia

# Table of Contents

<b>A Personal Story You May Be Able to Relate To .....</b>	<b>3</b>
<b>About the Challenges Aphasia Caregivers Face.....</b>	<b>4</b>
<b>Why is Overcoming These Challenges So Critical?.....</b>	<b>5</b>
<b>Challenge #1: Communication .....</b>	<b>6</b>
<b>Challenge #2: Dependence .....</b>	<b>7</b>
<b>Challenge #3: Motivation .....</b>	<b>8</b>
<b>Challenge #4: Self-Care .....</b>	<b>9</b>
<b>Challenge #5: Household Activities .....</b>	<b>10</b>
<b>Challenge #6: Finances .....</b>	<b>11</b>
<b>6 Steps to Conquering Your Biggest Challenges .....</b>	<b>12</b>
<b>How Lingraphica Can Help .....</b>	<b>19</b>
<b>Take the Next Step .....</b>	<b>20</b>



## A Personal Story You May Be Able to Relate To

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.

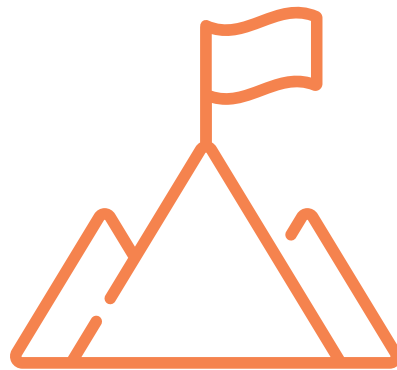
The result was our 2020 Aphasia Caregiver Report. It offered a never-before-seen look at the individuals who care for someone with aphasia.

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 to overcome them.**



## Why is Overcoming These Challenges So Critical?

An aphasia diagnosis can be one of the most devastating things to happen to someone who survives a stroke or traumatic brain injury. In an instant a person can lose their ability to comprehend and use language. Beyond that, they may also lose the very things that underpinned their life – their relationships, employment, identity, and independence.

Similarly, an aphasia diagnosis can be just as devastating for that individual's family and the persons who become caregivers.

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 work to overcome these challenges, they are likely to experience a serious decline in their own 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. More than 91% of caregivers reported that they assist with communication.

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 additional conditions.

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.





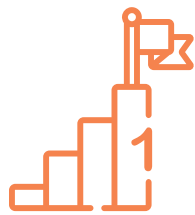
## 6 Steps to **Conquering** Your Biggest Challenges

Now that we've seen the top challenges facing aphasia caregivers, let's discuss six steps that can help caregivers to overcome these common challenges.

Over the next few pages, we'll learn how caregivers can balance the need to take care of their loved ones, while maintaining their own health and living a rich fulfilling life in the long term.







## Step No. 1: Take Better Care of Yourself

It may seem obvious, but the first step is to simply take better care of yourself.

This is perhaps the most difficult thing to do. When faced with so challenges, it can be hard to focus on the things you can do to take better care of yourself. With so little free time, prioritizing self-care often takes a backseat. However, even a few minutes per day of self-care activities can have a positive impact on your health and stress levels.

Have a free half an hour? Here are nine things you can do:

- Breathe slowly and deeply
- Be mindful and in the present
- Exercise or meditate
- Spend the time outdoors
- Go for a brisk walk
- Do some gentle stretching
- Play games with your loved one
- Watch movies and listen to music
- Block out time to do what you enjoy

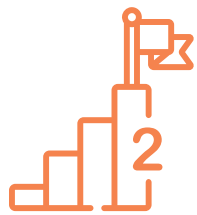
Additionally, your long-term health will benefit from:

- Eating a healthy and balanced diet
- Avoiding drugs, alcohol, and caffeine
- Drinking plenty of water
- Getting adequate sleep



Remember that although you want the best for your loved one, you won't be able to care for them unless you are in **good health yourself.**





## Step No. 2: Reach Out for Help

The second step is to simply be sure to reach out for help when you need it.

Aphasia doesn't just affect that one person. It touches the lives of everyone around them. If you are caring for a spouse, child, sibling, or other relative with aphasia, you are not alone. There are thousands of other people who are going through the same experiences.

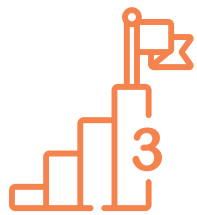
If you're struggling to communicate or feeling overwhelmed by the number of responsibilities that have fallen onto you, consider joining a support group. You'll find a number of support groups throughout the United States and online for caregivers and more specifically, caregivers of people with aphasia.

Additionally, you might consider respite care services. Respite care services generally take place at home or within an assisted living community for a short period of time – generally less than a month. Your loved one will be completely taken care of, allowing you to focus on your own health and well-being during this time.



Finally, if you are severely depressed, consider seeking the help of a mental health professional.

**Call 1-800-273-8255 to speak with someone at the National Suicide Prevention Hotline.  
You are not alone.**



## Step No. 3: Keep Your Loved One Healthy

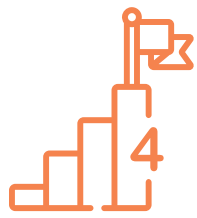
The third step is to keep your loved one as healthy as possible.

The healthier your loved one is, the less likely they are to be dependent on you. This means helping your loved one to follow recommendations from their healthcare team, particularly around medication and nutrition following a hospital stay.

Additionally, it's important to note that the incidence of stroke recurrence tends to be highest during the first year after the initial stroke. This makes it all the more critical to follow guidelines on preventing a future stroke. The more you can mitigate certain risk factors, the greater chance you have of keeping your loved one's condition from worsening and increasing their dependence on you.

Beyond following guidance on medication and nutrition, consider whether home modifications can make a difference for you and your loved one. Even a few minor changes can reduce frustration, increase independence, mitigate the risk of falls, and ease their transition back into everyday life. Examples of home modifications include:

- Doorknob extenders
- Tub transfer benches
- Grab bars
- Shower hoses
- Non-slip bathmats
- Night lights
- Rug grippers
- Raised toilet seats
- Ramps
- Soap dispensers
- Open shelves
- Closet tacks or rails
- Cord covers
- Adaptive cooking equipment
- Removing locks
- Clearing walkways



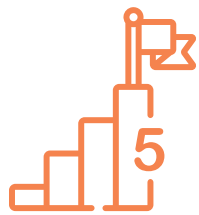
## Step No. 4: Learn and Practice Basic Communication Principles

The fourth step is to learn and practice 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, you can improve the odds of communicating your message properly as well as helping your 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: Get Supported Conversation Training

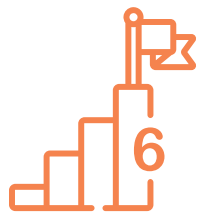
The fifth step is to get Supported Conversation Training.

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: Learn if a High-Tech Communication Aid Can Help

The sixth step is to learn if a high-tech communication aid can help.

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, communication devices can prove invaluable.

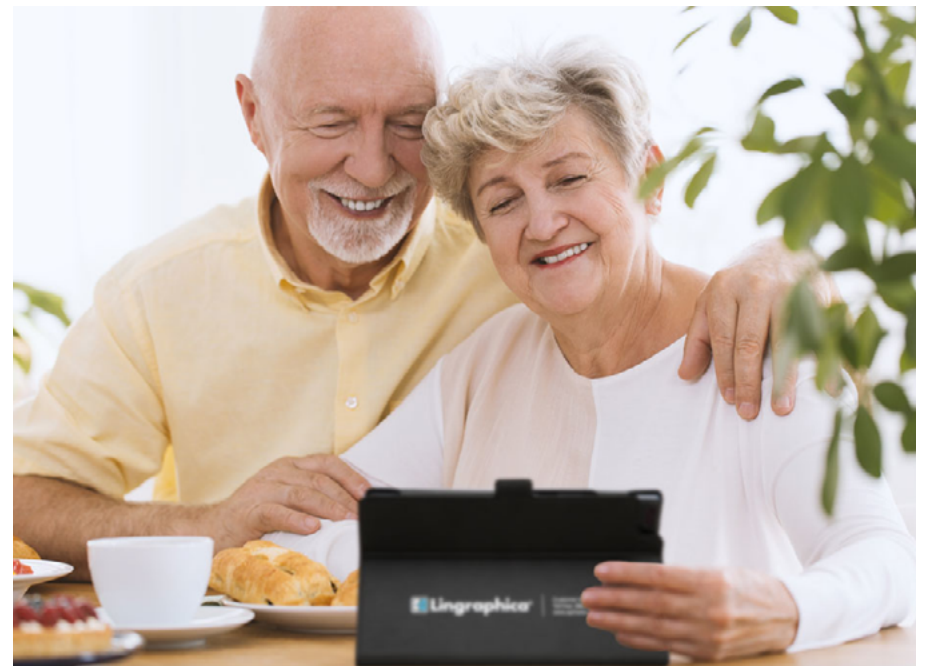
Communication devices, also known as **augmentative and alternative communication (AAC) or speech-generating devices**, come in the form of a tablet or laptop computer. They use a combination of pictures, written words, and spoken language to help people with aphasia more easily express what it is they'd 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 a communication 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 their loved ones to communicate more effectively and independently, caregivers can help alleviate some of their biggest challenges.

Finally, communication devices are often fully covered by insurance providers, meaning there's little to no burden on families 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 caregivers who want to improve communication with their loved ones and help to aid their recovery 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/improve-communication](http://www.aphasia.com/improve-communication)**

