



# LIVING WITH APHASIA

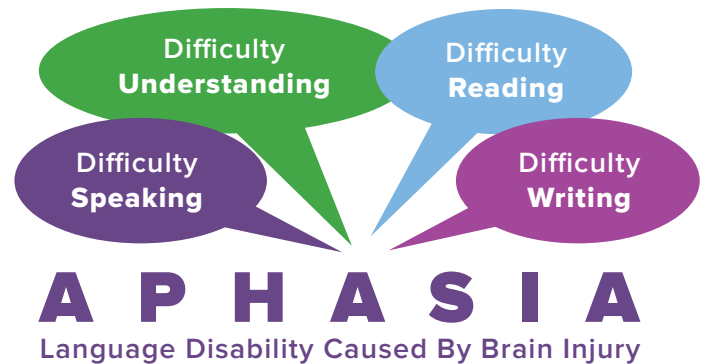
LIFE AFTER A STROKE



# WHAT IS APHASIA?

## Aphasia is difficulty with:

- coming up with words,
- saying what you mean,
- reading as fast or as easily as you used to
- knowing how to spell words that you used to be able to write
- understanding conversations or
- following what people say to you.



Aphasia occurs when a part of your brain that is required for these abilities is damaged due to a stroke, other brain injury, or neurological condition.

**If you are having these communication challenges, you are not alone!**

About 40% of people who have had a stroke experience aphasia. These communication problems may make it difficult to understand what the doctors are telling you. You may have a hard time asking questions about what is happening to you. You might be asked to sign forms or give your permission to things even though it is difficult for you to understand or write your name.

About 2 million people in the United States are living with aphasia. But, the number of people affected by aphasia is much bigger than that, because each one of those 2 million people have spouses, family members, and friends who are also living with aphasia.

We have written this guide to help you and your loved ones understand what is happening and what to expect during rehabilitation and beyond.

ABOUT **40%**

of people who have strokes  
**experience Aphasia.**

This is approaching

**2M** PEOPLE

**in the United States alone.**

## TIPS FOR USING THIS GUIDE

To help a person with Aphasia understand this guide:



Read each line slowly, using a plain card or your finger to help follow along. Hearing and seeing words, at the same time, helps people with aphasia understand.



Pause frequently. Look at the graphics together and discuss them.

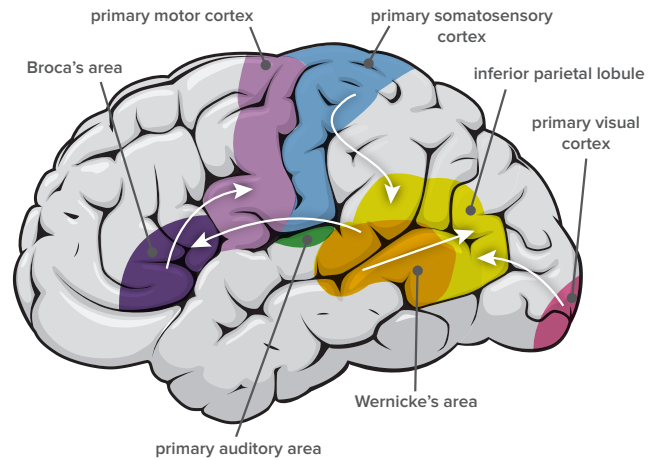


You can check to see if the person with Aphasia is understanding the information by using the true-false questions that are provided in the sidebars.

## What causes Aphasia?

Aphasia occurs when a part of the brain that is needed for communication is not operating normally.

For most people, the left side of the brain is the most important for language functions, like understanding words, coming up with words, reading words, and spelling words. There are several different areas on the left side of the brain that contribute to these abilities.



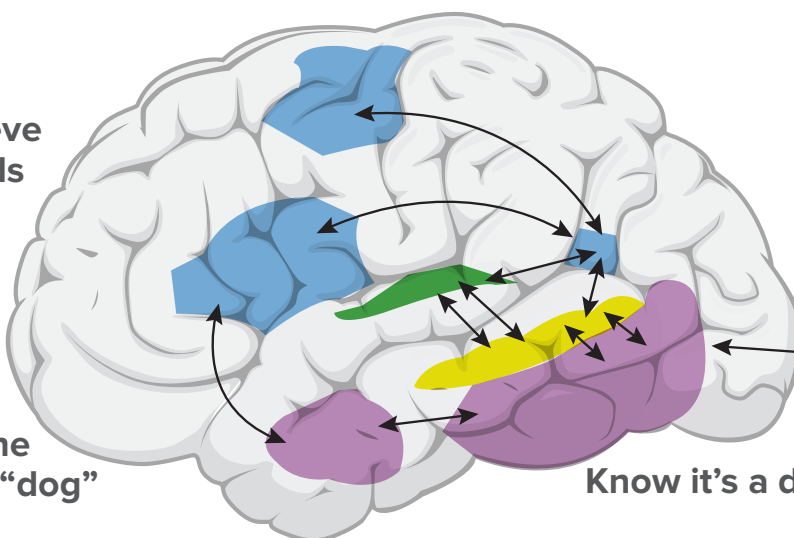
**Retrieve sounds**

**Say the word "dog"**

**Think of the word "dog"**

**Know it's a dog**

**See the dog**

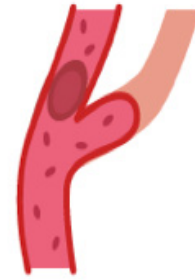


## What causes Aphasia? (cont'd)

A stroke is one of the most common causes of aphasia. A stroke is when the flow of oxygen-rich blood to the brain tissue is disrupted. Blood flow in the brain can be disturbed in one of two ways. First, a clot or build-up in the blood vessel can cause a blockage. This is referred to as an **ischemic** or thromboembolic stroke. A second way for brain tissue to be deprived of oxygen in the blood is when a blood vessel bursts. When this happens, it is like the oxygen in the blood taking a “detour”, so it does not get to a certain area of the brain. This is called a **hemorrhagic** stroke.

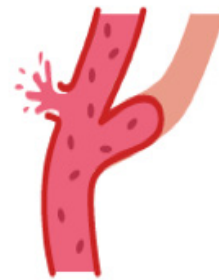
Other kinds of brain injuries or diseases can also cause aphasia if they affect the functioning of the important language areas in the brain. Many neurological conditions can cause difficulty with word-finding, because so many parts of the brain are needed to come up with different kinds of words.

Another type of aphasia is called Primary Progressive Aphasia (PPA). This kind of aphasia is NOT caused by a stroke or brain injury. Primary Progressive Aphasia is caused by a slow degeneration of brain tissue and function. A person is diagnosed with PPA when there are problems saying what you want to say that have slowly gotten worse over time. A neurologist will conduct tests to rule out other causes.



**Ischemic**

An ischemic stroke is due to an obstruction within a blood vessel supplying blood to the brain.



**Hemorrhagic**

A hemorrhagic stroke happens when a weakened blood vessel ruptures and bleeds into the brain.

## UNDERSTANDING CHECK

### True or False:

Aphasia is always caused by a stroke.

### True or False:

It is possible for someone with Aphasia to look at a word, know what it means, but not be able to say it out loud.

### True or False:

There are two different types of strokes.

# WHAT ARE THE SUBTYPES OF NONFLUENT AND FLUENT APHASIA?

## FOUR (4) SUBTYPES OF NONFLUENT APHASIA

### 1 Broca's Type Aphasia

**A person with Broca's type aphasia has:**

- Difficulties with grammar in speaking, understanding and writing
- Difficulties with "little words", like prepositions, articles, pronouns
- Difficulty repeating words, phrases, or sentences

### 2 Transcortical Motor Aphasia

**A person with Transcortical Motor aphasia has:**

- "Islands of fluency": longer phrases even though most speech is one or two words at a time
- Ability to repeat words, phrases, and sentences

### 3 Mixed Aphasia

**A person with Mixed aphasia:**

- Can say some content words
- Does not understand everything as well as it seems

### 4 Global Aphasia

**A person with Global aphasia has:**

- Difficulty in all areas of language: speaking, understanding, reading, and writing
- Often has apraxia as well

## FOUR (4) SUBTYPES OF FLUENT APHASIA

### 1 Wernicke's Type Aphasia

**A person with Wernicke's type aphasia may:**

- Say words that are not really words
- Be unaware of their difficulties
- Have difficulty repeating words, phrases, or sentences

### 2 Transcortical Sensory Aphasia

**A person with Transcortical Sensory aphasia may:**

- Use many "empty" words, such as "stuff", "thing", "that one"
- Ability to repeat words, phrases, and sentences

### 3 Conduction Aphasia

**A person with Conduction aphasia may:**

- Make errors with sounds in words
- Have difficulty repeating words, phrases, or sentences

### 4 Anomic Aphasia

**A person with Anomic aphasia has:**

- The mildest form of aphasia
- Difficulty finding words



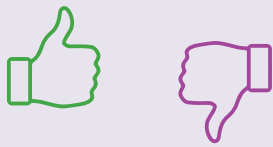
# WHAT KIND OF APHASIA DO YOU HAVE?

How many words do you say at a time?

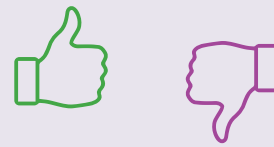
"Go...Store...You?"

"Well, I want over there to the prable area and then it was really different and I couldn't really tell what it was I mean I just don't know."

Can you understand most things that are said to you?



Can you repeat sentences?



Fluent or Nonfluent?	Understanding speech?	Repeating sentences?	Aphasia Type
<p>"Go...Store...You?"</p>			<b>BROCA'S</b>
			<b>TRANSCORTICAL MOTOR</b>
			<b>MIXED</b>
			<b>GLOBAL</b>
<p>"Well, I want over there to the prable area and then it was really different and I couldn't really tell what it was I mean I just don't know."</p>			<b>WERNICKE'S</b>
			<b>TRANSCORTICAL SENSORY</b>
			<b>CONDUCTION</b>
			<b>ANOMIC</b>

## Are there different severities of Aphasia?

- 1 Aphasia can be very severe.
- 2 Aphasia can also be mild.
- 3 Someone with mild aphasia may be able to express themselves, but get stuck coming up with words they want to say.
- 4 If you're not sure whether you have aphasia or not, you should be tested by a qualified speech-language pathologist. One place to find a certified speech-language pathologist is at [www.asha.org/profind](http://www.asha.org/profind)

### SEVERITIES OF APHASIA

#### MILD

The person with aphasia can express themselves, but has difficulty with words, reading and writing.

#### SEVERE

The person with aphasia is almost unable to understand what other people say, and has very limited ability to express themselves.

## WHAT HAPPENS NEXT?

### What are different types of Aphasia therapy?

After a person has a stroke with aphasia, they should receive therapy from a qualified speech-language pathologist. Most countries around the world recommend that all persons with aphasia receive aphasia therapy. You can get more information about International Best Practices for Aphasia on this website: [www.aphasiaunited.org](http://www.aphasiaunited.org)

### TYPES OF APHASIA THERAPY

#### Life Participation Approach to Aphasia (LPAA)

Focused on doing activities that are most important to you  
Targets people, places and things around you to make you successful

#### Impairment-Focused

Focused on specific skills  
Examples: Naming pictures, spelling words, practice saying words

Getting back to doing things in your life

## How do I know if the therapy I'm getting is the best therapy for me?

There are some important questions you can ask your speech-language pathologist about your therapy that will help you know if you are getting the best therapy for you.

### 1) Does this therapy have scientific evidence?

Some therapists use workbooks and other very basic types of "stimulation" therapies that have little evidence of being effective. You deserve better. Don't settle for Xeroxed workbook pages. Therapy that has been researched to have the best outcomes is what you want.

### 2) What will this therapy help me do?

Don't sit in therapy putting up with basic drills or other activities when you don't understand what it's leading to. Your therapist should be able to explain clearly to you what goals you are working towards. If you are not satisfied, ask for a different therapist.

### 3) Do you feel comfortable with your therapist?

If after a few sessions, you're not comfortable with your therapist, you need to talk about it or request a different therapist. The relationship between the therapist and the patient is a critical part of the work that is accomplished during the therapy time.

## What should I say to my doctor about getting therapy?

If your doctor has not recommended therapy for you, you should ask why. Best Practices in Stroke Care in the United States and internationally, recommend therapy. Stand your ground and say, "Speech therapy is recommended for people with aphasia. Please write a script/referral for me for speech therapy."

If you have had therapy in the past, and it ended, you may still be appropriate for additional therapy. If you have changed in your abilities or your medical status, your insurance may cover additional therapy. Ask your doctor to support you by writing a script/referral for speech therapy since you have changed since the last round of therapy.

Also, remember that therapy is available in other ways. For example, university clinics may offer therapy for discounted rates or provide other groups that can help you continue to improve. Also, if you have the funds you can private pay for services outside of your insurance benefits.

## How can I make my therapy matter in my daily life?

Practicing every day on language skills will only be beneficial if you can use those skills in real activities that you want to do.

At Voices of Hope for Aphasia, we offer groups in our "Living with Aphasia" program where people can practice the language skills they've been working on in conversation and other activities.

For example, do you want to discuss travels you've made or travels you'd like to make? Do you need a little extra time and support to do it? That's what we do in our groups, which are great accompaniments to your therapy. Even if you are not in therapy, groups like ours help you continue to make progress.



# WHAT SHOULD FAMILY MEMBERS DO?

## What is the best way for family members to help?

Family members of a person with aphasia walk a tight-rope between helping to ease frustration and helping to gain new skills that lead to independence.

It's not easy, or not even possible, to predict exactly when you should help and when you should let the person try on their own. But, it is important to let the person with aphasia try on their own. Try saying, "Would you like some help?" You don't have to help the person who is having trouble speaking right away. People who have aphasia may take 10-20 times longer to come up with a word (10-20 seconds, instead of 1 second). It's great to "count to 10", and then ask if the person with aphasia would like some help.

## When shouldn't we help?

If you help all the time, immediately, the person with aphasia will become more passive and take less and less responsibility for their own communication. That is not the goal that the two of you are striving for. It's not easy, but allow a few seconds to pass, and then a few more seconds, before you jump in and help. The person with aphasia, and you, will have the opportunity to discover new skills and ways to communicate when those seconds stretch out.

## How important is it for us to learn communication techniques?

It is very important for family members to become skilled communication partners. There is a training called Supported Conversation for Aphasia™ that science has shown is an effective way for caregivers to learn to support effective communication in aphasia. We teach this approach in our two-day family-focused workshop, "I have aphasia – now what?™".

When you support communication at home in the right ways, it actually helps the person with aphasia continue to improve and recover. If you ignore this critical element, the person with aphasia is denied an important opportunity to advance.



## UNDERSTANDING CHECK

### True or False:

Aphasia therapy is recommended for everyone with aphasia.

### True or False:

Aphasia therapy should give me a means to communicate.

### True or False:

Things you work on in therapy should help you do things that are important to you.

# WHAT HAPPENS AFTER THERAPY ENDS?

## How can we stay active?

Therapy is not the only way that people improve and our brain repairs. Formal therapy can focus on specific skills, but ongoing social interaction and engagement goes a long way towards continuing improvement.

Most people with aphasia end up losing their friends and often lose communication with their family members. In aphasia, this can result in social isolation. Social isolation has the same health risks as smoking 15 cigarettes a day, or heavy drinking. Social isolation increases the risk of premature death by 14%. So, losing connections to friends and family members is a serious matter.

Plan one night a week with friends who will support communication. Invite neighbors or friends over for a coffee chat about ways to support communication. When you go out to eat or to events, pick short times and situations that are less noisy. Prepare in advance for success by downloading and reviewing menus or other items.

If the person with aphasia was a part of a bridge club, shuffleboard club, or any other social venue, have a meeting with that group to review communication supports and strategies. Helping the person with aphasia get back to doing things of interest is a critical part of recovery.

## How can we keep improving?

Our brains are designed to adapt to the situations we are in. So, continue to put yourself in situations where you are challenged. On the one hand, don't aim so high that you will give up. On the other hand, aim a little higher than what you can do so you will improve.

Staying home, sitting on the couch, and watching TV will not help you improve. Make a schedule together that includes opportunities to stretch and improve.

## How do we keep communicating?

As time passes, communication strategies and techniques will change and evolve. That is good! But, it requires constant awareness. Aphasia groups and caregiver programs, like those offered at Voices of Hope for Aphasia, provide the opportunity for the person with aphasia to be challenged by others in similar situations, or for family members/friends to be challenged in how they are supporting and adapting to their skills.

**Contact us at [Voices of Hope for Aphasia](#), or a similar organization near you, to find out how you can continue to improve over years.**

## UNDERSTANDING CHECK

### True or False:

It is very important to find ways for the person with aphasia to connect with others.

### True or False:

There are ways for family members and others to learn how to communicate effectively.

### True or False:

Effective communication at home helps the person with aphasia improve.