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**NATIONAL APHASIA ASSOCIATION**

**OUR BEST POSTS OF THE YEAR**



**National  
Aphasia  
Association**

**APHASIA.ORG**

Dear Friends,

“Pandemic” was Merriam-Webster’s word-of-the-year, but the aphasia community could add a few more year-defining words including **isolation**, **ingenuity**, and **connection**. You’ll see this as we reflect on everything we learned and discussed this past year in this PDF.

While all Americans felt some level of **isolation** during stay-at-home orders, people with aphasia missed out on face-to-face speech therapy and communication cues picked up during in-person conversations with friends and loved ones. This isolate was keenly felt as people separated to keep safe.

At the same time, the pandemic forced us to get creative. As you read this year’s posts, you’ll find everything from emergency preparedness information to hosting Zoom support groups to practicing speech exercises at home. We used **ingenuity** and crowdsourced community practices to ensure that people with aphasia had ideas to weather this storm.

Finally, **connection** also played a large role in the content you’ll find in this PDF. Whether we were coming together online via our monthly online chat, reading each other’s stories in the newly-released *Aphasia Threads* book, or sharing the actions that moved our community—from Coleman Watson’s aphasia movie to Chad Amond’s amazing mini-golf fundraiser—we learned from each other and celebrated our champions.

You can find this content and so much more on [our website](#) and in our bi-monthly newsletter. We promise that there will be many more Aphasia Cafe chats and helpful tips in the upcoming months. So please, sit back and relax with these articles from 2020.

Warmly,

*Melissa Ford*

Editor

National Aphasia Association

## Explaining Aphasia to Other People



The definition of aphasia is straightforward: Aphasia is a communication disorder that affects a person's ability to understand, produce, or read written or spoken words. While it's straightforward, it isn't easy to sum up aphasia in a quick sound bite before the questions start coming. So how do you explain aphasia to other people?

### **Predict the Questions**

Start out by explaining aphasia as simply as possible to a loved one.

Aphasia is a communication disorder that affects my ability to read, speak, or write words.

Then have them ask you logical questions that may come next such as how is it caused or how is it treated? Start incorporating that information into your description. What you say will depend on your particular form of aphasia. In general, you can tell people:

Aphasia occurs after a head injury, stroke, or brain tumor. There is also a neurodegenerative disorder called primary progressive aphasia.

Or you can be specific and say, "My aphasia is caused by..." and then fill in the rest of the sentence.

Finally, you can tell them that speech therapy can improve word access in some types of aphasia, such as Broca's or Wernicke's, or it can help provide new communication techniques for people with PPA.

### **Accentuate the Positive**

People unfamiliar with aphasia may try to make sense of the disorder by comparing it to things they do know. Because of that, you'll want to add in that aphasia does not affect a person's intellect.

Aphasia is a communication disorder that affects my ability to read, speak, or write words, though it doesn't affect my intellect. The words are in my brain; they're just hard to access. My aphasia is caused by \_\_\_\_\_. I'm treating my aphasia with speech therapy.

### **Make a Card**

We've also created an aphasia card that can be handed to people to explain aphasia when you're having trouble communicating while you're out-and-about. **Right-click the image to save it and print a copy to carry with you.**

Front:

# I HAVE APHASIA

Aphasia is a communication disorder that affects a person's ability to understand, produce, or read written or spoken words.

Aphasia presents differently in each person.

In fact, the only thing everyone with aphasia has in common is that aphasia does not affect the person's intellect.

Aphasia can occur after a head injury or stroke. It can also be the result of a brain tumor. In rare cases, aphasia is the result of primary progressive aphasia (PPA), which is a neurodegenerative disorder.



FLIP CARD OVER FOR MORE INFORMATION

Back:

# I HAVE APHASIA

My name is \_\_\_\_\_

Please contact \_\_\_\_\_ in case of an emergency. You can reach them at this number: \_\_\_\_\_

Please keep your sentences short and simple. Give me time to think and respond. I can give you a thumbs up (yes) or thumbs down (no) sign in response to yes/no questions. Verify that we both understand what the other person is saying.

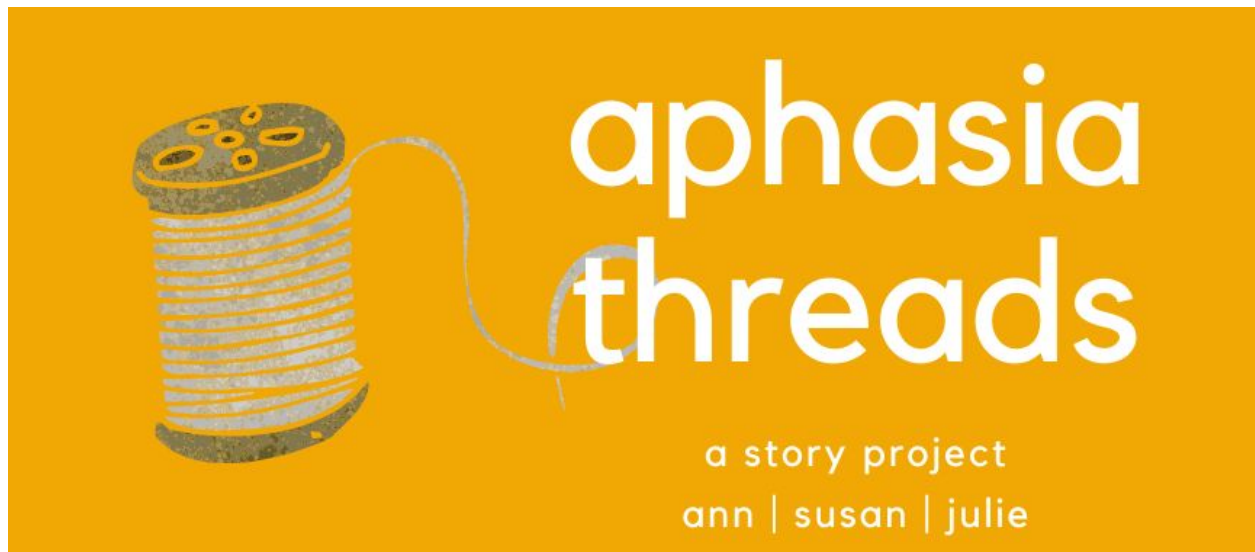


Of course, we are happy when interested people come to our site to better understand aphasia. While your job isn't to be an aphasia teacher for the rest of the world, pointing people in the right direction for more information makes

the world a better place for people with aphasia. So direct them to aphasia.org for more information so they can understand.

**How do you explain aphasia to other people?**

## Aphasia Threads: Ann, Susan, and Julie



Welcome to the **Aphasia Threads Project**, which weaves together three points-of-view: people with aphasia, caregivers, and the professionals who help each family navigate aphasia. Each week, we bring together three unrelated stories, one from each member of this triad, to learn from their experience. This week, we'll hear from Ann, a person with aphasia. Then, we'll hear from Susan, who is a caregiver for her son who had a stroke. Finally, we'll hear from Julie, who works with an aphasia book club in Clarksville, Maryland.

## Aphasia Threads | Person with Aphasia



Person with Aphasia

I have aphasia.

**Aphasia Changes Your Life**



Good.

### **But There Are Things That Help**

My iPad.

### **And Things You Learn Along the Way**

I know about aphasia.

### **What Caregivers and Professionals Can Learn From Me**

Danielle.



## **Aphasia Threads | Caregiver**

Caregiver

In 2013, my son suffered a massive stroke during a workout. He had been life-flighted to Duke University Hospital, undergone a life-saving craniotomy, and was in a medically induced coma for several days. He was only 18 years old and three weeks away from leaving for his freshman year of college.

When he was finally awake, there were no words. We soon found physical, occupational, and speech therapists to visit him daily. The speech therapist began to use the words aphasia, expressive, receptive, and apraxia throughout her conversations with me and my husband.

But what did it all mean? We had never heard the words aphasia or apraxia before. How could our son not understand what we were saying and how could he not be able to speak? I vividly remember the speech therapist's first question to our son: "Is your name Bob?" His name was Austin, but he couldn't understand the question nor answer it.





## **Aphasia Changes Your Life**

The first year was incredibly difficult as Austin was flown to Shepherds Rehabilitation Center in Atlanta, GA for 4 months of intensive therapy. We expected that Austin would be off to college and instead we were by his side at all times.

We found that Austin understood written language more than verbal, so we began with writing everything on a whiteboard in hopes that we would be able to communicate on some level. The realization that this was going to be a long journey of recovery had finally registered with us.

We could only show our love for Austin and support through our actions and constant presence as words of encouragement were lost. Austin had to trust us more than he ever had before knowing he did not fully understand what had happened or how long it would take to be “normal” again.

Our relationships are different than they were before aphasia. In some ways, they are stronger because of what we have been through together, but there

are many times I long for a deeper conversation with Austin and truly knowing his thoughts.

Early on, we were especially concerned about Austin's safety because he couldn't easily communicate with others if he needed help and many people wouldn't understand what aphasia was even if he said the word. It was also very hard for Austin to engage with friends, although texting for him was easier than conversation.

Now, six years later, we have been given the precious gift of having Austin with us so much longer than most parents have with their children before they grow up and leave home, But it has been at an incredible price. Our relationships are strong but it has also been our faith that has held us together through each trial knowing that we cannot always see what the plan is for our lives. Each day is completely focused on recovery from Austin's stroke, and many hours of speech therapy both with professional speech therapists and volunteers. It remains our highest priority.



### **But There Are Things That Help**

Days are still filled with speech therapy to regain what was lost in a moment. Austin has spent thousands of hours in speech therapy working tirelessly to continue to regain language especially speaking and understanding conversations.

The two things that have been most helpful in Austin's recovery have been music therapy and a communication support team to work on speech. Because Austin has both apraxia and aphasia, music therapy has given him words and a voice when often speech can still be a struggle. It has helped with the fluidity of words and provided an outlet of expression that is critical. Austin works with a board-certified neurologic music therapist who integrates music into Austin's sessions that he loves and knows many of the lyrics.

Secondly, having a speech therapist who really understands aphasia and helps guide a communication support team has been vital to Austin's speech recovery. A communication support team is a group of individuals who are willing to work as volunteers with the individual who has aphasia on regaining their speech. These individuals can be friends, relatives, neighbors, or even other speech therapists who just want to help. They work with the individual on a weekly basis and reinforce the work done in professional speech therapy sessions during the week. For every one hour of professional speech therapy Austin has received, he has spent an additional three hours with volunteers focusing on speech as well. Austin's communication support team has been in place for five and a half years!

### **And Things You Learn Along the Way**

Your life has taken an entirely new direction. It is so important to support your loved one and also give them room to struggle just enough to grow. Ensure they always have something with them that explains they have aphasia and what it means so if they can't find the words, they can hand it to someone and they will understand and be patient.

You will also find that you need an abundance of patience yourself as you can grow very weary, frustrated, and angry over the struggles to communicate with your loved one. Do all that you can to keep your loved one engaged in relationships with others. You will find that many friends and

family want to know how to help and may feel inadequate in knowing what to do. Let them know that your loved one is the same person with the same intellect, same memories, same interests, and desires. Spending time with your loved one is the best thing they can do so your loved one has the opportunity to work on regaining what they have lost.

### **What People with Aphasia and Professionals Can Learn From Me**

I believe therapists understand that being a caregiver is often physically exhausting. Aphasia is usually just one of a number of issues that an individual may be recovering from. What is harder for others to see is the emotional exhaustion that comes from having a loved one with aphasia.

I remember on many occasions standing in a grocery store check-out line and watching the conversation that a little child was having with their parent – something I could no longer do with my grown son. The reminders are all around us of what has been lost and relationships are the most precious thing impacted by aphasia.

The uncertainty of whether it will get easier and if you are doing enough takes its toll. The daily frustration is real, so words of encouragement to the caregivers are sometimes enough to get them through the day. Also, it is important for the speech therapist to engage with the caregiver and educate them on what you are working on in therapy.

What I have learned is that every opportunity to engage in conversation counts and the more the caregiver understands what is being worked on in therapy and what is working, the more it can be integrated into life outside of the therapy session. If an individual with aphasia is receiving other physical or occupational therapy, it is so important to engage those therapists in understanding what the individual is working on in speech so they can reinforce the ideas during their sessions.

The education of family and friends about aphasia is also extremely important as it is still something most individuals have never heard of. After Austin's stroke, we gathered many of his close friends and had our speech therapist come and talk with them about aphasia and tips on what would

help in having conversations with him. This was invaluable to them and gave them an opportunity to ask questions.

Having a loved one with aphasia takes you down a road you never dreamed of traveling. Every individual's journey looks different so don't let anyone tell you that your loved one has reached the end of what is possible!

## Aphasia Threads | Professional



### Professional

*Julie works at Neuro Rehab Network in Clarksville, Maryland.*

I have worked with adults with neurologic impairments for 15 years in an outpatient rehab setting. I became interested in working with people with aphasia when I observed how powerful and impactful the therapeutic group setting can be. I have worked in a day treatment program, leading functional groups and outings, in hospital-based conversation groups, and now in a community Aphasia Book Club. Through groups, people with aphasia gain support, learn strategies, and feel empowered to reengage and reconnect despite communication problems.





### **What I've Noticed Along the Way**

I learn more from my patients with aphasia than they learn from me. I witness incredible persistence and courage every day as we together tackle functional communication challenges that previously seemed so effortless. Frustration is a necessary part of the process, but overcoming those frustrations and accepting new ways of communication brings joy and a sense of accomplishment.

### **There Are Things That Help**

I love working in groups! In a group setting, people with aphasia are able to learn from each other's wisdom and try new communication methods in a supportive environment. In our Aphasia Book Club, people with aphasia empower one another to overcome obstacles and take part in activities that bring them joy.

## **And I Encourage New Professionals to Learn About Aphasia**

Talk to many people with aphasia. Ask questions about what methods of communication work for them. Learn about their preferences, tools, and devices that make communication easier. They are the experts and can teach you so much about aphasia.

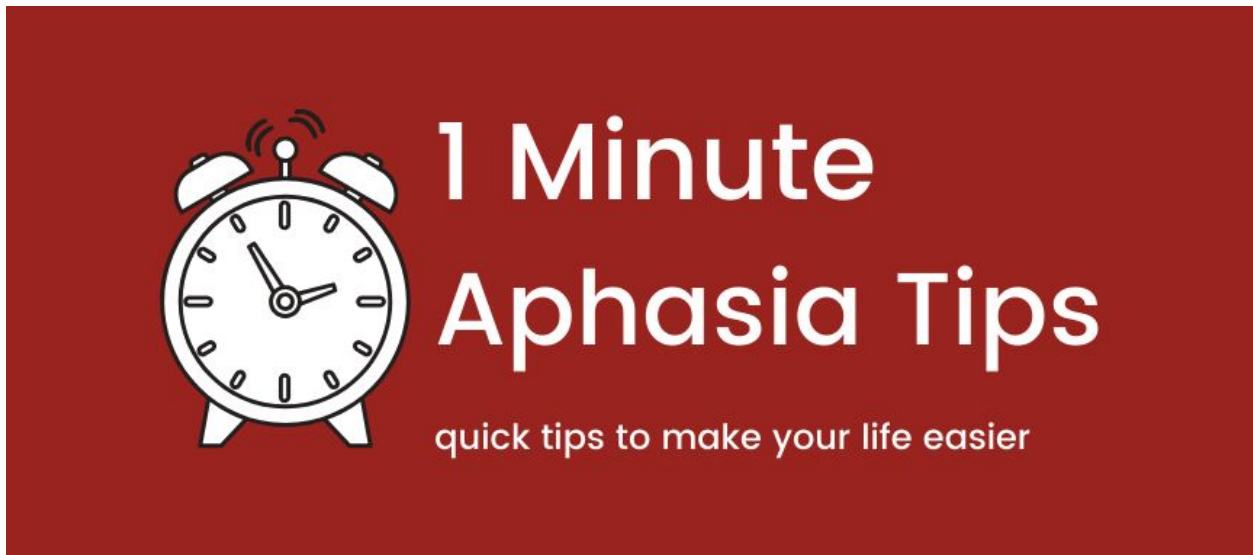
## **What People with Aphasia and Caregivers Can Learn From Me**

I want to learn about you and your life! To make group and individual sessions more successful, I need to know what you love and what you want to talk about. I also need to know what is working and what challenges you are facing in terms of communication and connection. It's important to involve the person with aphasia and the communication partners in therapy so that everyone is educated and equipped with the right tools for communication.

Come join our group! We are always looking for new members in our Aphasia Book Club to share in the joy of reading and conversation – It's all about connection!



## 1 Minute Aphasia Tips: Conversation Partner in Your Pocket



Welcome to our new series of one-minute videos aimed at delivering quick tips you can use to make your life a little easier if you have aphasia.

In this first tip, we talk about ways to use digital assistants such as Siri, Alexa, or Hey Google.



### **Conversation Partner in Your Pocket**

Siri isn't just awesome at providing facts at the ready. Digital assistants such as Siri, Alexa, and the weirdly named Hey Google can become digital conversation partners.

So they're not great at holding up their end of the conversation. But what they can do is help you practice word lists and be a patient partner as you work on enunciation.

Digital assistants never get tired, even if you sometimes need to plug them into the wall.

Try working through noun recall by asking Siri to show you images of things, such as "Siri, show me pictures of dogs on the Internet." You'll see immediately whether you were understood or not, and if not, simply try again.

Or you can play twenty questions with Alexa by saying, "Alexa, play twenty questions."

The point is that robots are our friends. So hang out with them.

## Grocery Shopping With Aphasia

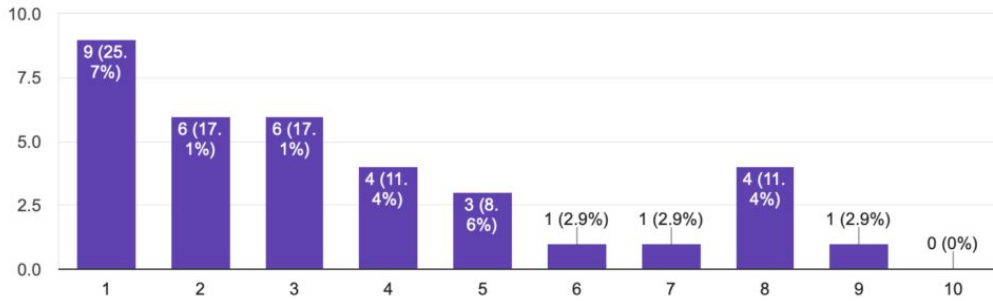


Grocery shopping can be difficult when you have aphasia because every trip contains a lot of words. Shopping lists, labels, and signs in the store come before questions about where they've moved products or conversations with cashiers. Grocery delivery services and self-checkout have made things a little easier, but this is still a task where pooling ideas together makes life better.

At a recent Aphasia Cafe chat, we asked you how difficult do you find navigating grocery stores on a scale from 1 – 10 (with 10 being super hard and 1 being easy)?

The majority of people didn't find it too stressful, though that may be because they're already using the ideas they suggested below.

35 responses



We also started by asking how many people had used a grocery store delivery service. Over half have never tried it because they like to choose their groceries, but the rest were a combination of loving the ease of ordering groceries online and interested in trying it.

I'm interested in doing it, but I've never used a service.

No, I like to choose my own groceries.

No, they don't even have that option in my area.

Yes, I have the store collect and pack the groceries for me, and then I drive to pick them up.

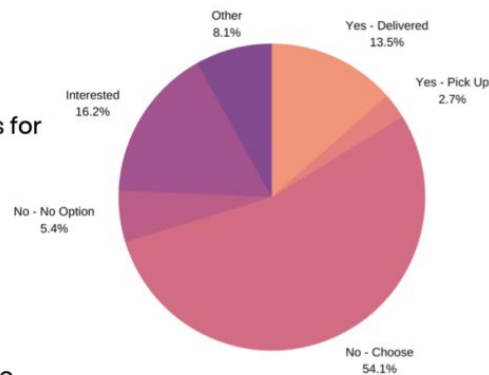
Yes, I love having groceries delivered to my home.

**Other:**

A combination of grocery store + Amazon

Tried it before but not doing it now

Used the service but didn't have a great experience



## Grocery Delivery

There are multiple ways to get groceries delivered. For non-perishable items, you can use Amazon or Target. There are services such as Instacart, which serves dozens of grocery stores in your area and drop off your groceries within one hour. Whole Foods has a delivery service for Prime members.

But local grocery stores often offer two types of services. The first involves ordering the items online and having the groceries delivered to your home. The second involves ordering the items online and driving by the store where they load the bags in your car. Beyond the obvious time-saving benefits of

not having to walk the aisles to find items, grocery delivery offers a host of other aphasia-friendly benefits.

Time is not a factor. You can do your grocery shopping any time of day; as quickly or as slowly as you need. Online shopping is free of impatient people behind you in line. But online shopping has drawbacks, too. You have less control over the items that go into your cart, and there is an added cost for the convenience. Still, if you have mobility issues or grocery shopping is a stressful experience, grocery delivery can be a life-saver.

## **Lists**

“Have a list and categorize your list before going into the grocery store.”  
–Trazana

Multiple people spoke about ways they organize their lists. While 16% of people never made a list, 58% of the people at the chat used paper lists and 26% used an app. When it came to organizing those lists, 60% said they used one of the ordering systems below, 30% dropped items haphazardly on the list depending on what they were thinking about at the time, and 10% said they sometimes organized their list.

“I make a list that is in the order of how I buy the majority of the food I buy.”  
–Bruce

One method is to choose the store you shop at most often and list your items in the order in which you’d encounter those items in the store. If you generally enter by the produce, all fruits and vegetables would go toward the top of the list. You then continue to list items in the way you move through the store. Other people grouped their list by sections of the store in the order in which they’re encountered, grouping together all produce, all dairy, all meat, or all freezer items. Individual items inside each section were in any order.

“Using a grocery store app with list keyed to locations in the store.” –Ed

Some grocery apps either allow you to set up your items in groups while others will rearrange your items for you if you put in your store’s location. The general Our Groceries list allows you to share a list with other people. Two or

more people can add items to the list, and the list syncs across devices. Remove items from the list with the tap of a finger. This app allows you to group items by section, though you need to first set up the store sections, such as Dairy, Meat, or Produce.

The Kroger app (specific for Kroger grocery stores) will tell you the location in the store for each item and helps you group your items based on your specific location. Most chain grocery stores have their own app, and these apps also allow you to build shopping lists inside the app or use digital coupons at check out.

“Make a list for your items. It proves to be very valuable. I’d suggest making a menu also.” –Yasmine

Some people also took it a step farther, adding in that making a menu beforehand helps you know which items you need so you can make fewer trips to the store. Yasmine creates menus two weeks at a time, but you can start small, plotting out three or four days at a time. Planning the menu also means that you stick to a healthy plan rather than getting distracted by delicious things when you enter the store.

### **Alternative Items**

“Prepare to have a list of alternative items if the kind of meat or brand is unavailable.” –Carol

Sometimes you get to the store, and the brand or item on your list is out-of-stock. Carol recommends having a list of alternative items at the ready. You can keep an on-going list of acceptable substitutions – such as Skippy peanut butter instead of Jif – or make it specific to the list you’re creating, such as listing other cuts of meat that would work in the recipe. Write down these brand names or substitutions so you have a list you can hand someone in the store if you need help.

### **Shopping Help**

“Ask for help.” –Ben

Most stores have an information desk. The point of the desk is to save you time and direct you to the correct place in the store. But if stores aren't busy, they're also sometimes able to provide hands-on help to customers in need. If you have trouble reading labels or navigating the store, speak to the manager at the information desk and see if they can assist during your visit. Many stores have in-store shoppers if you just ask.

## **Shopping Time**

"When I am in stressful situations (fatigue, noise, anxiety, tension, and frustration), I have much more difficulty speaking." –Trish

Shopping is stressful. Stores are noisy and people are impatient. Many people recommended shopping during "off" hours – choosing times when they know the store won't be as busy. Not everyone can shop in the middle of the workday, but early hours and late hours can help you find quieter moments in the aisles.

## **Shopping Consistency**

Returning to the same store again and again not only helps you cut down on time because you'll be familiar with all the sections, but you'll also learn which cashiers are aphasia-friendly. Even if the line is a little longer, return to cashiers who practice aphasia-friendly communication and are going to put you at ease.

## **Visual Prompts**

Several people wished that their store used visual prompts instead of text prompts to let them know what was in an aisle. You may be able to speak to management and explain how pictures can help all shoppers, not just people with aphasia. But even if your store isn't aphasia-friendly in providing those visual cues, you can construct your shopping list out of pictures. You don't need to sketch out your list every time – draw and laminate your small magnets and take along a small board. When you've got an item on your list, slip your homemade magnet into your pocket or slide it to the bottom of the board.



## **Laminated Lists**

If writing continues to be an issue, create a laminated list of all items you continuously need at the store. When you run out of something, place a checkmark next to that item on the list using a dry erase board marker. You can take this list with you when you go to the store, wiping off the checkmark when you place that item in your basket. Make sure you leave a few spaces at the bottom of the list for items unique to the shopping trip. Having a laminated list will save you a lot of writing time.

## **Aphasia Card**

Always have your aphasia card at the ready so you can hand it to anyone before you begin speaking. We've created a printable aphasia card that you can fill out with your name and contact information. You will need the front of the card and the back of the card. Make sure you laminate the two pieces together after you fill out the information.

## **Payment**

"Smile and pay with a card!" –Pat

Credit cards save you from counting cash and the self-checkout lanes save you from having to make conversation with cashiers. Another helpful item? Gift cards! You don't need to wait for someone to give you the gift of groceries. If you don't want to use a credit card, purchase pre-paid gift cards to your local grocery store. You can use them instead of cash or credit.

## **What are your best tips for navigating the grocery store?**

## The Verb Matters When it Comes to Aphasia



A new study detailed in *Aphasiology* looks specifically at verbs and aphasia. Action words give a sentence structure, letting us know *who* is doing *what*. But verbs fall into different categories, and some are more difficult to retrieve and use than others. This study works to determine what makes some types of verbs more difficult to remember and use.

### **Verb Structure**

Some verbs require the user to provide more information. Take, for instance, the verb “to bake.” You can say “she is baking” to let people know that a person is occupied and performing an activity. But more frequently, you’re expected to provide additional information to give context or meaning. In this case, you’re expected to state “what” the person is baking: “She is baking a pie.”

Or take the word “love.” It’s grammatically correct to say, “Bob loves.” But it doesn’t give us enough information. We need to know who John loves: “Bob loves Joan.”

Or the verb “put.” You can say, “He put,” but it’s going to invite more questions. What did he put and where did he put it? You need to add to the sentence: “He put the pie on the windowsill.”

In linguistics, this is called an argument. A verb argument is a word or words (or a short phrase or phrases) that give additional information about the action. In that last sentence “the pie” and “on the windowsill” are both arguments.

And that is what the researchers are looking at with the study: the best verbs that speech therapists or neurologists can use so clients have greater success when relearning how to form sentences.

They determined that people with certain types of aphasia can quickly recall and repeat single verbs that don’t require additional words to convey all the necessary information. They can also use those words in a sentence. But words that have one or more arguments (remember: additional words or phrases that give necessary information to understand the verb) are harder to recall and harder to use in a sentence. It is easier to remember and use, “He is jumping” or “she is sitting” than it is to remember, “He is watching.” Therefore, speech therapists can begin by using “to jump” or “to sit” before moving to verbs such as “to watch” in order to build success.

## Preparing for COVID-19 When You Have Aphasia



### emergency preparedness and aphasia

It's a scary time in our country, and we want to provide our community with aphasia-specific, helpful information. Emergency preparedness – or dealing with the unexpected – is the topic of our April 1st online chat. **All are welcome to register and join us.**

While we normally post a roundup of tips *after* the chat, this time, we're starting the post before the chat and updating it afterward. We want to make sure people who need this information get it as they need it, not afterward. So let's dive in.

#### **Be Prepared**

Hopefully, you already have food and toiletries on-hand for the next few weeks. If not, delivery is your friend, but don't wait until last minute. Schedule delivery long before you need it because businesses are struggling to keep up with demand. Make sure you also have a several-week supply of any medications you need.

The Aphasia Center of California has put together an aphasia-friendly emergency preparedness list with pictures. While you probably won't need everything on that list because some items are for weather-specific emergencies, it's a great list to use to make sure you have everything you need. Thank you, Trish, for passing this along.

Today is the day to make a plan for any standing appointments such as speech therapy or medical appointments. We've provided some tools below that you can use to continue to hold some appointments from afar. If you don't already have a plan for how you'll keep up care until the COVID-19 crisis is passed, make one today with each of your providers.

### **Communicate Aphasia**

Make sure you have an **aphasia card** with you every time you leave the

We also recommend creating **an aphasia explanation sheet** to hand to anyone who comes to help — from first responders to the neighbour who's stopping by to see if you're okay. A quick paragraph explaining aphasia as well as some helpful information or answers that you can point to on the sheet will help with communication. Make sure you include contact information for a loved one in case you need someone to make a call. Also include communication tips for the other person, such as speaking slower or asking yes/no questions.

Moreover, many areas have a **special needs emergency registry**. Google that term along with your local or state government to see how you can add yourself or your loved one to the list. For example, Rhode Island's registry explains that people with communication issues can add themselves to the list. The program passes along information to first responders in the event of an emergency.

### **Go Virtual, If Possible**

Not everyone has access to online devices such as mobile phones, tablets, or computers. But if you do, consider going virtual for the next few weeks. Many

doctors and speech therapists are temporarily expanding their telepractice offerings.

If you're feeling ill, you may be able to get a virtual appointment, speaking with a doctor or nurse from the comfort of your own home. Ask your speech therapist if they will switch to telepractice sessions for the next few weeks. Support groups can use tools to meet virtually and continue practicing speech and giving support to one another.

Zoom is currently the easiest tool for group conversations. You can download a free account and hold 40-minute calls with dozens of people. Skype is another video conferencing tool for one-on-one conversations. FaceTime is Apple-specific but will work between any two people who have an Apple device. Google Hangouts comes free with any Google account.

## **Keep Social**

Continuing to talk with others is vitally important when you have aphasia. It's not just communication; it's therapy to improve speech. Plus, isolation comes with its own set of problems. Losing speech is stressful.

While we need to practice social distancing, and visits even from friends and family can spread disease, you do not need to stop communicating. You just need to get creative.

Set up times with friends and family to host virtual coffee dates. Get your cup of coffee or meal and sit across from the computer or phone. You can chat while you enjoy your coffee, just as you do in a face-to-face cafe.

Host virtual playdates with grandchildren, asking them to bring their toys in front of the computer so you can talk to them as they play. Or get together with friends online to play a game.

The point is to set up these chats just as you would schedule any get-together rather than leave them to chance. Having a plan in place means you can look forward to conversations throughout the day.

## **Keep Calm**

We know that the world feels overwhelming right now. Take deep breaths, stay informed, and make common-sense decisions that limit contact and stops the spread of illness. We'll speak with you at our April 1st chat and update this post when we have additional recommendations or information.



## How to Host a Virtual Support Group



This guide will walk you through the steps for hosting an online support group or discussion group, similar to our Aphasia Cafe series. Whether you want to move an existing face-to-face group online or start a new support group that meets virtually, we have tips that will make your process easier.

### **Tools**

While there are many video hosting platforms out there, we use Zoom for hosting our Aphasia Cafe series. Zoom offers free accounts with limits. Meetings can only be 40 minutes long once you have over three people in your group. (Your meeting can be longer if you're only holding the conversation between two people.) You can have up to 100 people in that 40-minute meeting. It is a fantastic option for groups on a budget or who want to try Zoom for a bit before committing to a paid plan.

The paid plan gets you many extra features. The most basic plan is about \$15 per month. You can hold longer meetings and take advantage of Zoom's

additional tools, such as gallery view or managing participants. Paid accounts also allow you to add a co-host to the event.

The National Aphasia Association has a paid plan but the choice is up to each group. We definitely encourage you to get comfortable with the free version and make sure that it fits your needs before you upgrade.

## **Sign Up**

Set a time and date for your chat. If this is your first meeting, start small and only post the first date. You can add extra dates/times after the first chat. Our chats are an hour-long, and we find this is the perfect amount of time for our large group. You may want to set up a half-hour chat if you have a smaller group.

Let people know about the chat. We write a blog post and send the link to anyone who has signed up in the past for a chat. We drop information about the upcoming chat in our newsletter and post about it on social media.

Ask people to sign up so you know how many to expect for the call. Remember, a free Zoom account only allows 100 participants. That may seem like an enormous number, but if you put the link online, anyone can take up one of those slots. We do not put our links online--the dial-in information is only sent to the people who RSVP for the chat.

We use Google Forms to create our sign up form. We ask a few standard questions:

- First name
- Email address
- Your connection to aphasia (person with aphasia, caregiver, or professional)
- Whether you'd like to participate and speak or just listen

Then we ask questions specific to that week's topic. Some of the questions are to get a pulse on the situation, such as "how difficult do you find grocery

shopping on a scale from 1 – 10?” We share these findings at the beginning of the chat.

We also ask the key question at the heart of the chat. For instance, if the chat is about making grocery shopping easier when you have aphasia, we will ask people to tell us their best tips. We turn these answers into the discussion slides.

### **Discussion Slides, Scripts, and Emails**

About two days before the chat, we create discussion slides, pulling out quotes from the signup form and attributing them to the writer. The slides remove the need for people to think on their feet. They can draft their answer ahead of time and then use their speaking time to elaborate on their words. It ensures that we don't have long periods of silence during the chat.

The slides also provide a secondary way of communicating. People can either read the answer on the screen or hear the answer read aloud.

We also create a loose script or “run of show” for the moderators to aid our discussion. We mark down who is introducing each slide and extra follow-up questions we may want to ask. If we want to have a poll during the chat, we also mark this in the document. While everyone sees the slides, only the people running the chat see the script.

Two days before the chat, we also send out a reminder email with a unique link to the chat to everyone who RSVPed and we close the form to new sign-ups. We send a separate email to everyone who has been chosen to have their answer turned into a slide. Other people will chime in during the actual chat, but we like to give a heads up to everyone that we know will be speaking.

### **Discussion**

The moderator logs in a minute or two before the discussion. Make sure you have someone checking email in case people are having trouble logging on.

We also designate a notetaker on our team to gather ideas from the chat that we can pass along to others who can't join the chat.

We start out the chat with some light housekeeping. We ask that people mute their microphone if they're not speaking. The moderator can also mute all participants from their control panel. We ask people to use the "raise hand" button if they want to add something to the discussion or leave a note in the chat box so we can call on them.

Of course, our chat is an aphasia-friendly space. We also open every chat by reiterating that people should feel comfortable taking all the time they need to say what they would like to say. We encourage everyone to participate. Everyone on the call has a direct connection to aphasia--whether they have aphasia, are a caregiver, or a professional--and all understand how challenging speaking can be.

We run through the slides, asking the writer to elaborate on their answer. We sometimes use their answer to kick off a yes / no poll, asking people to vote and then sharing the answers in real-time. We also sometimes just ask people to give a thumbs up or thumbs down to voice their opinion.

We always leave a few minutes at the end for people to bring up whatever is on their mind.

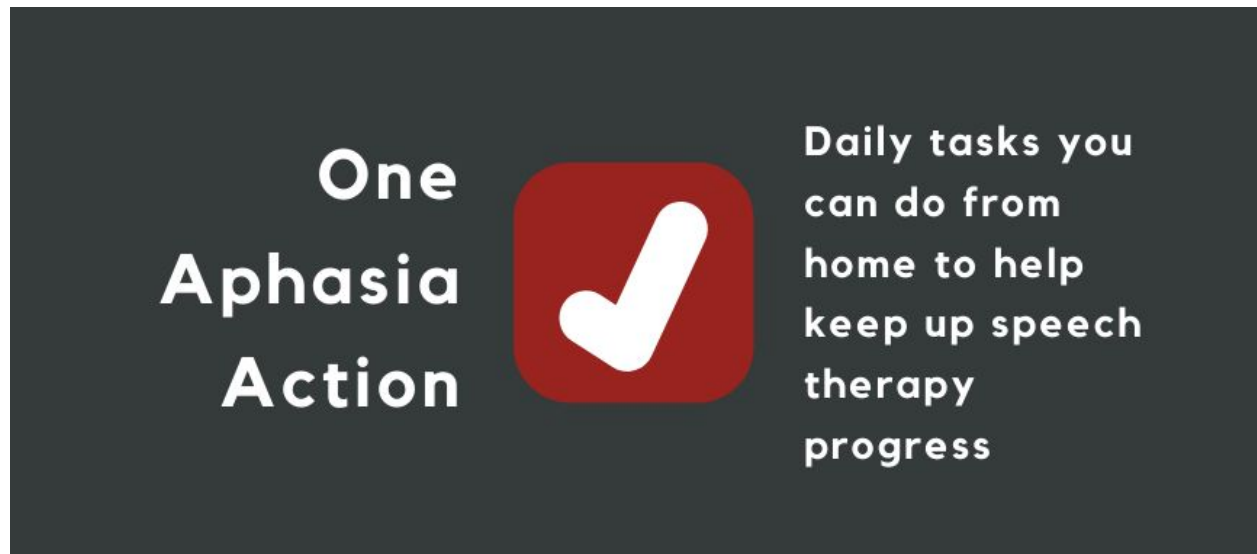
## **Follow Up**

While we don't post a roundup of advice and answers after every chat, some subjects clearly lend themselves better to a blog post. Our recent chat on grocery shopping brought up so many good tips that it felt like inventing the wheel if we didn't capture them and put them up online.

We create the posts out of a combination of quotes from the slides (attributed to the speaker) and comments made during the chat itself. We make sure we add any helpful links. For instance, we had someone describe an app during the grocery store chat, so we found it and linked to it in the post.

After the first few chats, we met as a team and asked for feedback from participants in order to fine-tune the process. We are thinking about also doing more unstructured and open-ended sessions in the future, but for now, the slides have helped make our chats useful and interesting for the participants.

## One Aphasia Action: Introduction



The social distancing recommended to contain COVID-19 is particularly difficult for people with aphasia. Isolation is not a friend of communication, and it can be frustrating to have your routine derailed, especially when it comes to lost speech therapy appointments.

While some therapists are offering remote, video appointments, other therapists aren't able to make the jump online. At the same time, clients may also lack the necessary tools or internet connection for continuing speech therapy appointments from home.

Even if you are continuing with remote speech therapy, you may be looking for small, actionable activities you can do from home that will help you retain speech progress.

### **What Is One Aphasia Action?**

We've compiled a list of things you can do to keep up your speech progress from home.

Every day – starting tomorrow – we'll post one activity early in the morning and share a link to the post on Facebook and Twitter.

Try every activity, even if you only do it once. Keep doing the activities you like, repeating them the next day along with the new activity, and drop the ones that don't work for you.

We hope that by the end of the first week, you'll have an hour-long (or longer!) new habit that will help you retain the progress you've made on regaining speech after an aphasia diagnosis or maintaining speech after a primary progressive aphasia diagnosis.

### **What If I Miss the First Day?**

This works best if you start on Day 1 and work at your own pace, even if you're finding this project after it has started. After 30 days, either continue doing the activities you've enjoyed from your first 30 days, or start the cycle again with Day 1.

Or spread out the activities. For instance, do Day 1 on Monday, Day 2 on Wednesday, and Day 3 on Friday. While it's best to go in order, it is not important to complete the activities in 30 days.

### **List of One Aphasia Actions**

- Day 1: **Chat Appointments**
- Day 2: **Library at Home**
- Day 3: **The Family List**
- Day 4: **Verb-a-Day**
- Day 5: **One-Minute Mystery**
- Day 6: **Creative Meals**
- Day 7: **Categories**
- Day 8: **Game Time**
- Day 9: **Storyteller**
- Day 10: **The Letter Game**
- Day 11: **Hangman**
- Day 12: **Breathe**
- Day 13: **Book Club for Two**
- Day 14: **Pictionary**

- Day 15: Knock Knock
- Day 16: Walking Challenge
- Day 17: Listen and Read
- Day 18: Positive Thought
- Day 19: Mini Puzzles
- Day 20: Delicious Lists
- Day 21: Connect Inside and Outside
- Day 22: Great Personality
- Day 23: Go on a Trip
- Day 24: Television Club for Two
- Day 25: Picture Perfect Conversations
- Day 26: Talk to Yourself
- Day 27: Sing It!
- Day 28: Puzzle Time
- Day 29: It's Puzzling
- Day 30: Doodle Stories

*This is not a special speech therapy program, nor should it be used in place of recommendations from your speech therapist. It is general advice of speech-rich activities that can supplement speech therapy work or help individuals to not lose progress while they are isolated at home. We cannot give individual recommendations.*



## Create Your Own Intensive Speech Program at Home



Not everyone has access to intensive speech therapy—and not just because we’re in the middle of a pandemic right now. Even before stay-at-home orders, intensive speech therapy may have been out of reach for many people with aphasia.

When we explored this topic during our last online Aphasia Cafe chat, only 47% stated they had done some form of intensive therapy. But 40% did not partake in intensive therapy, and an additional 13% didn’t know about intensive therapy programs. High cost, high time commitment, or distance are three obstacles for daily speech therapy programs.

This is why some people are making their own intensive speech therapy program and completing it at home.

### **An At-Home Therapy Solution**

Mert spoke about the program her late husband Tommy pulled together for her following her stroke. She started with formal speech therapy once or twice a week (for a duration of six to eight weeks), but he followed it up with her

so-called “homework.” She states that he showed her pictures and used them to have her recite “action words, basic personal items, clothing, family and friends in photos, feelings, grocery items, etc. Those that I couldn’t express with a word, I would do my best to describe what I was thinking.”

He didn’t let her give up. He would take her to the mall or park, even when she was tired and lovingly wanted to punch him. He would have her describe what she saw while they were out-and-about. She admits: “Although I disliked the grueling daily intensive therapy almost 16 years ago, the love of my life helped me to become a stroke survivor with residual aphasia today.”

In fact, Mert gives speeches via her local Toastmasters International club, a testament to all the hard work she put in with daily therapy guided by her husband after the stroke.

### **The History of Self-Therapy**

Mert is in good company. Roald Dahl, writer of *Charlie and the Chocolate Factory* and other beloved classics created a therapy program for his wife, Patricia Neal.

As we wrote in her profile:

After the stroke, Dahl was upset to learn that there wasn’t a set game plan to nurse his wife back to health. He was told that she would get one hour of rehabilitation per day, a fact that left him incredulous. Instead, he built a program where she constantly in speech therapy and brain training.

Due to Neal’s success, Dahl wrote a guide and inspired a new method of rehabilitation.

### **Everything Is Therapy**

A speech therapist on our Aphasia Cafe call asked everyone to expand their definition of therapy. For instance, participating in an online chat *is* therapy. You’re practicing speech, you’re using listening skills, and you’re working to put thoughts into words. All of the activities in our **30-day One Aphasia Action**

**challenge** are speech therapy (and they were designed by a speech therapist).

If each of those activities takes between five minutes and a half-hour to complete, you could design your own daily intensive therapy session by stringing together several activities from the list.

And while some people have a loved one, family member, or friend who can guide the therapy, others may need to guide their own therapy. Many of the activities on the One Aphasia Action list do not require another person to complete.

## A Community Comes Together Around Primary Progressive Aphasia



As President and CEO of the Westmoreland Chamber of Commerce, Chad Amond's job is to grow and support businesses in the community. And those businesses and residents of the county are turning around and supporting the Amond family as they navigate life with primary progressive aphasia.

### Learning About Primary Progressive Aphasia

The local newspaper gave us the first glimpse into the Amond family's story. After searching for answers for months, a neurologist delivered the diagnosis last spring—primary progressive aphasia.

Family and friends call him the heart and soul of the county, as he spends long hours at breakfasts, dinners, and business meetings. He speaks at about 128 events a year to promote the region, where he grew up in Derry Township. He has been, unabashedly front and center, one of the county's loudest cheerleaders. And words always came easy ... That skill has suddenly vanished.



The Amonds are facing the disease as a family, but they're also facing the disease with a lot of support around them.

## A Community Comes Together



Chad is applying years of communication experience to educate the community about primary progressive aphasia. Last weekend, over 400

people came together for a mini-golf tournament to raise money for the NAA and raise awareness about PPA.



“I can’t thank my family, friends, colleagues, business owners, and all of the people (more than 400+) that went to the mini-golf outing and served the grant to NAA. I always say, ‘it’s not about me.’ It’s such a rare diagnosis. I want to make sure people know about it, and it will be cured as soon as possible,” Amond says.





His ultimate goal is a cure, and he's currently seeking clinical trials that could provide a cure not only for himself but for others experiencing PPA.





In the meantime, he continues to work to support the community that is supporting him. He tells us, "I want to work as long as I can to positively impact Southwestern Pennsylvania, Westmoreland County, businesses in our community, the Chamber, my family, and all of my friends."





## New Movie About Aphasia Mixes Education With Hope



Coleman Watson is making a movie about aphasia, but unlike many other filmmakers, Coleman comes with an insider's perspective on the subject matter. His experience with aphasia and apraxia began after a stroke in February 2020.

### **Coleman's Story**

Coleman spent nine days in the ICU following his stroke. When he was released from the hospital, the doctor told him that he could go because he was okay now. But Coleman didn't feel "okay"—he had aphasia. "I had no idea what I was supposed to do with my speech. The hospital didn't really didn't give a plan going forward," he says.

Like many people with aphasia and apraxia, it was up to Coleman and his family to make a plan to restore speech. Outpatient centers had a two-month waitlist, and Coleman was frustrated. "I was worried because I needed to work on my speech. My family thought that we could just talk with friends and family at home, but I knew that was naïve. I needed a speech therapist."

He started therapy at Brooks Rehabilitation Aphasia Center's six-week ICAP program, which made him both excited and sad. He was excited to meet other people with aphasia and learn about aphasia, but he also knew there were many people out there who needed intensive therapy and couldn't pay for it or have insurance coverage.

Though he has an idea to remedy this problem: "I want to make a film to educate others on the types of aphasia and the fact that all types need intensive therapy and how to help them. Aphasia is an invisible healthcare crisis. We need to educate the community."



## **The Movie's Spark**

The idea for a film began when Coleman was trying to find movies about aphasia to understand it. He wanted to see people with aphasia in action. "I couldn't find any type of movie that really talked about aphasia and showed others with aphasia. I felt isolated because I didn't know anyone with aphasia. I knew there were websites, but because of aphasia, I was not able to read or write on the internet. I felt alone. Is it only me?"



So he set out to create the film he wanted to see, even though his background is in law. Before his stroke, he did pro bono civil rights work as well as patent law. But his love of his law work added to his passion for the film.

He says, “After my stroke and aphasia, my therapist gave me an article about the law and people with aphasia in court and how they are severely underrepresented. This made me upset because there should be rules in place to help those with aphasia in the courtroom. I also want to create awareness for creating laws for people like me, lawyers, to give us the ability to do our jobs even with aphasia. I am still just as smart, know all the facts, and have the same intelligence as before. I want to help people. I just need a little more time because my talking is not as fast as before.”



## **Learning About Aphasia**

Making the film has sent Coleman on a deep dive of the aphasia and apraxia world. After joining Facebook groups and meeting people with aphasia and apraxia, he has learned about key issues such as insurance, financial issues, divorce, family, children, jobs, and communication issues. Coleman admits that part of his understanding comes from his insider perspective. "People try to understand but it is truly hard to understand unless they have aphasia." Movies allow the audience to experience the world from a different point-of-view, and hopefully, they will gain a better understanding.

His wish in making the film is to bring the struggles of people with aphasia and apraxia to the general public. "I hope this film helps many with aphasia and apraxia. I also hope a large part of the audience are people who have never heard of aphasia or apraxia because I want to educate them. One day, they or a family member (wife, sister, son) might have a stroke and have aphasia or apraxia. I want people to know what it is so they are able to help them with resources instead of starting from scratch as we did."

He's currently fundraising to make the film, and he released the nine-minute trailer above to give people a taste of the final project. You can learn more about the project on his GoFundMe page.

What message does he want to send? "I want people with aphasia to know that aphasia is not the end of your life. Before my stroke, I wanted to be a federal judge or a Senator. Even after my stroke, I still believe I will be a federal judge or a Senator again. I want people with aphasia to know they can achieve their goals still."



