

The USC Aphasia Lab Newsletter

Research and Community News for People with Aphasia, Their Families, and the Rehabilitation Professionals Who Work with Them

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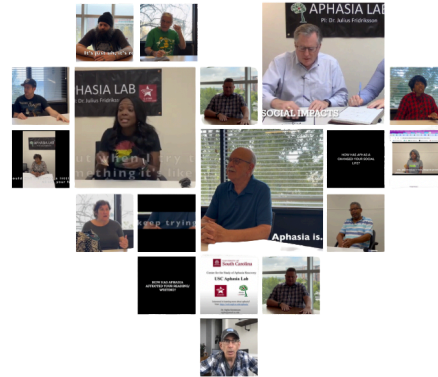
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What is Aphasia? Video Series

MEGAN RATTIE

Aphasia is a common language disorder that affects a person's ability to speak, understand speech, read, and write. But its impact reaches far beyond words. Communication is at the heart of daily life, whether it's connecting with family and friends, participating in work, or completing everyday tasks like ordering a coffee or scheduling an appointment for an oil change on your car.

At the Aphasia Lab at the University of South Carolina, we believe that understanding begins with listening. Our "What Is Aphasia" video series amplifies the voices of people living with aphasia and their families. These videos explore what it means to live with aphasia day to day. They share stories of challenges, triumphs, hopes, and ongoing journeys of recovery.

To view the full series online, scan the QR code below!



Interested in sharing your story?

We're always looking for new voices to feature in our series! If you or someone you know would like to participate, please **contact Dr. Sigfus Kristinnsson:**

803-553-4689
sigfus@email.sc.edu

The Real Deal: Ricky's Story

BY ALLISON CROXTON

"It's not about the cards you're dealt, but how you play the hand." – Randy Pausch, *The Last Lecture*

As a child, Ricky enjoyed **playing cards** and trying **simple magic tricks**. As he grew older, he dreamed of becoming a **screenwriter** and **director**. Now, as a young adult, he is learning something powerful: we all have the choice to write and direct the story of our own life.



Ricky playing pickleball.

When Ricky was **17 years old**, he was dealt an unexpected hand in life. He experienced a left-hemisphere stroke caused by a brain aneurysm. This resulted in **right-sided hemiparesis, decreased vision, and aphasia**.

Two years later, during **COVID**, Ricky was inspired to reconnect with his **magic**. He began watching **beginner cardistry videos**. Cardistry is an art form of movement using a deck of cards. Because his right hand was affected, he learned all his tricks with **one hand—his non-dominant hand**.

He **practiced every day**. He learned many tricks, created some of his own, and now can perform about **20 different moves**. This took **persistent self-belief**. Ricky brings the same perseverance to other parts of his life.

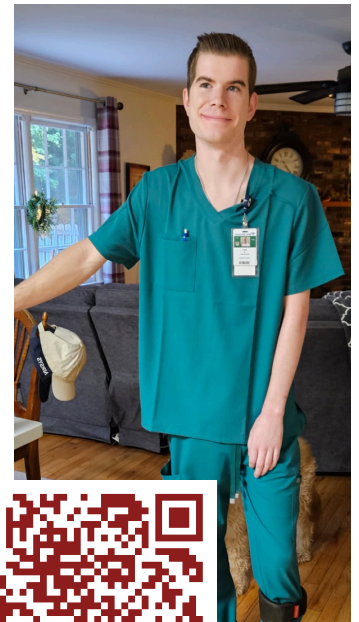
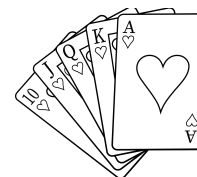
For fun, he loves playing pickleball. His low vision and right-sided weakness do not keep him from being a **competitive force** in the tournaments he plays in!

For work, he completed the **BeReady Internship Program** at **Bon Secours Hospital**. This program helps people with disabilities learn job skills. Ricky had been dreaming about working in a **medical setting**. Now, instead of entering the outpatient rehab center as a **patient**, he arrives in scrubs as a **staff team member**. His job is to help prepare and clean the space. Through his work he assists both the **rehab professionals** as well as the **patients** who are beginning their own healing journeys.

Ricky says about his current position, **"I love my job!"** When thinking about his future, he shares, **"I love the brain.** Further away, my dream is a **neuro MRI tech."**

Ricky continues to **write his own story**—one dream, one step, one swing at a time. He is an example of how we can **live** in our present circumstances and situations **with joy**.

The magic Ricky shares with the world as an adult is not just in his one-handed card tricks. His real magic is his **trust in life**, his **determination**, his **gratitude**, and the way he inspires others, **leading by quiet example**.



Check out some of Ricky's cardistry skills by [clicking here](#) or scanning the QR code!

Including Every Voice: Training Persons with Aphasia as Patient Experts

POSTER PRESENTATION BY AMY NEIRA

MAUSHMI PATEL, JEFFREY WOODWARD; KATIE PARRIS, SEBRENA BRINK, SARA SAYERS, LEONARDO BONILHA, ANN BLAIR KENNEDY, & NABIL NATAFGI

Despite the **growing need**, research falls short on **meaningful involvement** of **people with aphasia** (PWA) and **caregivers** as **research partners**.

The University of South Carolina Patient Engagement Studio (PES) united aphasia patients, caregivers, researchers, and clinicians to integrate patient voices into aphasia research.

This project aimed to:

- Build capacity among **PWA to engage as equal partners in research** through tailored training and communication supports.
- Create a **collaborative environment** where PWA, caregivers, researchers, and clinicians could **co-define priorities for aphasia recovery outcomes**.

Nine individuals with PWA and their caregivers were successfully recruited and trained in two cohorts.



The PCORI Approach to Patient-Centered Outcomes Research

Methods

Training

PCORI Research Fundamentals Modules



Team Building

Group Exercises (Synchronous)



Storytelling

Photovoice/Imagery



Communication

Chat, Text, Verbal

Training led to the co-creation of themes that reflected both **practical communication challenges** and **broader dimensions of recovery**.



- The panel will develop and test a **Discrete Choice Experiment** to identify **key recovery outcomes** for PWAs and caregivers.
- The panel co-authored a recent article led by **Dr. Ann Blair Kennedy** (see link & QR code)

CHECK THIS OUT

<https://tinyurl.com/From-Measures-to-Meaning>



Embracing my Independence and Nurturing my Well-Being through Traveling

DENISE MENDEZ

Hi! I'm Denise Mendez. I often say, **"I have aphasia, but aphasia doesn't have me!"** This affirmation is both my personal message to self, reminding me that the series of strokes, the craniotomy to remove a bleeding AVM, and the ongoing challenges of chronic aphasia do not define who I am. These experiences will not stop me from thriving and living my best life.

As Ella Fitzgerald famously sang, "Into each life some rain must fall." In 2024, I found myself in the midst of a torrential storm. I was confronted with unanswered health questions, the loss to death of friends and family, and a sense of dissatisfaction as I hit a plateau in my reading and writing rehabilitation. This period left me feeling uncomfortable, less confident, and more stressed than ever before.

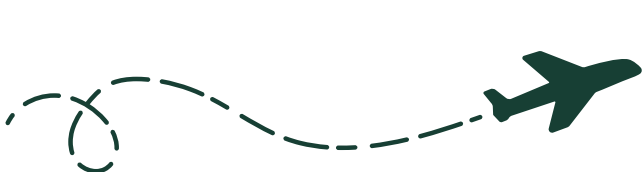
So, what did I do? I chose to travel! Traveling has always been a positive force in my life. Before my strokes, I explored the Caribbean, Cuba, South Korea, and much of the United States. With the challenges I was facing, I realized what I needed was more than just a quick getaway—I needed an extended trip, a journey that would present new experiences and challenges.

Since my first stroke in 2017, I had only traveled alone within the United States, navigating Amtrak train stations and domestic airlines—though not without considerable stress and anxiety. After three additional strokes, I was limited to traveling with family and friends, dictated by their vacation schedules. As a retired, disabled woman, **I wanted the freedom to travel on my own terms.** So, I made the decision to travel to France by myself in May 2025, enrolling in a tour group that specializes in solo travel. This trip was transformative—not only because of the landmarks, museums, restaurants, and beautiful vistas, but because I learned so much about myself traveling from Philadelphia to Paris as a person with aphasia.

Traveling can be hectic, but **I was determined to succeed by following proven self-care strategies.** I adhered strictly to my schedule for medications and vitamins. Each morning before our tours, I would walk through the neighborhoods near our hotels, enjoying the simple pleasure of exploring on foot. The days were busy, but I slept well each night and savored some of the best food I have ever tasted. The vegetables were especially fresh and flavorful! I sampled foie gras, though it wasn't to my liking, and I chose not to try escargot—I generally enjoy seafood, but I draw the line at snails. As someone who doesn't enjoy wine, I didn't have to worry about overindulging in vino. Along with eating healthy, staying well-hydrated was a top priority for me.



Denise and her travel group in Paris, France, in front of the Eiffel Tower.





Denise and her travel group at Saint Paul de Vence in the South of France.

As an **aphasia advocate**, I took the opportunity to talk with my tour mates and spread awareness about aphasia. I explained my communication challenges so they would understand if I frequently needed to pull back from socializing. Our group had 28 people, and when environments became overstimulating—like in noisy restaurants or concerts—I would separate myself or use earplugs.

I enjoyed using my senses to savor the sights, scents, tastes, and sounds of France. Aphasia did not prevent me from trying to order in restaurants or make purchases in stores and markets, even though I do not speak French. A **genuine smile** often bridged any language gap. Despite initial concerns, I found that communication difficulties were not emotionally

overwhelming. Instead, **I felt empowered** navigating new situations **independently**. Each accomplishment boosted my confidence as a traveler, communicator, and served as a reminder that I am more than aphasia!

Traveling solo gave me many opportunities to engage my mind—planning, scheduling, organizing, and using navigation or museum apps. Although I didn't read any books during the trip, (but was able to find a English written French cookbook!), I read signs and labels on exhibits and artifacts. The art, history, and local culture provided rich cognitive enrichment.

**I have aphasia,
but aphasia doesn't
have me!**

My solo trip to France was incredibly encouraging for my **self-esteem** and **confidence** as an independent person. I returned home fully aware of my **strength** and **resilience**. I now plan to return to France with friends so I can share the joy and wonder of the country with others.

I hope my story inspires others with aphasia to pursue their independence and embrace the possibilities that travel can bring.

Virtual Group Semester Project

A **key theme** discussed in USC's virtual aphasia group this semester has been **celebrating accomplishments, personal growth**, and things that make the group feel **empowered after their stroke**.

To showcase this, the group has put together a **slideshow** of photos that highlight what **Life After Aphasia** really looks like. **Click here** or scan the QR code to watch!

Video was organized by **Caylee Brand** and **Claire Niermeier**, featuring photos and music from **USC's virtual aphasia group**.

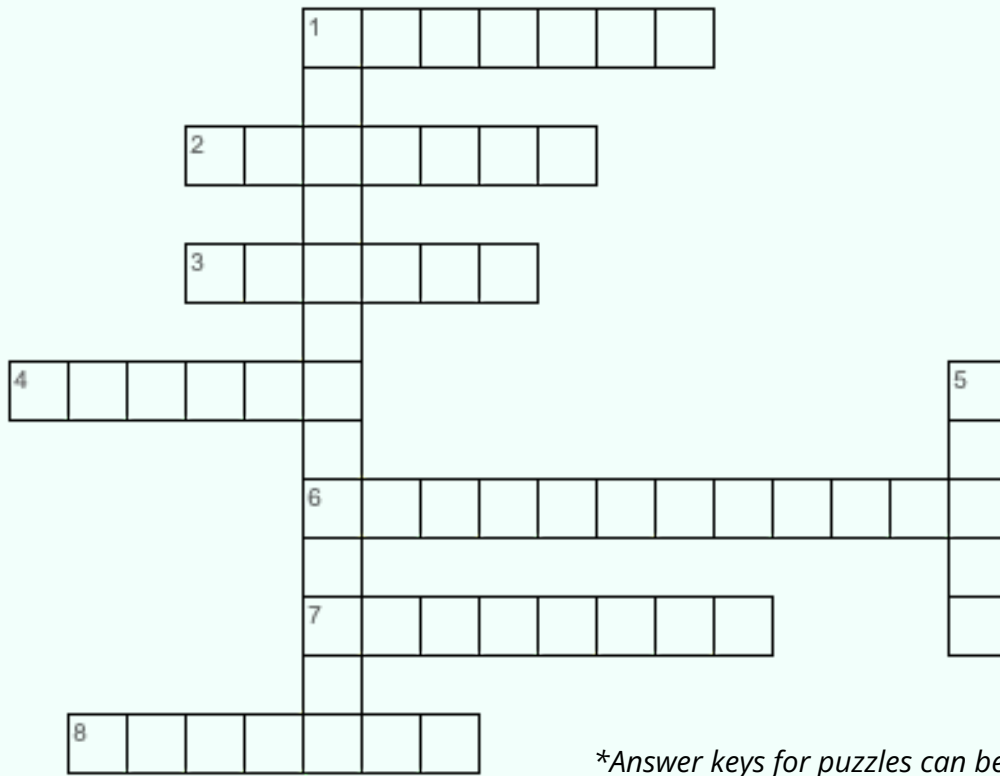
**LIFE AFTER
APHASIA**

VIRTUAL APHASIA GROUP FALL 2025



CROSSWORD

created by Aphasia Ambassador, Heather C.



**Answer keys for puzzles can be found on the last page!*

ACROSS:

1. The Christmas party is too loud, Jim. Would you mind if I put in my...?
2. ... is a rare genetic disorder that can block blood flow in the brain
3. I can't wait for holidays, to see friends, and ...
4. Aphasia's Christmas song; ... night, holy night
6. Aphasia is a disorder that affects an individual's ability to communicate, not their...
7. I am a warrior, or a ...
8. This crossword is in the USC ... Lab's newsletter

DOWN:

1. ... is a risk factor that may increase stroke risk in women.
5. Please ... in short and easy sentences, Aunt Barbara!

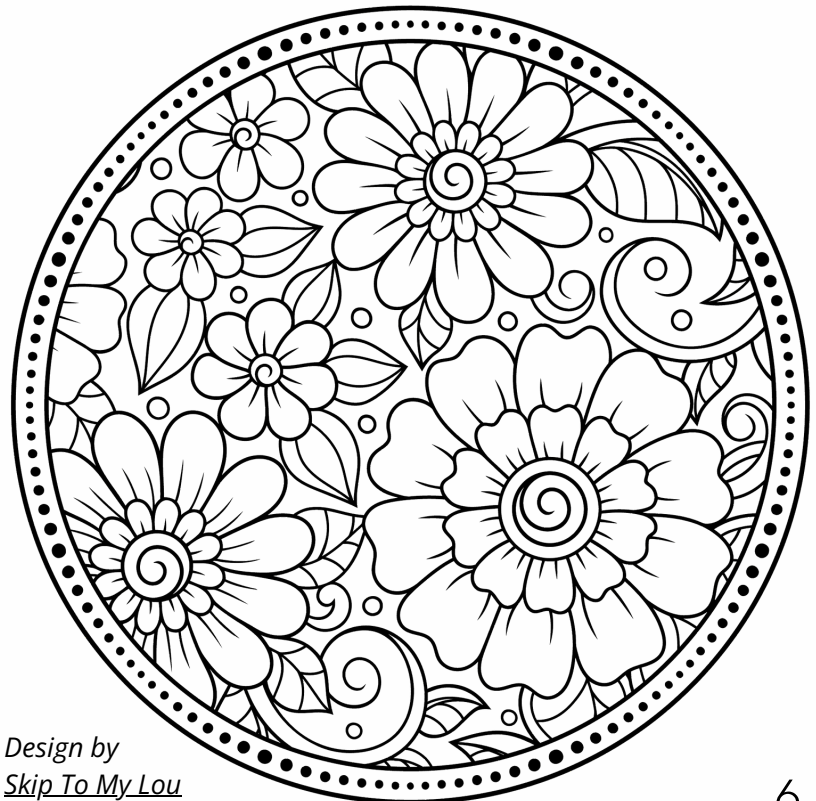
CHAIN REACTION

Instructions: Each word connects with the word after it. An example of this is:
Water - Bottle - Cap.

*Inspired by the USC Virtual Aphasia Group!
Hint for #2 - something you wear on your feet!*

1. Tube
2. S _ _ _ _
3. P _ _ _ _ _
4. M _ _ _ _ _
5. M _ _ _ _
6. G _ _ _ _
7. S _ _ _ _
8. O _ _ _

Coloring can be a great way to **relax** and practice **fine motor skills**. Give it a try below!



*Design by
Skip To My Lou*

RESOURCES

We hope these tools offer a little extra ease, confidence, and support for you and your loved ones—whether you're traveling, communicating, or navigating daily life.

Travel Support

- **TSA Cares:** A free helpline that supports travelers with disabilities during the security screening process. You can call within 72 hours of your flight for guidance or request a Passenger Support Specialist to assist you at the airport.
- **Hidden Disabilities Sunflower Program:** A simple sunflower lanyard or bracelet quietly lets airport staff know you may need extra time, support, or assistance. Many airports in the U.S. and around the world—including several in the Carolinas—participate in the program.



Resources on your iPhone:

- **Emergency SOS:** Quickly call 911 by holding the side + volume button.
- **Medical ID:** Store key medical information like medications, allergies, and emergency contact in the Health app. First responders can see it from your lock screen!
- **Emergency Contacts:** Add trusted people in the Health app. Using Emergency SOS alerts them with your location.

Smartphone Apps

- **AAC Apps (Communication Boards):** Apps like *Proloquo2Go*, *Lingraphica*, or *Avaz* allow you to select pictures, symbols, or words so your device speaks for you. These tools can be helpful when speech is difficult or tiring.
- **Constant Therapy App:** A therapy app created by neuroscientists and clinicians from Boston University. It *uses evidence-based language and cognitive exercises* shown to support people with aphasia and others with thinking or memory challenges.

Community Leadership Academy (CLA)

Become a Leader in Your Community — Free Course Begins Jan. 26!

This winter, the USC Aphasia Lab and Able South Carolina are teaming up to offer a unique opportunity: the Community Leadership Academy (CLA), a free 6-week online course designed to help people grow their **leadership** and **communication skills**.

Whether you're a person with a disability, a family member, a young adult, or someone simply eager to make a difference, CLA helps you learn to:

- ★ **Lead** with confidence
- ★ **Serve** effectively on **boards** and **committees**
- ★ **Strengthen communication** and **teamwork** skills

When?

Mondays, 10 AM–12 PM on Zoom
Jan. 26 – Mar. 9 (no class Feb. 23)



👉 Register here:

<https://forms.gle/5UC6FNH2h7UFY17b6>

**No experience needed -
just a desire to learn & lead!**



The USC Aphasia Lab

Communication Sciences and Disorders
Arnold School of Public Health
Columbia, SC 29208



- Group and study offerings for the spring semester will be sent out via email
- Community Leadership Academy online course begins on Jan. 26th



- Aphasia Prom hosted by SLPAIG student group at USC & the USC Aphasia Lab (more details to come!)



- Join us at the SC State House for Advocacy Day on April 14th 10AM-12PM



- Annual Aphasia Community Event (we will share more details in the new year!)



- Instagram: @uofscaphasialab
- YouTube: tinyurl.com/Aphasia-Lab-YouTube
- Facebook: Aphasia Lab – USC
- tinyurl.com/Awareness-Video-Series

ANSWER KEY

Crossword:

Across

1. Earbuds
2. Cadasil
3. Family
4. Silent
5. Intelligence
6. Survivor
7. Aphasia

Down

1. Endometriosis
2. Speak

Chain Reaction:

1. Tube
2. Sock
3. Puppet
4. Master
5. Mind
6. Game
7. Show
8. Off