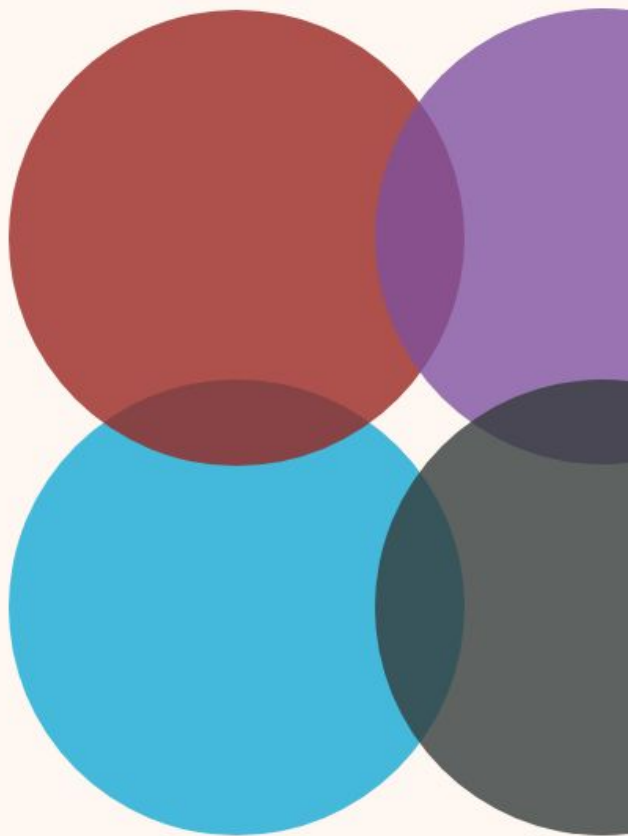


2018

NATIONAL APHASIA ASSOCIATION



**Our Best Posts of the
Year**

aphasia.org



**National
Aphasia
Association**

Dear Friends,

2018 is coming to a close. Once again, before we look ahead to the exciting projects we're planning for 2019, we wanted to take a moment to reflect on everything we learned and discussed this past year.

What will you find in this booklet? More of our ongoing series profiling famous people with aphasia. Helpful articles covering a wide range of topics such as winter preparedness when you have a communication disorder and wearable technology. There's coverage of new research including the hot topic of combining brain stimulation with speech therapy. Finally, you can check out our new short video series, or the opening posts from the two books we read this year for our online book club.

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 thoughts and helpful tips in the upcoming months. So please, sit back and relax with these articles from 2018 and recharge because we need your energy to make our 2019 outreach illuminating and helpful for all.

Warmly,

Melissa Ford

Editor

National Aphasia Association

Winter Emergency Preparedness and Aphasia



Winter is here. Whether you're managing the cold or dealing with an upcoming snowstorm, we have tips on how to stay safe during winter weather when you're navigating aphasia.

Special Needs Emergency Registry

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.

Hopefully, you won't need a first responder this winter, but it helps if the team comes in knowing about aphasia ahead of time.

Create an Explanation Sheet

In the same vein, create an emergency explanation sheet to hand to anyone who comes to help — from first responders to the neighbor who's stopping by to see if they can shovel your walk. 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.

Keep Communication Tools Charged

Some storms come with power outages, so make sure you're prepared if your communication tools require batteries. Pick up a few extra packages of batteries long before an upcoming storm since stores often run out of this item before a storm hits. If your device uses a rechargeable battery, keep your device plugged into a power source when not in use. If you do lose power, you'll have a full charge until they restore power.

Portable power banks can also be charged ahead of time. These devices will allow you to recharge a mobile device when you're without electricity.

Get Creative

If you're stuck in the house either due to inclement weather or extreme cold, ask if your speech therapist would be willing to do the session over a video feed such as Skype or FaceTime. Technology is a great way to circumvent the weather and stick to your speech therapy schedule.

What other wintry tips do you have for people navigating the weather and aphasia?

An Update about Still Sophie



Our article about the movie, *Still Sophie*, was our second most popular post in 2017. Sophie Salveson grabbed our hearts with her moving aphasia story, and she entertained us with her amazing voice.

We caught up with producer and cinematographer Chad McClarnon to hear how the film has been received as well as plans for release so you can see her story, too.

On the Film Festival Circuit

The film has been screened in 25 film festivals as well as a few non-festival spaces over the last year and a half. It has traveled through 15 states: Oklahoma, Colorado, Tennessee, Ohio, California, Alabama, Kentucky, Pennsylvania, Washington, Indiana, Wisconsin, Missouri, Georgia, North Carolina, and Massachusetts.

There are still a few film festivals doing their schedules, so there is a chance it will screen in more states in the future.

Reactions to the Film

McClarnon marveled at the audience reaction:

This story really touches people. One of the more surprising reactions to me has been that of the treatment providers. Speech pathologist and therapists reach out to us after nearly every screening asking how they can show the film to students or to their fellow clinicians. Our amazing director, Caroline Knight, even traveled to Massachusetts and gave a presentation, along with the film, for a speech therapy conference this past year.

Winning Awards

The film has been picking up awards left and right, which, of course, increases awareness of aphasia. Some of these awards:

- Best Documentary – Red Dirt International Film Festival
- Best TN Short Doc – Nashville Film Festival
- Best Documentary Short – deadCENTER Film Festival
- Best Documentary Short – Mid Teen Film Fest
- Best Documentary Short – Knoxville Film Festival
- Best TN Documentary Short – Knoxville Film Festival

The Future of the Film

The movie will definitely be out on iTunes in the future, but they're currently negotiating with other platforms for distribution. McClarnon did let us know that he will keep the NAA in the loop so we can pass along viewing information whenever it's available.

And What About Sophie?

McClarnon was able to give us an update about Sophie:

Sophie is doing great! And we had such a blast going around to the film festivals together. Last April, she underwent a stem cell treatment and has seen some significant gains with her aphasia. From everything she

tells me, she loves seeing herself on the big screen. She's constantly asking me when we're going to do *Still Sophie 2*.

One of the things I hope people come to realize from this is that she is actually a brilliant actress and performer. She has the training, she has the background in it, and it shows. She takes direction incredibly well and her performances are full of surprises and nuance.

I'd love to see her take on roles in the narrative film space. While she obviously has to work really hard at the words, her emotional delivery is spot on perfect, and I certainly plan on casting her in something when I first get the chance.

We can't wait to see her on the screen again. We'll keep you updated as we learn more about *Still Sophie's* release for home viewing.

Profiles of Aphasia: Julie Harris



Julie Harris entertained us for decades, whether it was in one of her Tony-award winning stage roles, movies, or on television shows such as *Knots Landing*. She received the National Medall of Arts, and entry into the American Theatre Hall of Fame. She also experienced aphasia.

We've been profiling well-known people with aphasia, including Ralph Waldo Emerson and Gabby Giffords. Aphasia can affect anyone; even actresses.

A Stroke Before a Performance

Perusing the 101 acting credits on Julie Harris's Internet Movie Database page only gives you a taste of a career that also included numerous stage performances. But being in the acting world almost came to an end after a stroke in 2001. When she didn't show up for a performance, the theater sent someone to her apartment who found her on the floor. She explains, "I knew something was wrong but I couldn't get help."

Recovery

The stroke left her with aphasia, which she treated with speech therapy for two years. She recounted her experience in an interview with The American Stroke Association:

This therapy helped her improve her vocabulary but not her fluency. Like many survivors with aphasia, she had difficulty finding the right word; she sometimes said words that rhymed with the word she was trying to say, e.g., “wife” instead of “life.” She avoided starting conversations, and when she spoke, there were lots of hesitations.

To keep acting, she played a role where the character was also recovering from a stroke, but aphasia was bringing her long-running career to an end.

A New Beginning

Five years after her stroke, University of Michigan Aphasia Program contacted her to see if she wanted to try a different therapy. She started a very intense therapy plan, completing 23 hours of speech therapy per week for six weeks. The therapy changed her life, giving her ways to circumvent her aphasia and return to conversations with people. Even though she didn't return to acting full time, she did return to connecting with people.

Rather than being on the stage, she switched to a life of theatergoing, attending performances in New York and Boston and tracking those performances in a personal scrapbook.

When Julie Harris died in 2013, Broadway theaters dimmed their lights for a full minute in her honor. A fitting tribute to a woman who lit up the stage and screen.

Profiles of Aphasia: Paul West



Paul West was a prolific novelist, writing book after book by playing with words. His *New York Times* obit described him as having a “Shakespearean vocabulary,” but even that doesn’t touch upon the quirky situations and subject matter that popped up in his creative novels. That vocabulary was reduced to a single sound – *mem* – after a stroke in 2003, though he continued years later to write what his wife called “the first aphasic memoir.”

We’ve been profiling well-known people with aphasia, including Ralph Waldo Emerson and Gabby Giffords. Aphasia can affect anyone; even prolific writers who have a way with words.

After the Stroke

West experienced a language-ending stroke in 2003. His wife, the writer Diane Ackerman, explains in a preface to an essay he wrote for *Scientific American*:

Paul had had a massive stroke, one tailored to his own private hell. The author of more than 50 stylishly written books, a master of English prose with the largest working vocabulary I’d ever encountered, a man whose

life revolved around words, he had suffered brain damage to the key language areas of his brain and could no longer process language in any form. Global aphasia, it's called – the curse of a perpetual tip-of-the-tongue memory hunt. He understood little of what people said, and all he could utter was the syllable “mem.” Nothing more.

She went on to describe those days with global aphasia in her own book, *One Hundred Names for Love*:

Taking words from Paul was like emptying his toy chest, rendering him a deadbeat, switching his identity, severing his umbilical to loved ones and stealing his manna.

That love is what led him to find his way back to writing.

Writing Again

West did intensive speech therapy following the stroke to get back some language. His wife knew how important writing was to his happiness, and she helped him write novels again by having him dictate his thoughts. She led him to fill in the missing words until he was strong enough to write on his own. Five years after his stroke, he published that book as well as three other self-published books before his death in 2015.

As his obit explains:

Before and after his stroke, Mr. West was intoxicated with words, a sworn enemy of minimalism in fiction and a passionate advocate of extravagant language.

Words meant everything to him, and his wife helped him find them again.

Promise Me, Dad: Joe Biden, Caregiving, and Aphasia



Joe Biden understands aphasia and has been a tireless advocate, spreading awareness through speeches and his new memoir.

For the next few weeks, we will be discussing *Promise Me, Dad*, Joe Biden's account of balancing his duties in office, the decision to run for president, and his son, Beau's, final year of life. Biden speaks candidly about Beau's struggle with aphasia due to a brain tumor, and his frankness has helped spread awareness about aphasia to the general population.

The Bidens understand aphasia. They have seen aphasia up close and personal; the experience of someone they love.

We've chosen this book because it is a perfect segue into our committed support for caregivers. Joe Biden writes eloquently about this position: the high points and low points of helping a loved one struggling with language.

But it is a different sort of book, not just because it covers a lot of political ground that we won't discuss as part of this book club selection, but because

we know the ending of the story, and it is not one of recovery but rather one of loss.

Biden's caregiver journey may be different from other stories we've read so far about life after a stroke, but there is a lot that can be gleaned by reading the words of someone who is unapologetic in honoring deep feelings and letting love guide their decisions.

The Title

The title of the book comes from a promise that Beau begs his father to make. On page 201, Beau is beginning to accept the possibility that he may die. He asks his father to make a promise, one that is impossible to keep and impossible not to follow: That life will continue regardless of what happens.

“But you've got to promise me, Dad, that no matter what happens, you're going to be all right. Give me your word, Dad, that you're going to be all right. Promise me, Dad.”

“I'm going to be okay, Beau,” I said, but that wasn't enough for him.

“No, Dad,” he said. “Give me your word as a Biden. Give me your word, Dad. Promise me, Dad.”

I promised.

Beau isn't the first person to ask his caregiver to promise that life will not fall apart if the worst happens. In this case, Beau is referring more to his cancer, but it's a promise that people after a stroke or traumatic brain injury or primary progressive aphasia have asked of their caregiver, too.

Promise me that this won't be it. That this won't define everything that comes afterward.

It's what Beau needs to hear in order to keep fighting his fight, and it's a promise that serves as a guide for Biden's caregiving more than foresight into

the future. When you know the end point is that you need to be okay, you make all decisions beforehand with that frame.

We hope that you'll join us for this latest installment of our online book club.

Kimberly Williams-Paisley and Primary Progressive Aphasia



Kimberly Williams-Paisley was beaming at the altar, marrying the love of her life after playing a bride in the movies. She had pulled off the wedding of her dreams, surrounding herself with the people she loved, including her mother. She had no clue how life was going to change in the years after that wedding.

Welcome to the first post in our new book club selection: Kimberly Williams-Paisley's book about her mother's primary progressive aphasia called *Where the Light Gets In*.

First Moments

There may have been moments beforehand, and there were certainly moments after, but the first time primary progressive aphasia made its presence known to Kimberly Williams-Paisley was at her wedding.

Her mother was tasked with reading a poem, and she stumbled over the title and words as if there were typos on the page and she was frustrated to get an imperfect copy on such an important occasion.

This is how the book opens, marking the before and after. The before where her mother was an adventurous, no-nonsense sort who nudged her children to explore the world and everything it contains. And the after where her mother was unable to find the words to understand herself or that world around her.

Primary Progressive Aphasia

It's emotional to mark the moment where everything changed. Of course, with primary progressive aphasia, it wasn't the abrupt type of change that occurs with a stroke or traumatic brain injury. It was a slow loss that required the family to keep coming to terms with the situation again and again.

For the next weeks, we'll be exploring this story of primary progressive aphasia, loss, and love. We hope you'll grab the book from your library or bookstore, and join in the discussion. We want to hear your primary progressive aphasia story, too.

Unlocking the Future of Aphasia Treatment by Studying the Brains of Babies



Is the key to treating aphasia in adults to look to the brains of babies? Researchers at Georgetown University are studying how brains of babies adapt after a stroke. Researchers discovered that their brains make up for the damage by using a different part of their brain to process language.

Young Brains

Brains of babies have high plasticity, which means that they can adapt and change as they grow. Researchers looked at 12 people who all had strokes right before or after birth. All 12 participants in the study currently ranged in age from 12 – 25 years old. While they may still have physical indications of their stroke, such as a limp, they all had sufficient language skills.

Elissa Newport, who led the research, explained why this happens:

These young brains were very plastic, meaning they could relocate language to a healthy area, (but) it doesn't mean that new areas can be

located willy-nilly on the right side. We believe there are very important constraints to where functions can be relocated. There are very specific regions that take over when part of the brain is injured, depending on the particular function.

In other words, locating which region of the brain takes over when the language centers are damaged is the key in treating adults after a stroke.

Adult Brains

Newport applied their findings forward:

They are also carrying out more research into the molecular basis of plasticity in young brains in order to try and work out how to “switch on” plasticity in adults who have suffered a stroke or brain injury.

Switching on this plasticity may involve creating a drug that could revert the brain to a “child-like state” in terms of adaptability. Doing so could “rewire” the brain:

Adults who have experienced a stroke may one day be able to take a drug to help their brain “rewire” itself so that tasks once carried out by now-damaged areas can be taken over by other regions.

This idea has already been picked up by other researchers. The Guardian reported on additional research out of Harvard:

Takao Hensch, a professor of molecular and cell biology at Harvard University, who was also speaking at the meeting, said that his research in mice showed that by blocking certain molecules in the adult brain that hinder plasticity, it was possible to increase its ability to rewire.

Hensch is already working with drugs that exist to see if they can be applied to creating this neuroplasticity:

Hensch is already working on possible therapeutics. He said that among the possibilities, drugs routinely used for mood disorders might show potential to increase plasticity in adults. His previous research has

shown that adults given the drug valproate, used to treat bipolar disorder, regain the ability to learn perfect pitch – a skill that is usually only seen in children who began studying music before the age of six.

These all may be small, initial studies, but the findings are exciting news and point toward future ways forward in treating aphasia.

Wearable Electronics and Aphasia



Wearable electronics are any technology that can be worn on or implanted in the body, ranging from smartwatches and activity trackers (such as FitBit) to hearing aids. Scientists are turning their eye to creating wearable electronics that could aid in recovery after a stroke. One of these inventions is a throat sensor that could be a game-changer for treating aphasia.

Throat Sensors

John Rogers, a professor in Northwestern University's engineering department, is working on an electronic device that adheres to the skin with a sticker. As the person moves through their day, it sends back important information. In this case, it's tracking the patient's ability to swallow and their speech patterns.

A Chicago news station reports that "the tools traditionally used by speech-language pathologists to monitor patients' speech and swallowing, such as microphones, can't distinguish between patients' voices and ambient noise."

Moreover, these sensors could give speech therapists accurate information, removing the need for patients to track their progress:

The throat sensors also allow clinicians to track how frequently patients with aphasia are talking and use that data to set goals. “Not only are we as therapists getting the feedback, but the patients can get feedback as well ... and then they have goals to strive for,” said Cherney. “It can be very motivating for them.”

That feedback is more objective than subjective, giving patients concrete evidence of their progress and rate of recovery.

Real World

This invention is important because it takes patients out of the speech therapy world and into the everyday world, which is where that progress counts the most. By wearing this trackable device, speech therapists can measure speech abilities when patients are relaxed, hanging out with friends or going about their lives at home. Information can be gained over a long period of time because it's not reliant on office visits.

As one of the researchers points out:

“Talking with friends and family at home is a completely different dimension from what we do in therapy,” said Cherney. “Having a detailed understanding of patients’ communication habits outside of the clinic helps us develop better strategies with our patients to improve their speaking skills and speed up their recovery process.”

Moreover, speech therapists can use the information to pinpoint the best times of day for therapy, or better understand how an individual uses language throughout the day.

The Psychological Effects of a Stroke



A new study out of the Cleveland Clinic is looking at the psychological effects of a stroke.

The physical effects are well-documented. While every stroke is different, there are certain shared physical symptoms for a stroke. The American Stroke Association brings those symptoms together with their helpful acronym--F.A.S.T.--which can be used to know when someone is having a stroke. Face drooping, arm weakness, and difficulty speaking are all physical signs of a stroke.

But what about the psychological effects afterward? How do strokes affect people emotionally?

Impact of Stroke Damage

Irene Katzan from the Cleveland Clinic looked at how people's lives changed after a stroke. "The three aspects of health that were most impacted in patients who have had a stroke are physical functions, cognitive abilities – their ability to think through things – and their satisfaction with their roles in society," said Dr. Katzan.

The study questioned 1,195 people who had experienced an ischemic stroke to discover what was different after they returned to their day-to-day lives. The study aimed to uncover the hidden quality-of-life impact of strokes. Moreover, it provided valuable information for caregivers helping a loved one after a stroke to better understand what may be happening emotionally.

“For people with more disability, what bothers them the most? Problems with sleep? Depression? Fatigue? Not many studies have asked people how they feel about these problems, and we doctors have often focused just on physical disability or whether they have another stroke,” [Katzan] says.

The study reported:

While 63 percent reported greater physical challenges following a stroke compared to the general population, 46 percent reported having increased difficulty with thinking. Likewise, 58 percent reported greater dissatisfaction with their ability to participate in social and work-related activities.

As Katzan points out, these findings are only a first step. More information is needed in order to best understand a stroke’s impact on emotional health. This study opens the door for more research to be done looking at how to ensure that people still feel socially connected following a stroke. Life changes following a stroke, which means that all aspects of a person’s life need to be addressed, not just the physical effects.

New Research on Treating Aphasia Examines Language Comprehension



New research out of Arizona State University is taking a look at whether we've been thinking about things backward when it comes to aphasia. Is it better to first focus on speaking or understanding? A doctoral student has been awarded a grant to study whether changing the way the speaker conveys information can bring about better understanding. This could lead to better speaking down the road for people with aphasia:

With that premise in mind, speech and language researchers at Arizona State University's College of Health Solutions are testing an innovative way to help people who struggle with communication following a stroke. Rather than focusing on a patient's ability to speak, they will instead conduct research to determine if the way speakers talk can improve a stroke patient's ability to understand.

The researcher, Arianna LaCroix, focuses on one piece of communication at a time, starting with comprehension. The idea is that it may be easier to treat aphasia once it's confirmed that a person understands language.

Possible Treatment

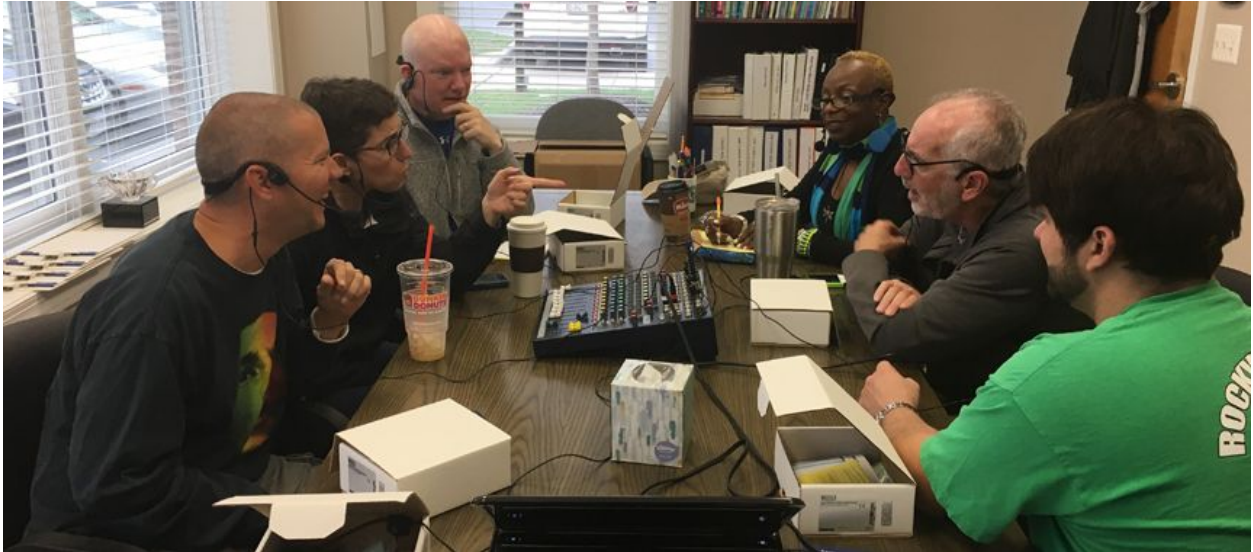
LaCroix is beginning by observing the effects of tone. Her theory is that some people will benefit from over-pronunciation while others will be better served by a lack of inflection. The option depends on the type of stroke and damage:

LaCroix theorizes that speaking in an exaggerated way will help patients whose attention span is better, while those whose memory is better will understand more if they are spoken to in a flat, even tone.

The person's strengths will guide and shape their speech therapy once comprehension is established.

This research has just begun, so we're still two years away from seeing whether or not these hypotheses hold. But it's exciting to see a different approach to treating aphasia and imagine the possibilities.

Listen to a Great Podcast About Aphasia



Two episodes. That's all I had to listen to The Slow Road to Better podcast before I felt as if I was part of a conversation between old friends. Each subsequent episode feels like I'm hanging out with people I know and like, grabbing coffee and speaking about aphasia.

Feel Like You're Part of the Conversation

The podcast, produced by the Stroke Comeback Center, just aired its 33rd episode, but it's worth going back through the archives and jumping into past topics. Each episode has the same center members speaking on a theme or about their lives. You get to know each member; their personal progress and life beyond aphasia.

The Purpose of the Podcast

The point of the podcast is three-fold: awareness, inspiration, and practice. The podcast aims to explain aphasia to the greater world by telling individual stories. At the same time, it provides much-needed inspiration for people at

the beginning of a journey. The participants are at various points of recovery after strokes or traumatic brain injuries, and they present a wide range of possibilities after a life-changing event.

The podcast also gives participants speaking practice. Each episode is a round table conversation, guided by a speech therapist. Episode 27 (“Celebrating Life”) has the participants explaining how aphasia impacts their ability to mourn. When funerals and wakes have people talking about a loved one, how do you participate in the mourning process with aphasia? In Episode 28 (“Setbacks and Resiliency”), the participants discuss how they define and move past a setback.

Every episode is fascinating and addresses common situations for people living with aphasia. Moreover, it’s a warm group who clearly enjoys one another’s company.

The best part is that the podcast is portable; download it to your phone and listen in the car or at home. You’ll feel like you’re part of a conversation where everyone understands.

A Virtual World for People with Aphasia



What if speech therapy involved hanging out at a virtual tiki bar or taking the TARDIS (any *Doctor Who* fans out there?) for a spin? A new therapy tool called EVA Park, which is currently being tested in the UK and will launch this summer, will do just that. Participants can fly through blue skies or explore grassy islands, conversing with other avatars. It's a virtual world, made specifically for people with aphasia.

An Exploration Tool

A recent study out of the University of London “found that time spent in a virtual world called EVA Park can improve the communication skills of people with aphasia, a communication condition which results in loss of speech and difficulty with communication following a stroke.”

It does this by providing an interesting virtual setting that people want to spend time exploring. Therapists can use the tool to encourage speech, having players describe what they're seeing or doing, or practice holding different types of conversations. Aphasia support groups can also use the tool to facilitate conversation between members meeting up in the virtual world.

How Does it Work?

The tool isn't currently ready for use, but in the future, users will be able to do the following things, according to the site's FAQ page:

- Walk or fly around to explore the environment.
- Touch or sit on things to interact with them.
- Talk with other people in the world.
- Practice speech therapy tasks, or work toward functional goals.
- Have a group discussion.
- Dance, swim, or relax.
- Watch videos.
- Meditate on a giant rubber duck...

In other words, they can practice ordering food in a virtual restaurant and then smoothly move to another part of the environment to practice holding a meeting in a boardroom. Participants can experience diverse real-life situations in the virtual world without needing to move from their living room.

While that last one — meditating on a duck — may sound a bit odd, it's the novelty of the environment that keeps people engaged. When people are engaged and actively exploring, they can relax and not focus on finding words.

Mood Matters

Mood matters when it comes to the effectiveness of speech therapy. Treating aphasia takes work, and this tool aims to make speech therapy enjoyable. By turning therapy into play, participants may want to spend more time working hard at regaining language.

Moreover, the study found that EVA Park impacted mood:

The new findings from the study also show that EVA Park users frequently experience laughter and enjoyment, which may help to counter some of the negative emotions strongly associated with stroke,

such as depression, which affects up to 60 percent of people with the condition.

This finding is particularly interesting because people often experience a diminished social network post-stroke. This tool could help build new friendships between others in a similar situation, fostering understanding and camaraderie.

What is Primary Progressive Aphasia?



This post is part of a larger video series that contains numerous short films about different types of aphasia and best communication practices.

You asked us for more resources involving primary progressive aphasia (PPA), and we listened. Our current book club selection is *Where the Light Gets In* by Kimberly Williams-Paisley, a moving account of her mother's experience with PPA. We recently profiled Terry Jones as part of our ongoing series of celebrities with aphasia. And now we're kicking off our new video series with a brief explanation of PPA:



Our New Video Series

The video series has been a long time in the making, and we have several that we'll be uploading over the next few months. We tested the waters with a short video for Aphasia Awareness Month:



The success of that video convinced the NAA to put the finishing touches on a series of short videos meant to educate the general public or the newly diagnosed. We thought it was important to start with primary progressive aphasia, not just because it is often misunderstood but because there are so few resources available for this particular type of aphasia.

Thank you for helping us share these videos and get them out to the general public, either through social media platforms, direct email, or clinic newsletters. As we said at the end of our Aphasia Awareness Month video, we could all use more understanding in this world.

How to Be a Good Question Asker and Answer Keeper



Knowing the right questions is a skill, and it's one that all caregivers are expected to suddenly acquire the moment they enter their role. But how can you learn to be an expert question asker? This guide will help you not only to know how to ask questions so you can gather information but also record the answers so you can find it again.

Get the Tools

Few people come prepared with note taking supplies the moment after a stroke or a traumatic brain injury. Of course, mobile phones have a notetaking capacity. If you don't have a smartphone, ask hospital personnel for a paper and pen so you can record the doctor's notes. You can also use the voice memo function on your phone to record an audio note if you can't take down the words quickly.

After the first day, or if it's not an emergency situation, carry a dedicated spiral notebook with a pen. This will be your note taking space. It's also a space

where you can tape in pamphlets, receipts, or handouts so you can find them again.

How to be a Master Answer Keeper

Each day or appointment, you'll start by writing the date at the top of the page. Next, you'll list any questions you need to ask. Finally, you'll create a list of action items. Draw an empty square next to each task you need to do (such as set up an appointment, fill a prescription, or remember to bring a sweater because the waiting room is cold) so you can put a checkmark in the box once the action is completed.

The bottom of the page is where you'll record any notes from that day.

The next day or appointment, you'll start a new page, but you'll rewrite any questions or actions items that were left unasked or undone from the day before. That way, nothing will slip through the cracks.

Learn When to Ask

Your relationship with your loved one's doctors, nurses, or speech therapists are like any other relationship. It will take time to learn each other's patterns. Does the health specialist or speech therapist react well to getting all the questions at once instead of scattered throughout the appointment? Questions at the end of the appointment? Questions at the beginning?

Once you know, tailor your question asking to match the other person's style to best get the information you need.

Give Them a Heads Up

Telling people that you have questions and how many goes a long way. If you begin the appointment by telling the person that you're going to ask them three questions, you've set the expectation that three questions are coming their way. If they forget and start to leave the room, you can remind them that you still haven't gotten your questions asked and answered.

It can even help to hold up the correct amount of fingers as you tick off each question so they can anticipate how many more there are to go.

Of course, this means reducing your question list to the most urgent questions. A doctor, nurse, or speech therapist probably won't have time to answer a dozen questions.

This is where writing them down ahead of time is a vital part of the process. Not only does writing them down ensure that you won't forget anything, but it gives you a chance to rank or combine questions so you address the most important ones first.

Getting Information from Reluctant Answer Givers

There will be times when health specialists or speech therapists will not be able to answer your question; either because they don't know the answer yet or because it isn't information they're in a position to give. It can help you a lot if you inquire when they will be able to give you an answer, or a person to contact who will be able to give you the information.

Some people are always in a hurry, and it's okay to politely point out your needs, too. Set up a question asking appointment separate from the "care" appointment or ask if you can reserve the last five minutes of the next session/appointment for questions.

Some specialists may be willing to answer quick questions via email rather than using face-to-face time, so inquire which medium would be most helpful for the other person to get you the information you need.

We rolled out four posts directly for caregivers for Aphasia Awareness Month. This was the first one in the series.

Turning People with Aphasia into Teachers



People with aphasia may make the best teachers when it comes to aphasia. The Waterloo Wellington Regional Aphasia Program in Canada is pairing people with aphasia with doctors, nurses, and speech therapists for conversations to promote understanding. It ensures that medical personnel can learn and people with aphasia have the space to express themselves at the same time.

The Main Message

The main idea the group is trying to get across to medical personnel is that aphasia may impact communication, but it doesn't impact intelligence. They need to understand that the adult in front of them is still an adult. The Canadian Broadcasting Company wrote about the initiative recently, following the story of one participant, Steve Goff. His wife, Carol explained that "because her husband couldn't speak after the stroke, people would often treat him like a child – even one hospital nurse."

Steve Goff offers this eye-opening question for medical personnel: "Imagine if the last sentence you say tonight is the last full sentence you will say for the

rest of your life.” By placing medical personnel in the shoes of people with aphasia, they can better understand what people with aphasia need and communicate accordingly.

Why Educate Medical Personnel

It’s not just about dignity. It’s also about educating medical personnel so they can best care for people with aphasia. They need to know how to get important information from the individual as well as impart their treatment plan.

People with aphasia, especially those further along their treatment plan, are in a good position to express how to best communicate with people with aphasia. For instance, allowing the person with aphasia to speak for themselves as much as possible. Making sure they understand the question or any information you’re imparting about their treatment plan. One great analogy the group makes is that just as people with mobility issues need wheelchair ramps, people with aphasia need communication ramps; in both cases, when modifications are made, it allows the person to participate fully in getting around and understanding.

As Carol Goff states, “You don’t have altered intelligence, you just have to find a different way to communicate.”

It’s an interesting program. What would you want medical personnel to know about aphasia?

Using Music to Treat Aphasia



The San Francisco Chronicle recently had an interesting article about Mindy Rowland using music to find her way back from aphasia. A ski accident four years ago left her with a concussion and aphasia. She couldn't find words anymore, and she had to leave her job because communication was too difficult. She was in speech therapy and seeing doctors when she had a breakthrough, courtesy of Elton John.

Speaking Through Music

Her husband left on music and came home to find “Mindy singing along to Elton John’s ‘Tiny Dancer.’ At this point, Mindy could hardly string words together, but for some reason, she could sing.” It’s something we’ve spoken about before with Randy Travis and the movie *Still Sophie*.

The article states:

Music therapy has been used to treat people with traumatic brain injuries in many cases, for people who suffer strokes or car crashes or other situations that cause trauma to the brain ... Once Mindy started

singing, she saw similar strides. Stew said her speaking is 10 times better now than it was before she started singing.

Mindy performed at Folk Fest, singing the songs “seamlessly, never needing to pause to remember a line.” It’s a place where the words still come fluidly.

Why Music Works

There has been plenty of research done in using music to treat aphasia. One theory is that because music crosses the hemispheres of the brain, it creates new neural pathways for language. In addition, music is ripe with repetition and patterns, two things that aid memory.

Is music therapy right for you? There are plenty of ways to formally and informally engage with music. Some clinics may offer melodic intonation therapy (MIT) or neurologic music therapy (NMT). You will need to inquire with individual local practices if they provide music therapy.

But while you’re waiting, try throwing on familiar albums and seeing if you connect with music in the same way. We hope that melodies help you find words again.

Do you find it easier to sing than speak?

Using Toastmasters to Work on Speech After Aphasia Treatments



You can find Toastmasters clubs across the United States. The public speaking club helps members hone their speaking skills, getting them in front of crowds to deliver their thoughts. Many people use Toastmasters to get over performance anxiety. But a Minnesota newspaper recently covered a story about a man who used Toastmasters to help him gain speaking confidence after aphasia.

Toastmaster Meetings

An aneurysm removed Joe Oppold's ability to speak. Intensive speech therapy brought it back, but he still wasn't feeling confident with his public speaking skills. He joined Toastmasters in order to practice speaking in front of a supportive group.

At meetings, participants deliver short speeches in front of the other members. Not only does this give them performance experience, helping them get comfortable to speaking in front of a small crowd, but the feedback is invaluable. Other members have the chance to tell you how they processed

your speech. You learn by doing and get supportive suggestions to help smooth out rough areas of your speaking skills.

It's a space for people far along their aphasia journey looking for continued improvements after speech therapy ends.

Toastmasters and Aphasia

Oppold isn't the only person with aphasia using Toastmasters to help smooth out their speaking skills. The University of British Columbia holds a program once or twice each semester where they bring a Toastmaster to their group to give tips. The Toastmaster doesn't just give tips for getting out words. They make recommendations by looking at all facets of speaking – from intonation to body language.

Boston University has an aphasia group modeled after the Toastmaster format:

This group will focus on communicating fluently and concisely when you are speaking in stressful situations such as when you meet new people, are speaking to a large group, or are using the telephone. This group is modeled after the Toastmasters Club, whose philosophy is to learn by doing in a supportive environment.

And there has even been research into using the structure of Toastmasters to treat aphasia.

Do you have any experience with a Toastmasters club?