2017

National Aphasia Association

BEST OF 2017

Dear Friends,

2017 is coming to a close. Before we look ahead to the exciting projects we're planning for 2018, we wanted to take a moment to reflect on everything we learned and discussed this past year.

What will you find in this booklet? Helpful tips such as how to speak with children about aphasia or turn your e-books into audio books. We included our four-part series on the exciting Netflix documentary, *My Beautiful Broken Brain*, following a woman trying to regain her speech after a stroke. You'll also find two examples of our ongoing series profiling famous people with aphasia. It's hard to feel alone when you know that people as diverse as past presidents to movie stars have had the same speech struggles.

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 2017. And recharge because we need your energy to make our 2018 outreach illuminating and helpful for all.

Warmly,

Melissa Ford
Editor
National Aphasia Association

Talking to Kids About Aphasia

It's understandable for kids to be confused by aphasia because aphasia is also difficult for adults to understand. How do you convey that the person is still the same on the inside though they may have trouble expressing themselves verbally on the outside? We've pulled together some ideas to get this conversation started.

Just the Facts

There are so many unknowns with aphasia and no one can predict the future, so stick to the facts you know in the moment. Additionally, aphasia presents differently in each individual, so make sure you only state the problems the person is currently experiencing. Explain that aphasia affects a person's ability to speak, read, and write, and that they may or may not have difficulty understanding someone else's words.

You can open your conversation about aphasia by talking about the underlying cause such as a stroke or head injury. Make sure your child can ask questions and express their fears so you can reassure them.

Still the Same Inside

One important point to make is that the person with aphasia is still the same person they were before experiencing communication issues. Aphasia affects the ability to speak and write but not the person's intellect.

Choose Good Activities

There are plenty of activities — with or without words — that can fill a visit. Arts and crafts, movies, looking at photos together, taking a walk, reading aloud to one another, and playing board games are all good ideas. Kids may enjoy being a special helper with the iPad while using apps for aphasia therapy.

The most important point is to spend that time together. Too many people with aphasia feel frustrated by a loss of social interaction. Make sure you set up plenty of unrushed visits between the child and the person with aphasia.

Be a Helper

Kids love to know how they can help, and you can give them concrete communication tips. Explain that the person may need for the child to slow down their speech, use short sentences, or repeat their words. The child also needs to understand that they need to give the other person time to form their words. Just as kids don't like it when adults speak for them, adults with aphasia want kids to give them a chance to speak their own thoughts.

Kids can tap into their creativity and find new ways to communicate, such as pantomime or using pictures to express ideas.

Remind your child that people get frustrated when things are hard, and while they may witness that frustration, it isn't directed at them. People with aphasia may also get tired more easily due to underlying causes or the hard work of negotiating communication issues. Knowing these two possibilities can help the child understand a moment of frustration or having to end an activity early.

How to Turn e-Books into Audiobooks

Audiobooks are a necessity for many people with aphasia, but audiobooks are also expensive to produce. In many cases, audio counterparts are not made for print books until months after publication release, and in some cases, not at all. Luckily, there are apps out there that can turn any word-based document — including ebooks and PDFs — into audiobook equivalents.

Start With Siri

Apple's virtual assistant, Siri, is capable of reading any text aloud. To access Siri's read-aloud capabilities, navigate to Settings > General > Accessibility. This is where you'll find dozens of options you may not have known existed on your iPhone or iPad.

For instance, you can turn on options that allow you to do the following:

- Highlight a selection, tap the Speak menu that pops up, and hear Siri read it aloud.
- Open an ebook, drag two fingers from the top of the screen toward the bottom, and access a menu that will have Siri continuously read the book until she is told to stop.
- Set the speed at which Siri reads.

- Change Siri's voice and accent.
- Read aloud anything you type into your device.

Find Apps that Read Aloud

No Apple device? No problem — there are plenty of apps that will read aloud text from the screen. Search for text-to-speech apps in the device's app store. Some examples:

- Talk
- AIReader
- Speak It
- NaturalReader (Android)
- NaturalReader (Apple)

Computer Resources

There are also resources for your computer if you want to turn your desktop into a spoken-word machine. Natural Reader also has a computer version that can be downloaded for Windows or Mac. You can try the free resource before downloading by pasting text into the box on the screen. After the software is downloaded, it can read PDFs and ebooks, but it can also read web pages and emails.

Aphasia Hacks

Aphasia hacks. They're the little things you do to navigate the world with aphasia or help someone else navigate the world with aphasia. They're the tricks that you have up your sleeve to communicate. The things that make a hard situation a little easier. We've compiled a few of our favorites below, but we want YOU to share your favorite aphasia hacks, too.

Carry a Card

Some people carry a card explaining they have aphasia, but it's equally helpful to carry a card with the most commonly-needed phrases for while you're out and about. Think about things you'll want to communicate while you're at home with all the time in the world, such as instructions for a hairdresser or what you want to order at a restaurant, and write it down. Bring the card with you in case the words don't come while you're in the moment.

Draw a Picture

They say a picture is worth a thousand words, and an image can certainly help you convey an idea when you're struggling with words. Give this communication tool a bit of artistic flair by using a sketch pad and a special marker. Carry it with you and you'll always paper at the ready.

Use humor

Joan Pfeiffer wrote on Facebook that "one of my favorite sayings when people realize my speech sounds foreign and asks where I am from is: 'I am from Aphasia and I speak Aphasian'." Using a joke not only explains a difficult situation while making the other person feel at ease, but it generally makes the conversation flow better once everyone understands.

Write it Down

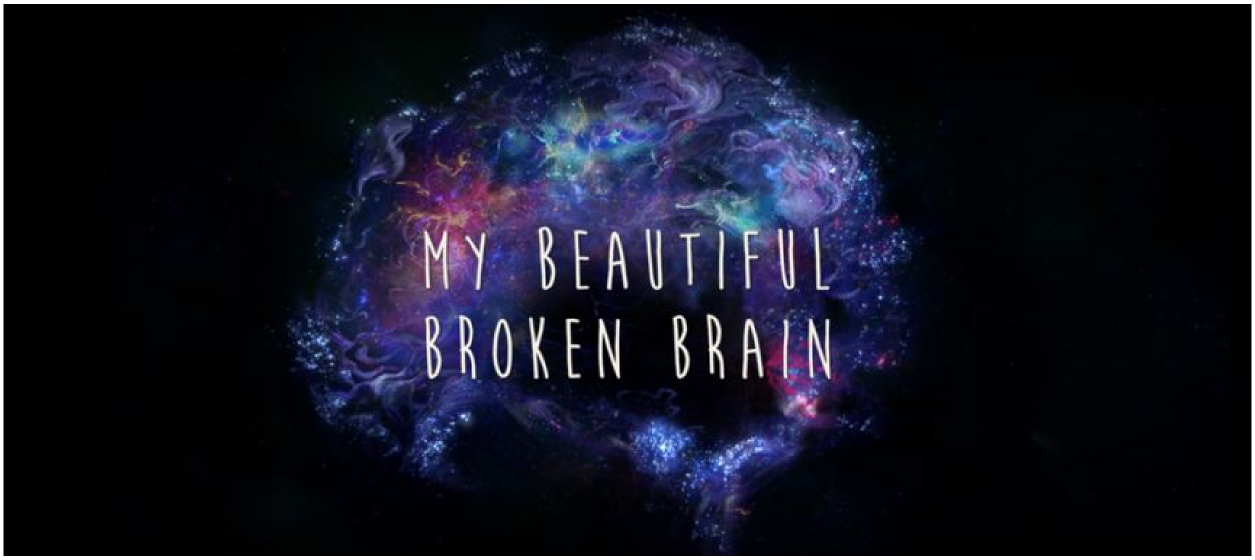
Lauren Marks writes down every word she suddenly remembers, keeping a journal of reclaimed words. She writes on page 31 of her memoir, *A Stitch of Time*, "In my journals, a discovered word was a sacrament — a thing I could write. And if I could write the thing, I could read it. And if I could read the thing, I could often say it."

This process brings her back to the old words she used to know, one at a time.

Circumlocution

Circumlocution is saying all the words around the unknown word. For instance, if you can't remember the word for the object, you may describe it using all the words you do know in connection to the missing word: fruit, food, eat, red, juicy, sweet... APPLE! Even when you don't remember the missing word, the other person can help supply it because they figure it out from all of the great clues you give based on everything you know about the object.

The Stuff We Take for Granted: My Beautiful Broken Brain, Part 1



Words are something we take for granted. But all of that changed when Lotje Sodderland woke up in her apartment, disoriented, ill. A headache made it difficult to think. Impossible to speak. She left her apartment and stumbled into a nearby hotel, where she collapsed. Lotje was having a stroke.

This is the emotional opening of Netflix's documentary, *My Beautiful Broken Brain*, a culmination of Lotje's efforts to understand her new way of seeing and interacting with the world with aphasia. We're unpacking this wonderful documentary in a series of four posts.

Waking Up

She explains in an article she wrote using Siri for the Guardian that when she woke in the hospital, she was unable to reassure her family and friends. She recognized her brother but explains: "When I woke up, I knew who he and my mother were – but I couldn't be sure the familiar stranger inhabiting my body was me."

> My brother and mother loomed down at me, and a funeral line of friends came to the ward. They looked at me with sad eyes; I wished I could say something to assuage their sadness. There is no silence more resounding than that of a cognitive communication malfunction.

That communication malfunction is the focus of the film.

Unable to Speak or Read

Lotje describes her inability to speak as “beyond terrifying.” While she can’t comprehend or produce language after the stroke, her brain begins to find new spoken language routes a few weeks later.

For instance, with practice, she reaches the point that if someone says a word, she can repeat the word. But despite repeating the word several times, she can’t hold it in her brain. She is retaught the word “record,” and repeats it over and over again. Yet each time she looks at the object, she asks the videographer how to say the word.

She is candid about her recovery, admitting “I didn’t think I’d have trouble with the word ‘the’.” She struggles with retaining information and remembering the order of things. Prior to the stroke, she was a writer and reader, working at an advertising agency. After the stroke, she can’t read and admits as she looks at an Internet page that “it’s gobbledygook.”

The Stuff We Take for Granted

What she lost was “the stuff we take for granted,” her brother says in the film. In exchange for her words, she gains a heightened sense of reality. She experiences colors and sounds differently, and everything is intensified.

Living Situations: My Beautiful Broken Brain, Part 2

Lotje's living situation had to change after her stroke. She went through a period of time when she couldn't take care of herself. She understood that she needed the help, but she still had big feelings about losing her autonomy.

Revisiting Home

Lotje tried going back to her apartment, the scene of her stroke, but she felt physically ill being back in the space. She described it as being back in a nightmare. She couldn't remember all the details from the night of her stroke, but being in the space triggered enough memories to make her dizzy.

Moving Day

Instead, Lotje moved back in with her mother. In an article in the *Guardian*, Lotje unpacked how she felt about leaving the hospital:

> The hospital's language therapist had promised to get me discharged as soon as possible, assuming I was eager to go home. But I felt anxious

> about leaving. It was decided I would go and live with my mother. A formidable Baltic nurse ripped the metal staples from my blood-caked scar. The taxi slid over the speed bumps on the way home; it felt as wild and frightening as a lifeboat on a stormy sea.

In the film, she sighed that she was 34 and living with her mother again; her first time since moving out at 18. She stated, “I feel like a baby, but I’m a grown-up.”

Someone Else’s Property

Later in the film, she returned to the hospital for in-patient therapy. She bluntly explained that being in the hospital felt like people were hijacking her life.

In the hospital, she felt like property more than a person. She was sick and tired of other people taking over her plans, telling her what she needed to do and when. She had a hard time adjusting to the hospital’s schedule. This stemmed from the fact that she was at a stage of life where she should be able to take care of herself but couldn’t. That thought brought out a lot of frustration.

Lotje had big feelings about her living situation, understandable considering that aphasia upended her life and changed everything.

Recording Your Life, My Beautiful Broken Brain, Part 3

Lotje became obsessed with recording her recovery after the stroke. She filmed others during her career, so it made sense to turn toward this familiar medium while she recovered. Recording herself became the path to finding Lotje again.

The Importance of Hitting Record

Lotje admits that she is obsessed with recording her recovery because she's worried about forgetting it. Because she can't keep details in her brain, she wants them on film so she can review and remember.

Moreover, she is trying to make sense of the world around her. Everything feels as if it is trapped in a dream-state, and she can't keep thoughts in her brain. Recording her world means that she can rewatch her day and sometimes find understanding in those moments of reflection.

Connecting with the Filmmaker

Lotje discussed connecting with Sophie Robinson, her co-director and the producer of *My Beautiful Broken Brain*, in an article last year in *Vogue*. They met once during a project, and Lotje remembered her while she was still in the hospital.

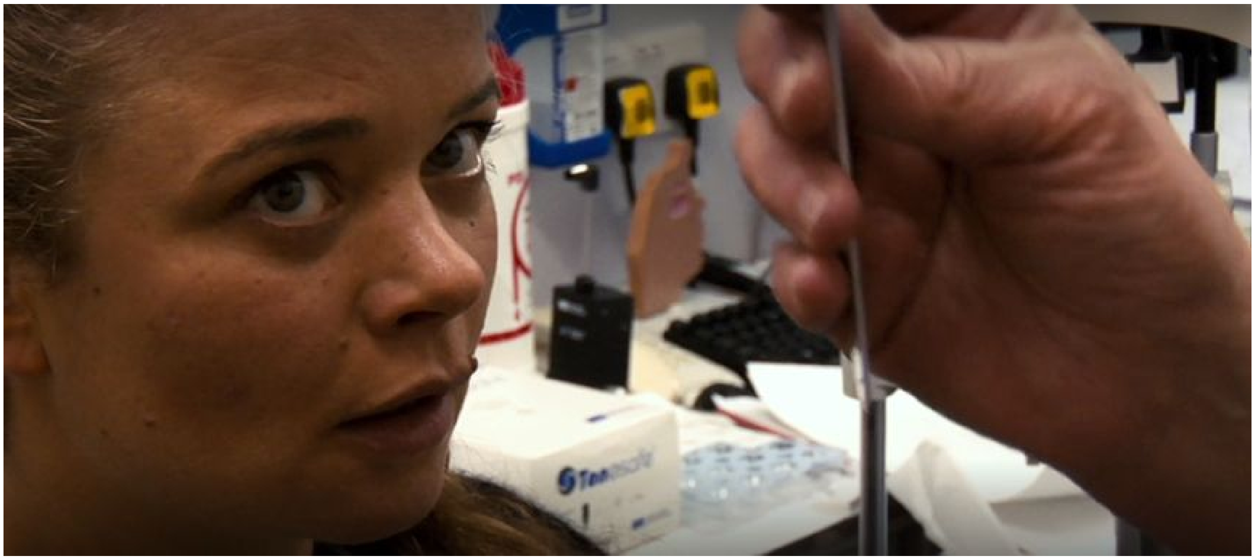
> Our relationship professionally really developed once I'd had the stroke. I was in hospital, unable to speak or communicate. But I had this desire to document everything—a sense of wanting to make a documentary, but not in a very logical, coherent way. At some point, I was able to communicate with my brother that I really needed to get in touch with this woman. I'd forgotten her name, and I couldn't really explain what I wanted. But I used diagrams and drawings and eventually he understood.

Lotje recorded some of the footage for their film with her phone, while Sophie recorded the rest.

> In the first three or four months, I was recording everything that was happening through the day, because I was so fascinated by it and because I had problems with short-term memory. I didn't want the experience to pass through me.

Recording herself ended up serving two purposes: providing Lotje with a means to remember and reflect, but also a film that provides a window of understanding into the world of aphasia.

Being Okay with the Difference, My Beautiful Broken Brain, Part 4



Lotje tries many things to get back to her old style of communication, including in-patient therapy and a medical trial. She ultimately comes to embrace the way things are, but it takes her a long time to become okay with her new status quo.

Therapy

Lotje reluctantly checks herself into an in-patient program for three months to try to regain speech and language comprehension skills. She can't sift information. She can't sequence her thoughts.

She leaves the hospital willing to try almost anything once she realizes she may never be the same again. She takes part in a brain stimulation study to see if she can jump-start her language abilities. They shock her brain while she does intensive speech therapy at the same time. She describes the tingling in her skull as "stinging nettles." While her recognition of words improves, she also thinks of herself as "an innocent guinea pig."

Her therapy ends when she experiences a seizure that undoes some of her progress. Once she is told that 1 in 5 people will have a seizure in the year after a stroke, she feels a sense of defeat. She explains that if anything can happen to anyone at any time, it's "better not to have faith in anything."

Finding a New Way of Looking at Things

Lotje finds a kinship with David Lynch's view of the world through his films. Later she reads a magazine article about him with her therapist, and she connected her need to record her recovery with this new, visual way of interacting with the world.

She moves away from words towards moving pictures. Lotje explains this process in a *Vogue* article:

> Now I still tell stories, but I tell visual stories. I've got a really nice camera, and I make documentaries. I earn a living that way, but I no longer read and write. I don't use words in the same way that I did before. The world is much more visual and much less cognitive.

Getting Better Isn't a Moment

It takes Lotje awhile to come to this realization, but she ultimately decides that recovery isn't a moment in time. It isn't a day where a person wakes up and all is back to normal. Recovery is about coming to terms with a changed life. She remarks that it takes a long time to get accustomed to a new brain, but now that the newness feels familiar, she doesn't feel the need to return to her old life.

It's time to keep moving forward. With her camera.

4 Ways to Get Through Job Interviews With Aphasia

Going to a job interview is stressful in the best of circumstances. Going to a job interview when you have aphasia adds a whole extra level of frustrations to navigate. Take a deep breath. We've provided four ideas to help get you through the process.

Deep Breath

Yes, we'll start with that deep breath. Not only did we tell you to take one to center yourself, but taking a deep breath before you answer a question will give you time to collect your thoughts. Interviews are not a race; you can take the time you need to think before you begin speaking. When you practice your interview questions, also practice those deep, deliberate breaths. They'll calm you down and give you time to get started.

Silence could even work in your favor, according to this article from the BBC. Instead of looking at these pauses as a problem, make them into something that is working to help you to speak deliberately and highlight what you want people to hear. Hey, it worked for Steve Jobs.

Practice Makes Perfect

No, we can't see into the future and predict everything you'll be asked, but there *are* common questions out there that you can use to practice ahead of time.

Inc has a list of the 27 most common questions, the Muse has the 31 most common questions, and Glassdoor has the top 50. Sit down with these questions and a friend and have them run through a few pretend interviews. Jot down notes so you remember what you want to say and then practice, practice, practice.

Be Honest

Should you tell your potential employer about your aphasia? Yes. Tell them without apology because you have nothing to apologize for. Tell them without embarrassment because you have nothing to be embarrassed about. Aphasia is one fact about you, and one fact only.

People will take their cue from you, so if you are comfortable addressing it, they will be comfortable addressing it. You can reassure them that aphasia does not affect a person's intellect. You can point out that aphasia means you slow down and think deliberately; that you're not going to be an impulsive employee. Ask them if they have any questions about aphasia because you'd be happy to answer them.

Remember, no apologies. Show them that aphasia makes you a unique individual, and that unique point-of-view will help you bring something different to their workplace.

Ask for What You Need

You are interviewing your potential employer just as much as they are interviewing you. So tell them how you best communicate. Does it help you to have them repeat the question twice? Write down their words? Give you a chance to find the word you want through circumlocution? Do you get overwhelmed if more than one person is speaking to you at the same time? Be open about what you need and ask for it before the interview.

If they're not willing to accommodate your needs, you're getting a glimpse into how they'll be as an employer. A good interviewer will see more than the aphasia; they'll see the unique qualities that you can bring to their workplace. So thank the people who help you do your best job, and let go the ones who show you beginning with the interview that they're not going to support the members of their team.

Go on a Text Adventure

When I was in elementary school, my father brought home a text-based video game and said, “Play this.” The game was *Zork*, one of the earliest text adventures, and he bought it because I was a terrible speller. Because text adventures require the player to read a small paragraph of information and then type out brief instructions such as “go left” or “take rope,” interacting with the game not only showed me the proper spelling of words, but it forced me to learn how to use those words, too, if I wanted to keep moving through the story.

These games are a fun way to practice reading and writing skills by interacting with words in short bursts. They allow the player to enter a story, becoming a character and changing the plotline as they make decisions.

Entering a Text Adventure

Text adventures, also called interactive fiction, follow the same format. They give you a description of what you’re seeing. For example:

> **West of House**
>
> This is an open field west of a white house, with a boarded front door.
>
> There is a small mailbox here.

Underneath that description is a space where you can type what you want to do next. If you type “examine door,” the game gives you a little more information about the door:

> I see nothing special about the door.

You can knock on the door, open the mailbox, or walk in a few directions. Anything you can think of doing, you can type into the dialogue space and the game will either give you more information that you can use to make a decision or take you to another space. You can pick up objects you encounter (you’ll often need to be holding them to solve puzzles later in the game) and interact with other characters you meet.

The nicest thing about text adventures is that the vast majority of interactive fiction is offered online for free through the Interactive Fiction Database.

Move Ahead

So how can you work text adventures into aphasia therapy? First and foremost, the passages are usually brief, sometimes only a few words. You can practice reading the passages aloud. Instructions are also brief. In fact, most games have trouble with long sentences and do better receiving two or three words at a time. For example, “go north” works better than “walk in the north direction.”

If you’re having trouble typing, you can state what you want to happen next and have another person tap out the words. (This is a great activity to do with two or more people!) If you’re not having trouble with typing, you can still say the words aloud before typing them into the dialogue space.

Take Game

Some people find text adventures frustrating because they contain puzzles. If you can't solve the puzzle, you can't move forward. While there are usually hint guides built into the game and sometimes whole walk-throughs if you search online, there are also non-typing interactive fiction games called choice-based games.

Time's Game of the Year for 2014, *80 Days*, was a choice-based game placing the player inside Jules Verne's story *Around the World in 80 Days*. There are plenty of other games like *80 Days* in the app store or online (search for "Twine games" in the Interactive Fiction Database) that have players read a brief passage and then tap on two or more choices to make a decision and move the story forward.

Aphasia Book Roundup

There has been an explosion of aphasia-related books in recent years. These memoirs provide first-hand accounts, from people with aphasia or caregivers. We've rounded up a few of these books in case you're looking to connect with another person's story.

Where the Light Gets In: Losing My Mother Only to Find Her Again

By Kimberly Williams-Paisley

Actress Kimberly Williams-Paisley writes about her mother's experience with Primary Progressive Aphasia (PPA). PPA is a form of dementia that slowly removes a person's ability to use words. The book covers "her early-onset diagnosis at the age of 62 through the present day. Kim draws a candid picture of the ways her family reacted for better and worse, and how she, her father and two siblings educated themselves, tried to let go of shame and secrecy, made mistakes, and found unexpected humor and grace in the midst of suffering."

A Stitch of Time
By Lauren Marks

“Alternating between fascination and frustration, she relearns and re-experiences many of the things we take for granted — reading a book, understanding idioms, even sharing a ‘first kiss’ — and begins to reconcile ‘The Girl I Used to Be’ with ‘The Girl I Am Now.’ Deeply personal and powerful, A Stitch of Time is an unforgettable journey of self-discovery, resilience, and hope.”

Love Stroke
By Kelly and Brad Marsh

Love Stroke tells the same story from two points-of-view: Brad, the caregiver, and Kelly, a person with aphasia. Read about how a stroke changes their lives and thrusts them into new roles. “This memoir narrates the first hand, chronological views from both the survivor and the primary caregiver, including their life before, the day everything changed, and the first two years of recovery.”

The Word Escapes Me
By Ellayne Ganzfried and Mona Greenfield

The Word Escapes Me pulls together the thoughts of people with aphasia, caregivers, and speech pathologists to give readers a 360 degree understanding of aphasia. “Imagine living each day trying to find the words, understand what is being said, having trouble reading and writing. Welcome to the world of aphasia.”

The Professor’s Tumor
By Michael Susca

A professor who treated aphasia becomes a patient with aphasia in this book. The description states, “You can think, but without words. You can feel, but without words. You are aware, but without words. Now communicate that without words. Welcome to aphasia. This is the true story of a speech-language pathologist who treated people with aphasia and other neurogenic communication disorders and later became a professor who taught students about those communication problems. Then he was diagnosed with a brain tumor and, after brain surgery, was left with aphasia and other challenges. This is a first-person perspective of losing the gift of communication and regaining it."

Ralph Waldo Emerson and Aphasia

Ralph Waldo Emerson was a beloved American essayist, author of “Nature” and “The American Scholar.” He was a leader in the American transcendentalism movement. He was a friend and colleague of Henry David Thoreau, co-founded the literary magazine *The Dial*, and spoke passionately about abolishing slavery. And he had aphasia.

So many famous and beloved people, from actors and musicians to writers and politicians, have experienced aphasia. We are going to profile some of these brilliant people and how aphasia changed their lives.

The Great Writer

Ralph Waldo Emerson was a poet, essayist, and lecturer — three mediums that all rely heavily on words. Yet later in life, he experienced aphasia.

When he was 64 years old, his health started declining and he began experiencing memory issues. He continued to write essays and poetry for several years beyond the start of his aphasia.

He first noticed that he had trouble organizing his thoughts and writing his lectures. This “distressed him personally and alarmed his family.” He was experiencing non-fluent aphasia, probably Broca's aphasia according to Albert J. von Frank (author of An Emerson Chronology), caused by a stroke.

In the forward to *The Collected Works of Ralph Waldo Emerson* Ronald Bosco states,

> He rudely refused [his daughter] Ellen's assistance in the organization of his lectures and public readings, locked himself away in his study for long periods of time but emerged with little or nothing to show for the time he had spent there, and until May 1872, when Ellen insisted that he cease accepting them, routinely overextended himself by accepting invitations to lecture near and far.

His Later Life

Robert Richardson, who wrote the book *Emerson: The Mind on Fire*, stated that Emerson continued to be able to read somewhat until the end of his life. He depended a lot on circumlocutions, speaking around the missing words by providing all related words. For instance, *red*, *round*, and *fruit* when he couldn't remember the word *apple*.

As he neared the end of his life, he forgot his name from time to time. Yet the earlier distress seemed to have left him. John McAleer, who wrote *Ralph Waldo Emerson: Days of Encounter*, said that when people asked him how he felt, he said, "Quite well; I have lost my mental faculties, but am perfectly well."

Emerson was an incredible writer, thinker, and speaker.

Patricia Neal and Aphasia

Patricia Neal was an Oscar-winning actress. She was a holder of one of the very first Tony Awards, and an accomplished television star. She had five children while married to author Roald Dahl. *And* she experienced aphasia.

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

Strokes During Pregnancy

Neal experienced three strokes while she was pregnant with her fifth child. She would go on to deliver a healthy child, but Neal was left paralyzed and with severe aphasia. She was able to regain mobility, but she struggled with words for two years. Sometimes she was unable to think of the word at all, and other times, she simply invented a new word in its place.

Roald Dahl and Recovery

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 her a program where she constantly in speech therapy and brain training.

> He feared she would become an "enormous pink cabbage", so he set up – with friends and neighbors in Great Missenden, Buckinghamshire – an intensive six-hours-a-day regime. Some professionals warned this was too much, but he ignored them. Pat was coached back to normality "slowly, insidiously and quite relentlessly". She eventually resumed her acting career, even getting another Oscar nomination.

Neal spoke about her recovery in *People* magazine:

> During my stroke, our relationship was very good. Those were terrible times, but my husband pushed me to get well. He's really the one who did it. He pushed me to go to a military hospital for exercises and swimming, and he pushed me back into acting. I had no confidence at all after the stroke, but my husband insisted. He had married an actress, and he thought it would be good for me.

Many other stroke patients benefited from his program after he wrote a guide and inspired a new method of rehabilitation.

Aphasia and the BFG

Neal's aphasia inspired Dahl's character, the BFG. He wrote down all of his wife's made-up words while she was recovering and later wove them into his infamous tale about the life of giants.

> Dahl made careful notes of these neologisms, which helped with an article he was writing about her stroke for Ladies' Home Journal, but he may have thought they would come in useful elsewhere. It would be more than 15 years before The BFG would greet little Sophie with a bellow of laughter and the words: "Just because I is a giant, you think I is a man gobbling cannybull ... ! Please understand that I cannot be

> helping it if I sometimes is saying things a little squiggly … Words is oh such a twitch tickling problem to me all my life …”

In fact, the BFG’s explanation for his speech sounds very much like aphasia:

> “You must simply try to be patient and stop squibbling … I know exactly what words I am wanting to say, but somehow or other they is always getting squiff squiddled around … what I mean and what I says is two different things …”

Patricia Neal died in 2010, but her stroke experience continues to affect people to this day.

Does Hodor from Game of Thrones Have Aphasia?

Game of Thrones just ended its 7th season, leaving fans until 2019 to think long and hard about their favorite characters before the 8th and final season. One character that occupies *our* thoughts (we promise — no spoilers!) is Hodor, the servant stationed in the stables who only speaks one word — his name — though he can understand everything other people say.

We looked at speech-language therapists weighing in on whether or not Hodor's communication impairment is aphasia, both before and after his backstory came to light.

Hodor Does Not Have Aphasia

SpeechIRL weighs in strongly on the "no" side at first and states calling Hodor's condition aphasia is damaging for people who actually have expressive aphasia.

> Unfortunately, Hodor is anything but a “textbook example” of aphasia, and it is incredibly damaging for real people living with aphasia to have this gentle giant become their poster boy.

At the same time, she returns to her post after Hodor’s backstory is revealed to admit that his communication disorder was acquired; meaning, something happened to cause him to only be able to say his name vs. being born without the ability to express himself verbally.

> On the whole, Hodor’s story in S06 turns what was an aphasia awareness disaster (“simple-minded” aphasia poster boy) into a huge win. Viewers are painfully aware of just how stereotyped and mistreated Hodor was, due to his communication disability, which is likely not equal to his cognitive ability.

Hodor Has Expressive Aphasia

On the other side is Business Insider, which ran an article two years ago stating that Hodor was experiencing symptoms of Broca’s aphasia.

> Whether he intended it or not, Martin created a character who is a textbook example of someone with a neurological condition called expressive aphasia.

The article continues to state that Hodor, like the people that Broca encountered, is an extreme example of a person experiencing expressive aphasia.

> Leborgne, Lelong — and even Hodor — are actually more extreme examples of individuals with expressive aphasia. More commonly, a person with the disorder will express themselves in “telegraphic speech”, which usually comprises three or so words, including a noun and a verb. For example, someone may say, “Anne, dog, walk” to mean “I walked the dog with Anne today.”

Hodor, of course, is an extreme example in that he can only say his name, and now that we know his backstory from season 6, we know that his communication issues were not caused by stroke or other forms of brain trauma.

Wordless Date Night Ideas

Going to the movies is one of most popular date night activities. When Viola Davis won her Oscar on Sunday for best-supporting actress, she pointed out that *Fences* is a movie "about people and words." August Wilson's writing is fantastic, but it drove home an idea that bubbled up while reading about the art gallery group in *The Word Escapes Me*. When you're experiencing aphasia, sometimes it's nice to leave the well-travelled date night path to the movie theater. Instead, spend time with an activity that transcends words.

Here are five activity ideas to get you started, and we'd love for you to add a few of *your* favorite activities in the comments below.

Listen to Music

You don't need to leave the house to enjoy music. Cuddle on the sofa and listen to a whole album from beginning to end. Of course, it's equally fun to go out and attend a concert. The newspaper often lists free performances in your area, or splurge and get tickets to your favorite show. And don't just head for the concert hall. You can find music in Irish pubs and jazz clubs. In fact, make it a game to try a different music venue every week.

Tour an Art Gallery

Take a slow stroll through an art gallery, enjoying the paintings and sculpture. Afterward, head out to the art supply store and get your own hunk of clay or blank canvas. Strolling through the aisles of the store may spark your creativity or remind you of an art technique you've always wanted to try.

Become Photo Tourists

You don't need a fancy camera to document an outing. You can use the camera on a phone or get a disposable camera at the drugstore. Look closely and take in the world around you. Give yourselves a goal for the outing such as photograph as many textures as possible or all objects of the same color. When you get home, look through the pictures you took together.

Be in Nature

You don't need to go on a hike to get out in nature. Simply pick a beautiful spot — maybe a national park — spread out a blanket, and soak in the outdoors. You can engage in an activity, such as birdwatching, or simply sit still and enjoy the scenery and each other.

Take the Wrong Turn

One of my favorite things to do when I have time is to opt for the turn not taken. I look for roads that I've never turned down or intersections that I've passed through without wondering what is to the left or right. Taking a different turn sometimes means that you find interesting places close to home. Taking a train to nowhere falls into this category, too. Small, local trains sometimes run scenic, round-trip routes that last a few hours at most. Watch the landscape unfold out the window while you relax on the train. To find train routes, Google "scenic train ride" for your area.

Word Games and Aphasia

Games are a great way to continue practicing word use at home. They can reinforce speech therapy work or keep the mind active during the early stages of Primary Progressive Aphasia. Word games will keep you interacting with letters, but even visually-based activities are great for getting the conversation rolling. Look at some of the options below to see if you can work them into a fun activity night.

Crosswords Together

Team up with another person to figure out crossword puzzle clues. The person with aphasia can be the thinker and speaker, and the person without aphasia can be the writer. The best part is that there is no time limit. Stretch out solving a puzzle by spending a few days tackling the clues.

You can also team up for other word games like Scrabble. Play regular Scrabble two-on-two, or opt for Scrabble Junior, which is a streamlined version of the game with multiple difficulty levels.

Board Games

There are plenty of word-oriented board games you can play to stretch your mind. ThinkFun's Zingo has the player creating three-letter words. Quiddler's words get longer with each round, beginning with three letters, too.

Word Game Apps

There are dozens of word apps in both the iPhone and Android app stores. Word Search Pro has free word-find puzzles. Pictoword gives the player picture clues for finding a word. For example, giving a picture of a beach (sand) and a witch (wich) to put together to form "sandwich". Words With Friends is like a giant, on-going game of Scrabble that you can play with friends or family over the phone.

Talking Games

Games don't have to be focused on words to be helpful. Trivial Pursuit has general sets, like the original Genus edition, as well as specialty sets. You can target by year, such as the Baby Boomer edition or pop culture topic, such as Doctor Who. Answering trivia questions gets you thinking and speaking.

5 Tips for Traveling with Aphasia

In an ideal world, traveling with aphasia would be easy. The front desk staff at every hotel and waitstaff at every restaurant would be well-versed in aphasia. They would know how to communicate patiently and give customers the time they need to ask questions or give answers.

Since we don't live in that world (yet), we've pulled together a small set of tips for traveling with aphasia.

Research

Traveling with aphasia means doing a little extra research. Get familiar with the TSA's guidelines for people traveling with aphasia. Print out the TSA's notification card beforehand and give it to the TSA agent when you get in the security line. The card also contains helpful phone numbers you can use before or during your trip to ask questions.

If you're driving, plot your route and know where you're stopping along the way. Have someone speak to the hotel staff before you arrive to make check-in easier. Taking a few extra steps before your trip means that travel will be easier during your trip.

Take Some Company

Make your vacation relaxing by taking along someone who can do the majority of the communication work along the way. Navigating the unknown can be stressful, and bringing someone with you ensures that you can unwind.

Write it Out

Think about the various places you'll go and things you'll see along the way, and then print out a paper with important phrases you'll need. Place a simple explanation at the top of the paper about your aphasia, but then write down questions you'd want to ask in the moment or answers you'll have to give along the way. You may never need this sheet of paper, but it will make things easier if you have the words at the ready.

Order Beforehand

Most restaurants post their menus online. Read the menus before you leave for your trip so you don't feel rushed in the moment. You can write out what you want to order and show the waiter so you don't have to find the right words.

Don't Tire Yourself Out

Travel is not the same as being home, and it's easy to get exhausted when you're on the road. Tiredness can affect communication, so make sure you set a reasonable pace for your trip. Even though you may not need any help getting around while you're at home, use any means necessary to conserve your energy.