

Finding enrichment and a new sense of purpose when your identity has become that of “caregiver”

REHABILITATING BEYOND THE PATIENT

As a Speech Language Pathologist, I spend a majority of my focus on my **PATIENTS** with Aphasia... developing and constantly adapting their treatment programs, trying to find new approaches to assist them in regaining their communication abilities. However, I also try to spend time **educating and supporting the CAREGIVERS** of my patients...the husbands and wives, daughters and sons, and even mothers and fathers, who have taken on that extra “caregiving” role. However, what will become evident by the end of this article is that the role of “caregiving” takes on **many jobs and responsibilities**, many of which are **unexpected and unplanned**. I believe it is important to acknowledge this, especially as a medical professional working with individuals who have Aphasia, further supporting our obligations to **be there for our caregivers just as much as we are for our patients**.

What can we as Speech Language Pathologists do to support our caregivers?

When we first start seeing someone with Aphasia, we ask them (the patient), as well as the caregiver, what the individual with Aphasia wants to work on – what are their goals for improving communication related to talking, understanding, reading and writing. **Why don’t we ask our caregivers what their goals are?** Not their goals relating to their loved one improving his/her communication, but what are **their goals as a caregiver**? What do they themselves want or need, and how can we as SLP’s help to **support them along their challenging journey?**

Tami Howe and colleagues (2012) looked into exactly that. They conducted interviews with 48 family members to identify goals they themselves wished to receive from Aphasia rehabilitation. When they collected this information, **7 different categories were revealed**, and they are ones that I feel we should take the time to further explore and consider when addressing the needs of our patients with Aphasia. **The patient is not the only one who needs the support, the treatment, the strategies...our caregivers need the tools to allow them to move forward, taking care of themselves and their loved one.**

EMOTIONAL TURMOIL AND CAREGIVING FOR A SPOUSE

The Emotional Turmoil of Being a Caregiver

Caregivers experience a **range of emotions**, and no matter where they may be in the process of dealing with caring for someone with Aphasia, these **feelings will come and go**. No matter how successful a caregiver, no matter how good they’ve gotten at figuring out a plan and developing



strategies to help them adapt to their new lives, **there will always be new challenges sent their way to deal with**, to cope with. These are just a few of the emotions caregivers I know and have worked with have shared feeling:

RESENTMENT: *“How does he expect me to do all this on my own...I am only one person and there are simply not enough hours in the day.”*

GUILT: *“How could I get upset with him...he can’t help it...It’s not his fault that he has Aphasia.”* or *“How could I even consider going out with my girlfriends when my husband needs me?”*

OVERWHELMED: *“My entire life has been turned upside down and there is no end in sight.”*

ALONE: *“I just want my wife back, and to be able to have a conversation like we used to, share our feelings and thoughts with one another without it feeling like a constant game of charades.”*

SAD: *“We used to be such social people, but now I feel like when Bob does hang out with his friends, it’s because I’ve arranged it, and I play interpreter and translator during the entire conversation.”*

A Wife’s Caregiving Perspective

“If I had to choose one thing that is the hardest for me, I would say it is being the one who is ultimately responsible for making all the decisions.”

This is something I hear again and again, and is actually a direct quote from the wife of one of my patients who has been living with Aphasia for over 6 years. Although our loved ones with Aphasia **still have opinions**, their **challenges with being able to verbalize these opinions**, provide explanations to back up or support their opinions, and abilities to process complex issues is somewhat restricted. Therefore, it is **often up to the caregiver** to decide things like: *“Should I hire an accountant or try to do our taxes on my own? When should I call the plumber about the leaky sink? Should I call Bob’s friends since he hasn’t talked to them in awhile...I don’t want him to lose another friend? What should I make for dinner? Should we go on vacation and where should we go? Where should the kids go to camp, or college? Should I switch insurance plans to better suit our needs?”*

The wife of another one of my patients openly shared how **“Any decisions we used to make as a team are solely on my shoulders. I have become that right side of his body that no longer works like it used to and the area of his brain that cannot think for itself or help his mouth to form words.”** She further expressed that **her husband is still her husband**, there is no doubt. However, there is a part of her that feels **she has lost her “partner,”** as she no longer has that



sidekick that used to participate in decision making and would provide her with emotional support when she had a rough day at the office.

CAREGIVING FOR A PARENT

A Daughter's Caregiving Perspective

What if we are a child who is now caring for our mother or father with Aphasia, who not only has trouble taking care of themselves but is no longer able to communicate his/her wants and needs?

A daughter of one of my patients shared *“From when we are young, we always go to our parents to share the joy, grief, ups and downs in your life. When we are young, our parents provide physical support. As we all age, the physical support from our parent’s transitions into emotional support. Parents provide us with unconditional love and support.”*

I would imagine it can be challenging for someone with Aphasia to **provide the same level of emotional support they once did to their children, their spouses, and even to their friends**. And it’s not that they no longer have these feelings, or even that they are unable to show these emotions, but the **verbal and listening pieces necessary for providing emotional support have been impacted** by the language disorder. It may be that we need to acknowledge and accept their **new ways of demonstrating this emotional support**, whether it’s through more **nonverbal cues** (i.e. facial expressions) or **physical expressions of emotion** (i.e. hugging, holding hands).

Imagine being the daughter of a father who has Aphasia. This “daughter” also has a family of her own – two children, and a husband – and now she has **taken on the role of caring for her father** who has significant Aphasia. **She is his personal secretary** - having to make and keep track of appointments; **she is his speech therapist**, practicing tasks daily and making sure the other family members implement the activities throughout the day; **she is undoubtedly his advocate**, searching for the best therapists that implement methods by the latest research...and the list goes on. She also has a successful career and **her own family responsibilities**. *When is there time to simply be a daughter? How can she possibly be on the receiving end of that **unconditional love and support** when her day-to-day schedule is bogged down with the 30 other roles she has taken on?*

Let’s also keep in mind she is **trying to be a mother to her own two children** and a **wife to her extremely supportive husband**. She feels **guilty** when she’s googling the latest research in Aphasia because she should be spending time with her kids. So she takes her children to the playground and reads to them during the day, and googles in the middle of the night when her kids and husband are asleep. She’s trying to care for her father who has taken care of her, but struggling to find a balance between **caregiving for her father** and **caring for her own children**.



This is a lot for someone to deal with, to cope with, and it is a **tunnel where that light at the end is difficult to find**. When our **gas tanks are empty**, how can we **convince ourselves** that **it's ok to do what we need to do for ourselves in** order to get a refill, and recharge? *Is there something we can do as rehabilitation specialists to encourage this mindset and provide our loved ones with positivity, and encourage them to look after their own emotional and physical well-beings?*

REEVALUATING OUR CAREGIVERS NEEDS

Tami Howe and colleagues wrote an article in 2012 discussing the **need to rehabilitate families** in addition to our patients, and conducted a survey that revealed specific goals family members had for themselves during the rehabilitation process, here are the 7 categories that were identified based on the **wishes of caregivers** during the goal identification process:

1. **To be included in the rehabilitation process, especially during the early stages**
2. **To be provided with hope and positivity**
3. **To be able to communicate and maintain their relationship with the person with Aphasia**
4. **To be given information**
5. **To be given support**
6. **To look after their own mental, emotional, and physical well-being**
7. **To be able to cope with new responsibilities**

Some of the categories identified might seem **obvious**...that our **caregivers want to be included in the rehabilitation process**....they want to be given information and support. It should be inevitable that we provide our caregivers with many of these tools to help support them, so **they can be a strong support for our patients** with Aphasia. Perhaps we think we are doing a good job, and checking all of these off our list, but I encourage all of us to really **delve into the specifics of these categories**.

For instance, perhaps you feel you're including the caregiver in the rehabilitation process but giving them updates on the progress of their loved one, but you're **not truly INCLUDING them in the rehabilitation process**. *What are you working on? How are you addressing it and how will this task that is targeting individual sounds help my loved one have a conversation again? What is the connection between what you're doing here during your therapy session with how it's going to impact his communicative abilities at home? How can I help to facilitate this?*

Or maybe we're thinking..."Of course I give caregivers information on Aphasia and stroke. I provide them with a handout during the initial assessment and give them a sheet that lists communication tips." This is potentially a great start, but **is it enough?** Maybe we only provided verbal education and it is **too much information to process at the early stages** of rehabilitation, so the information was **not retained or learned**. Are we providing education



visually, verbally, and perhaps even in a video or CD format? Are we providing ongoing education based on each individual's recovery progression and how they're responding to treatment? Education needs to be ***adapted, updated, ongoing*** to meet the changing needs of our patients with Aphasia and their family members.

MOVING FORWARD WITH A NEW APPROACH

How to move forward and find fulfillment in life

Is it possible to **still be a daughter, be a wife**, to someone who has become **so dependent on us?** How can we turn this ***seemingly burdensome life and these feelings of resentment and guilt into a fulfilled, enriched alternative, appreciating our new normal?***

I have seen a lot of great online resources targeting caregivers, providing suggestions for what they can do to help with **"caregiver burden."** Often, these suggestions sound great, in reality, but may be difficult to implement depending on the resources available to you. So I've instead put together a ***list of motivators and encouragement*** that I feel each and every person living with Aphasia (whether you are the one directly or indirectly impacted by the language disorder) can **follow and believe in**, to hopefully ***help you put one foot in front of the other on that recovery road...***

- ***Never give up on the road to recovery, and accept that it can be slow, and there will be bumps along the way.***
- ***Tiny victories are victories and they should be celebrated. A new word, a new sound, a new gesture...these should all be celebrated!***
- ***Accept the bad days, because there will be bad days. Allow yourself to cry, scream, hide in the closet for 2 minutes alone with a candy bar...knowing you will wake up tomorrow with a fresh start...a new day. Do not allow yourself to feel guilty for how you feel. What you are feeling is NORMAL.***
- ***Experience life, live life, as this becomes a big part of your therapy, however you may define it and experience it!***
- ***Accept your new purpose, your new course, and learn to adapt. Acceptance allows you to move forward whereas denial can hold you back from who and what you can truly become.***
- ***Find the humor in things...laughing is truly the best medicine! When your loved one's favorite words have become profanity or your dad called you by your mom's name, it's ok to laugh it off and even poke fun a bit!***
- ***Allow for creativity and flexibility in recovery – everyone with Aphasia is different. It is unfair to compare your situation or your recovery process with others. Everyone responds to different people, different situations, differently. Build off strengths and find new approaches for weaknesses.***



My hope is that through this blog series, **as a caregiver**, you have perhaps found a small amount of comfort in at least knowing that ***what you're feeling is normal, and it is ok***. Maybe this series allowed you to discover a ***new perspective or a new outlook on your life***, living and caring for a person with Aphasia.

And my hope for those Speech Language Pathologists that have read this series is that you may now ***approach your caregivers a little bit differently***, and put a little extra thought in how you educate and support them, in addition to what you're already doing to help their loved one with Aphasia. I hope I have motivated you to **REconsider** the **needs of our caregivers, ALL** caregivers of the patients we see, so we can ***better serve our patients and their families*** and make a more ***positive impact on their quality of life and overall recovery***.

******I want to thank the women, the amazingly strong caregivers, who contributed their stories and feelings, and allowed me to share them in this article. What you do each and every day, along with all the other caregivers out there, is truly admirable. Your loved ones would not be where they are in their recovery if it weren't for you. Thanks for what you all do!******

1. Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). 'You needed to rehab ... families as well': family members' own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*

