Paul is our new support group member. His caregiver and spouse, Joan, has provided a thoughtful, saddening but inspiring tale of the ways that relations between Survivors and Caregivers change from their “normal” way, to: -ed.

The NEW NORMAL
by Joan M. Livesey

The day settles into dark...and quiet. The house breathes a sigh of relief as the busyness of the light falls into slumber.

Paul has made his way to bed after a long day of attempts, failures and achievements. Now it is my time to converse on the phone, follow up on emails, pay bills and once again make sure he will find food to eat and have everything he needs to feel safe in his adventures tomorrow while I am at work. Sometimes there is the spare moment to read something not associated with re-learning, recovery or the latest brain game. Generally those moments become an extra ten minutes of sleep – while standing in the shower. As I turn off the lights and secure the doors on my way toward the sound of the quiet breathing down the hallway I smile. I shake off the thoughts of what could have been had I not gone home from work right away that day. I once again thank God for the new opportunities to learn and build a stronger bond between us; for the things I never dreamed I would ever know and am so comfortable with now. I ready for bed knowing tomorrow will have its challenges and miscommunications – and then I will leave for work!

Mornings bring time together like we never could share before. We talk a lot longer – mostly because it just takes longer for him to put words together – but that is good and most every day there is improvement. A word so long lost suddenly finds its way to his mouth. Whether it is pertinent to the conversation at hand or not, it is a newly found word to add to the list that is being recreated in his brain’s database. There is celebration in that. There is a LOT of laughter in that! Laughter so bridges the miscommunications, wrong words, improper gestures – all of those things that are precious about an Aphasic.

As I watch my husband, Paul, grow within the world of Aphasia I see so many amazing and awe-inspiring things. You do not know what you as a Caregiver have brought home with you. It was an almost childlike beginning when I brought him home. It was a frightening prospect to bring home someone that looks like the one I had
sent off in an ambulance, yet acts totally different.

Just like bringing home a newborn: there is no manual. Oh, but this time you cannot call your mom or grandma for advice. You are in a totally unique place where your only help lies between the covers of books or endless hours on the internet...or until you find or create a support group.

I watched my husband. I watched him struggle to remember - to remember how to shave and dress, how to make a sandwich – how to speak. Watching the determination in his eyes to find the proper noise or pointing gesture that would allow me to help him achieve whatever goal he had set for the moment encouraged me. His efforts encouraged me to learn more and support him and push him a bit harder each time. The goals he reached for became more and more readily attainable. It encouraged him because I was fighting just as hard. Watching him set me on a mission to find people in a like situation so he could have someone to communicate with on his new level. People that had survived like he had that could share their experiences. Mentors. Achievers. New friends. They just had to be out there somewhere.

I watched my husband more. I watched him realize he would never be “the same”. I watched as he tried to find an explanation for that. I watched him work so hard to count to ten, to say the alphabet...to remember my name. His hard work bolstered my efforts to help him learn even more. I looked harder to find somewhere he could go to get assistance/guidance in order to learn and achieve more. I had to face it: I was tired of hearing my voice saying “Try again.” He must have just been sick of it!

A person with Aphasia has two faces: the one they wear today and the one they remember wearing before. I have come to believe that the face my husband wears now is more happy – albeit sometimes more frustrated. What was once so outrageously important is dandelion fuzz in the wind now. Life is measured differently – he looks at life as being more relaxed and perhaps whimsical. This is a dream/skill most of us are saving for our old age. He has taught me to start living that philosophy now.

I wonder if he thinks of or remembers the “Old Times” and if he does. When I ask him he cannot describe what it was like. He remembers some events – more pop into his memory all the time, sometimes at the oddest moments! Still, I watch him as he shakes his head in disbelief that he cannot do what he once could do. It may be as simple as holding a screwdriver in his hand and wondering what to do with it. Looking at it long enough, setting it down, if he must and picking it up again. Given enough time it does re-register with his brain and he knows that he had the screwdriver in his hand to open the can of paint. Then a new process starts: Hmmm, what was I going to paint?

We have learned it is okay to laugh at the failed attempts at words, misused words or gestures, forgotten tasks and totally blown charade games. One cannot make this stuff up. This is real life...a New Normal and it is the most special gift we have ever received.

We learned about the University of Washington’s Speech and Hearing Department through our Speech Therapist at Evergreen Hospital. My husband was accepted and started out gingerly and with great trepidation. It was yet another new adventure with new-found independence traveling across the 520 bridge and negotiating the streets of the UW campus to find the Speech Clinic. This small adventure, as rewarding as relearning is, was very scary.

Attaining independence is a giant step - just like initial learning was when we were children. We take that initial learning for granted until a drastic event takes it away from us and leaves us starting over. Who knew we have a reset button in our brains? As much as Aphasia is a disability its counterpart is that of great ABILITY. I observed that certain senses became keener: his listening skills improved; his eye for detail greatly improved and he became much more aware of his surroundings. I
have noted the Survivor’s brain works to balance itself out for survival first and then to begin embarking upon the relearning process.

The UWSHC has provided a safe and progressive environment and curriculum allowing those in need of therapy and their caregiver(s) to get guidance while supporting the growth and development of the Students. It is a rewarding program that feeds the Survivors’ needs by reinforcing the great strides they have made and encouraging them toward what more they can achieve. The group sessions are priceless. With The Group my husband has found: Mentors. Achievers. New friends. I have found comfort in getting to know the other Caregivers. That sense of being singled-out disappears when you get to know others that are walking the same path.

We live a New Normal. A Normal that has and will change with each step he takes in his journey with Aphasia. This Normal provides a lot of smiles, laughter, learning and love to share.

*The day settles into dark...and quiet. The house breathes a sigh of relief as the busyness of the light falls into slumber. He has made his way from the dark and into the light of a brand new life.*

---

Tom and Su Hagerty have been active and supportive members of our group for three years. Here are additional articles from them to tell more of their stories. A simple experience can lead to inspiration, which may yield --- contentment. -ed.

**Trigger - an Inspiration**

by Tom Hagerty

When asked to write something that I had learned or experienced since the last time I had submitted a piece on being a caregiver, my brain took over and said “Sure that will be easy!” when in reality I had no idea what to write about because each and every person with a brain injury or a stroke is an individual with their own unique persona. Now having said all of that, I will pass on something I found useful in the hope that it can inspire some thought or the formation of a solution for you.

My wife and I do a lot of driving just to see what is out there in the world that we have not seen before. A lot of it is in the state of Washington and in doing so we find many places to eat. Some are exceptional and some not so good but that is also part of the adventure. I am one who will try new things but not so with my wife. She has found that pancakes are the same no matter where you choose to eat. That is one of our ‘in house’ jokes and the “joke” part of it is what caused me some extra thinking.

I understand that many people who have had a stroke need to learn how to compensate for speaking, hearing, or other disorders. For example, perhaps one part of the body is weaker and so one learns to use the stronger part to compensate for that. What came as a huge surprise to me, though, was ‘invisible’ weaknesses like the senses of taste, smell, or being able to swallow or chew.

Those are things that we always take for granted. However, they are major things that every caregiver MUST become aware of. I feel that we must ask more and more questions about the unseen effects of a stroke or brain injury. It made me extremely happy to hear at one of the Aphasia retreats that there is a concerted effort to make physicians more aware and to give them some tools to communicate with us (patient and caregiver). So ASK, ASK, ASK, ASK, ASK and more.

Ask any of the medical personnel you have contact with, doctor, nurse, therapist, pharmacist or even another caregiver because they may trigger an idea that may help to better the life for your loved one, friend, or patient.

---
Our MedSLP Class

The Medical Speech-Language Pathology (MedSLP) program in the UW Department of Speech and Hearing Sciences is for a two year MS degree. The degree is based on communication and its disorders and focuses on careers in hospitals and community-based rehabilitation centers.

The first year of the program starts with purely lecture and book knowledge of brain activities in speech, language, thought, and swallowing disorders.

This quarter, the first-year Medical SLP students are in a practicum at a graduate level, Kelsey Leighton’s SPHSC 553 class, giving the students a supervised practical application of the theories taught in class.

The practicum introduces them to adult communication and the process of evaluating adults so that they can make informed decisions about a clinical treatment plan. They now have their first hands-on experience with real life problems from adult Aphasia Support Group volunteers.

In the process, including interviews of us (volunteers), students practiced getting an individual’s medical history, social experiences, and treatment goals.

They administered standardized aphasia test batteries to learn about our adult aging and communication, our language structure and use in different age groups from 55 to over 75.

Later student assignments include a chance to participate in a group treatment session and an opportunity to conduct mini-evaluations on volunteer clients at the end of this quarter or during the next Aphasia Retreat, this fall.

In this MedSLP program, while there are still students in that class that will go on to work with pediatric populations in the medical setting, most will seek positions
working with adults.

The pictures here are to show the two student class groups this year (above top & middle), how they interfaced with aphasia volunteers (far L top, near L bottom), collected, shared, and evaluated data (near L top, far L bottom) AND had a class performance review (above bottom).

During the second year, students in the MedSLP degree program complete four off-site clinical experiences, three part-time practicum rotations, and one full-time internship experience during their final quarter.

This article attempted to get perspective about how us Aphasiacs deal with student clinicians, how we affect each other and how we can best work our way through our problems by working together.

This editor asked for student comments:

“really supportive environment to practice”; “stroke survivor . . . experiences contribute more to our education than any lecture.”; “we can learn from each other.”; “want to know what is most important”. -ed.
Trigger - a Contentment

by Su

I have written one thousand plus songs. Here’s a story about one of those songs, “Contentment.”

On a Sunday morning, I was in the Kirkland (WA) Church of the Nazarene. Reuben Welch, a professor from Nazarene Theological Seminary in Kansas City, was preaching. And then, he was singing a song. It was a song that his young people sang in Sunday school.

Wait! It was “Contentment”, MY song! It was a thrill to hear my song!

After church service I went forward and asked him how he liked “Contentment”. “Oh!”, he said, “It is so dear!”

“I know,” I said, “I wrote it!”

Tom’s article triggers some thoughts to this Aphasiac-addled brain. First, a side talk with Tom and Su explored subjects that they had brought up in previous articles and in our Group meetings. This inspired follow-up articles by them, and contentment in this editor by including them in this newsletter. Much thanks to both.

Second, the heart-warming article by Joan, of course calls for a companion article by her husband, Paul. We look forward to that, and more about this Clinic’s activities, soon.

---ed.

UW S&HC Research Study

Do you have problems talking with doctors during medical visits?

Do you have Aphasia, Dysarthria, or Apraxia of Speech?

PhD candidate Mike Burns is studying these questions. If you are interested in learning more about this study, please call or email Mike at:

(206)543-0597 or, mburns@uw.edu

We want to learn about communications during medical visits, about people with communications disorders, and want to talk with their caregivers and doctors.

We will interview you and your caregiver two times at this clinic or at your home. Each interview will take 60-90 minutes and will be compensated.

Again, please contact Mike if you are interested.

University of Washington
Speech and Hearing Clinic
4131 - 15th Ave. NE
Seattle, WA  98105
Phone:  (206) 543-5440
Fax:  (206) 616-1185

Visit our web site in order to:
- learn more about our services; and,
- to access past issues of the Writer’s Guild quarterly newsletter:

"In Search Of …"