



Mid-Atlantic Aphasia Conference Newsletter

www.midatlanticaphasiaconference.org

Volume #1



Issue #4



October 2024



MAAC President – Mark Harder

APHASIA CAMP!

I have been a member of the Thursday Night Poets for over two years on zoom and wanted to meet the group in person. I was not a big camper but thought this would be a good opportunity to meet some friends. I met Professor Jerry and Michael two years ago at Temple University during the National Aphasia Awareness Month and conference. Michael is a member of Poems in Speech for four years and Cindy Lam Walker for three years. Katie Paulson has worked with me for the Harry S Truman High School and John K. Harder Poetry Grant Scholarship as a Judge. Naomi Bitter and Audrey Nelson are dear friends for Thursday Night Poets.



My wife, Donna, accompanied me to the Aphasia Camp for a weekend adventure. The first day was sessions of Storytelling, YouTube Art, and Yards Games with a tri-band concert at night.

The second day was sessions of Archery, Theater, and Board Games with Show-n-Tell at night. (I told you that I am not a big camper, I didn't select fishing, boating, and biking.)

What made it so special was the students and volunteers. Oh yes, and the participants and caregivers/care partners! **You have to be there at the next time!**

From The Editor's Desk:



"FALL IS FOR PLANTING..."

This slogan at the local home and garden store is reminding us to prepare now for the **future** "garden" we want!

We must choose and then bury the flower bulbs **NOW** before the ground freezes!

~~Waited bulbs the right time~~ They "**rest**" and **store energy** thru the **fall** and **winter** - **spring** to sprout, grow, and bloom with new life!

**...AND FOR THE APHASIA COMMUNITY,
FALL IS FOR PLANTING AND PREPARATION TOO!**

Let's plan and prepare that our future is bright! Let us choose our "bulbs"-our activities, exercises, groups and social opportunities and DO THEM!

The progress of our goals may seem to be 'asleep' but in the SPRING, we will see new "sprouts and blooms"- new skills, achievements, and goals acquired!

Denise Mendez, Editor

Comparison Is the Thief of Joy!

By Crystal Laughlin

They said "comparison in the thief of joy" - well... guilty as charged! I am constantly comparing myself with the "old Crystal" and "the new Crystal", pre-stroke and post-stroke. The grieving process that happens with your identity nobody talks about it or maybe they do in a book, that I still can't read because I have aphasia.

As a "newcomer" with aphasia - I had my stroke in December of 2022 and am coming up on the 2-year mark! I have been on the "struggle bus" **learning to live with aphasia**. I did not know what aphasia was, let alone how this can **shape my whole entire life**. Funny story: I was in school to be a therapist when I had my stroke. My mom always said I was her thick-headed one. *I learn best with experience*. I would not believe anyone until I tried it first. I had to see it to believe it.

Well , the universe was like "hold my beer"!

I went through 6 of the 7 stages of grief.

- √ shock (stroke is very shocking!!!)
- √ denial (how can these be happening to me?!)
- √ anger and bargaining
- √ depression
- √ guilt (I should be grateful to be alive)
- √ at

I have accepted that I am no longer going to be the old Crystal, but is that necessarily a bad thing? **People have to change in order to grow as a person.**

I kept thinking that new meant bad, but in fact it isn't at all. **I just had to shift my perspective from one negative to a positive.**

It's now a new improved Crystal and I have learned to give myself grace and practice patience with myself and others.

I have to constantly remind myself of that fact everyday, and that it is ok!

QUESTIONS WITH TIE!

Flowers can talk?



Tie said, "What do you mean that flowers can talk?"

Well Tie, flowers represent emotions and characteristics, like:

- Forsythia—Anticipation



- Red Rose—Love



- Cactus—Endurance



- Dandelion—Happiness



Tie said, "I was pretty happy when I ate the dandelion! Okay, what is the anarthria flower?"



The anarthria flower is named for an Ancient Greek word, meaning '**without joints**' or '**cannot articulate**'.

Anarthria is also a condition of complete loss of speech. It usually results from a stroke - like aphasia, communication is affected but aphasia and anarthria are affected in different parts of the brain. In both cases, intelligence is not affected.

People with anarthria **cannot speak**, but they have a lot to SAY! They can communicate with written words, paragraphs, gestures and volumes of thought.

Don't underestimate people with anarthria, dysarthria (difficult to speak clearly and distinctly), or aphasia!

Care Givers/ Care Partners Corner

By Dorothy Laven
MAAC Caregivers Support Group Facilitator

Hi everyone, my name is Dorothy, and I am one of those people who had no idea what aphasia was **until my daughter had a stroke**. The first week or so she was not fully conscious, so I sat in the hospital and was able to do some research to find out what aphasia meant. She was first diagnosed with global aphasia, so I knew we had a lot of work to do.

She had inpatient rehab at Moss where everyone was wonderful. The Speech therapist suggested several apps to use, and we used them faithfully for quite some time. She also did out patient at St. Lawrence and then speech at Moss again. In the meantime, I looked for support groups and became very frustrated, because I was not able to find anything locally and all the leads I did find were not in existence.

When I learned about the Mid Atlantic Aphasia Conference, I was so excited! **We are a group of individuals with aphasia and caregivers, supporting individuals with aphasia and care partners and connecting aphasia support groups!** I feel as though this is a valuable tool for people with aphasia and care partners of people with aphasia.

TGI Fridays Langhorne, PA
FRIDAYS
Dine to
DONATE
October, 24th
ALL DAY DINE IN OR TOGO TO DONATE &
20% OF YOUR TOTAL FOOD BILL WILL BE FOR
MAAC!
"Show this or mention "Mid-Atlantic Aphasia Conference" to your server"
It is that simple!
685 Middletown Blvd, Langhorne, PA 19047
(215) 750-8002
THANK YOU FOR YOUR SUPPORT!

A Caregiver's Story

Written by Debbie Burd-wife of Jim

Several years ago, my husband suffered a traumatic brain injury (TBI). When someone you love suffers trauma, everyone who loves that person suffers trauma too. Remember, you are not just a caregiver; you are also a victim. Please treat yourself accordingly. In my case, I was blessed with an amazing home team. Family members traveled far to offer their assistance. My mother moved to my home. My niece took over managing my business. My son, daughter-in-law, sisters, brothers-in-law, nieces, nephews, cousins, friends, church family all reached out and supported us along the way. I cannot tell you how important that is for everyone's recovery.

Don't turn away help. You cannot do this alone, and those who love you really do want to help. People want to drive you, make you food, sit with you, hold your hand, give you a clean house. Say yes to all these things. It gives you time to rest, and it gives them something to hold on to while they are grieving with you.

The hospital and rehab centers are also full of angels. Watch for them and turn to them when you have a question, need advice, are confused or frustrated. They also want to help you, and they have the knowledge without the emotional baggage to see you through every day. Make friends with the social worker at every facility. They are your guides through the entire mess.

They have seen it all before, and there is no question they are not willing to help you with. Ask your therapists and nurses lots of questions. The things you learn during your loved one's recovery will be very helpful when you return home.



Before your loved one is transferred to rehab, have one of your home team take you to tour possible rehab facilities. Places that specialize in TBIs are the best. Many of your therapists studied at these places, ask them questions. For us, JFK Edison's traumatic brain injury unit and Magee Philadelphia's Riverfront Rehab brought dramatic improvements to my husband's quality of life.

As of now, you are also a therapist. Talk to your loved one as much as possible, read to them. Bring the get-well cards and read them. Play their favorite music. Sometimes people can sing before they can speak. Fill their room with pictures of loved ones. Tell them stories of home. When my husband was still in ICU, one nurse recommended that we play his favorite card game. I thought she was crazy, but guess what, the brain was working, and Jim could still play Canasta. These little victories are important to both of you. Every time a milestone is met, celebrate. At JFK, we were allowed to visit the hospital cafe. Family milkshake parties brought all of us joy and provided a sense of normalcy. In Philadelphia, we traveled by train. Walking around Philly, learning the route, exploring new neighborhoods all added to our physical and mental well-being. I cannot tell you how important exercise is. The more Jim walked, the more his brain seemed to wake up.

Rehab ends quickly, so ask the therapists for ideas for how you can continue their good work. Read articles from reputable journals, seek advice from all the therapists you meet. Make sure your loved one is trying to read every day. We sought the help of a friend who was a retired reading specialist. She came often and helped Jim read very simple books.

Jim also spent part of everyday trying to read the newspaper. One day he turned to me and said, "I can read again." Those are the moments that we aspire to. Take day trips. Jim and I love museums, so we would venture out often. I would read all the signs that I thought would interest him. Soon he could explore the displays at his own pace.

Give yourself a break. Sometimes you need time away from this new person. It can be weird living with someone that looks just like the man you married but no longer behaves like that person. For a long time, I described Jim as flat. He was there, but he didn't seem emotionally connected to us anymore. That healing took time. Sometimes I would go shopping or out to lunch with a friend. I needed some me time, and Jim needed the time to be independent.

Be careful not to live in fear. Sometimes I was guilty of smothering Jim. I was so afraid he would have another accident or get lost. I also went through a period where I felt I had to make excuses for his occasional lack of social skills. Everyone does not need to know your story, especially when you probably will never meet that person again.

Because of Jim's accident, he had to give up his career. He was a very outgoing person who loved his work. Fortunately, he became involved with an aphasia group in Philadelphia. That gave him a social outlet and helped him rebuild his social skills. Helping others with brain injuries has become very important to Jim. He is part of two mentoring programs at Jefferson in Philadelphia. One where he visits patients facing some of the challenges he faced, and another where he helps medical students understand the importance of seeing those they serve as a person as well as a patient.

He also was a force in developing an aphasia program at Capital Health so that those living in our area could also benefit from this type of support.

God walked with Jim and me through this entire process. I could write an entire article about the many miracles we experienced. Pray often; ask others to hold you in prayer. As I said earlier, look for the angels. Seek out someone to talk to. For me, it was my pastor, and later I began to see a counselor. You might also benefit from a caregivers' support group. Don't try to do all this on your own. Professionals can really help you to process the anger, grief, and frustration that you will have.

This process is a journey. I called it an adventure. Don't take yourself too seriously. Humor is a terrific medicine. Laugh, laugh, laugh and play. When Jim was in rehab, they had to keep him in a tent for his safety. When I was visiting, I would unzip it and climb in. We would pretend we were camping. We enjoy dancing so often at home I would turn up the 60s music, and we would rock out.

Our stories are unique to ourselves, our outcomes will be different, but I hope you found something helpful in reading a part of Jim and I's adventure. The best advice I can offer is—to be a good caregiver, you need to care for yourself.

Debbie Burd



Aphasia Awareness and Connection!

2 Baseball Stadiums-2 Cities

1 Vision and 1 Mission !





Mid Atlantic Aphasia Conference

1st Annual Holiday Get Together

- Arrive at 5:30 pm
- Dinner Served at 6:00 pm
- MAAC Aphasia Support Group starts at 7:00 pm (In person AND on ZOOM!)

Monday, December 9, 2024

Three Monkeys Café



9645 James St.
Philadelphia, Pa. 19114

\$25 per person

Includes dinner and "soft" drinks

MAAC QUARTERLY SCHEDULE/CALENDAR

October, November, December

MAAC Support groups
for persons with aphasia
Virtual (on ZOOM)
Monthly
every 2nd Mondays at 7pm



MAAC Care Givers Support Group
New and current Caregivers are welcome!
(on ZOOM) Monthly
Thursdays (after the Monday Support Group)
7 pm

| Date | Session | Topic/Guest |
|--|--|---|
| Monday, October 14 th at 7:00pm | Joint Support Group for people with aphasia AND caregivers (on ZOOM) | Shai Anbar Author |
| Thursday, October 17 th at 7:00pm | Caregivers Support Group (on ZOOM) | Open to all caregivers |
| Sunday, October 20th 11am-5pm (rain date October 27 th) | OKTOBERFEST Veterans Park 2206 Kuser Rd. Hamilton, NJ | MAAC in the Community Aphasia awareness |
| Thursday, October 24 th open til closing | Dine to Donate! Dine at TGI FRIDAY'S Langhorne, PA | MAAC Fundraiser |
| Friday, November 1 st 10am-2pm | Senior Health Fair <i>At GIANT Supermarket</i> 315 N. York Rd. Willow Grove, PA | Sponsored by Nancy Guent |
| Monday, November 11 th at 7:00pm | Support Group for Person's with Aphasia (on ZOOM) | JUST ASK, Aphasia... Denise Lowell |
| Thursday, November 14 th at 7:00pm | Caregivers Support Group (on ZOOM) Open to all caregivers | Aphasia Readers Anna Teal |
| Monday, December 9 th at 7:00pm | Winter Holiday Support Group for Person's with Aphasia (on ZOOM) and Face-To-Face MAAC End of Year/Holiday Celebration | Three Monkeys Café 9645 James St. Phila., PA 19114 |
| Thursday, December at 7:00pm | Caregivers Support Group (on ZOOM) | Open to all caregivers |

GET THE WORD OUT!! APHASIA!!



SCAN FOR MORE INFORMATION!