**2nd Annual Aphasia Retreat**

About 80 caregivers and stroke survivors met on April 30, with ~60 professionals & students to share the latest about aphasia.

They spent six hours to cover testimonials, presentations, and information sharing in the Community Center space donated by the Lake City Lions Club.

For those who could not attend, we have attempted to summarize, here, the speaker’s most meaningful points: – ed.

**“Your Brain: A User’s Guide”**

*by JoAnn Silkes, PhD., CCC-SLP*

**UW Post-doctoral Research Fellow**

When a sudden crisis strikes, like with a stroke, you’re suddenly thrust into a whole new world of medical and technical terms and procedures that you may never have thought about before. I hope that this helps people to better understand their own brain injuries, and the resulting challenges.

The brain is an amazing, and amazingly complex, organ. It only weighs about 3 lbs, but it has more than 15 trillion connections (that’s a 15 followed by 13 zeros) between about 100 billion neurons. These neurons are responsible for everything that we think, say, feel, and do. Wow! In order for the system to work well, it’s highly organized, with specific areas doing specific things. This means that there is some way to predict what functions someone may have if they have an injury to a particular part of the brain, and there may be ways to direct therapy to recruit particular parts of the brain after an injury.

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Language is interesting, because it involves both representations, which are the language knowledge that we have, and processes, which let us access and use the representations in a way that makes sense. For example, we use certain processes to get to the representations of the ideas and words that we want. Then we use other processes to string them all together in a way that makes sense. As we understand it now, certain parts of the brain are involved in the processes, but many of the representations are actually distributed across different parts of the brain. This means that an injury to the language centers of the brain, like in the strokes that cause aphasia, may damage the processes but generally leave the actual information intact.

Because our brains are made up of complex networks, sometimes new parts of the network can be recruited to help when other parts are damaged. Knowing this, we can work on developing and using therapy techniques that use other ways to get to the information.

There are different ways that language can improve in aphasia. These include:

1) moving the function to another part of the brain, either on the same side or on the other side of the brain, and

2) re-wiring the language networks to rely less on the damaged areas and more on undamaged areas. Finally, there is research being done now trying to get nerve fibers in the brain to re-grow, so that damaged brain tissue can actually be repaired. It’s a long way from being available for clinical use, but it gives hope for the future!

The brain is an incredible organ, and for everything that we know about it there are plenty of things still to be discovered and understood. Knowing something about the brain and how it works may not solve all of the problems of aphasia. Hopefully it makes it easier for stroke survivors and their families to understand their experience with stroke and aphasia recovery.

Do you doubt that your capabilities are growing? Remember that your ears and nose never stop growing.

Dr. Bishop made this presentation to the full group in the morning. In the afternoon, she expanded that talk and oriented it specifically to caregivers, reminding them: Care for Yourself Before Assisting Others. – ed.

Stroke is the third leading cause of death in the U.S., with 600,000 new and 200,000 recurrent cases a year. It is the most prevalent cause of long term disability.

It is Life Shattering and affects all aspects of our quality of life, in physical, psychological, social, functional, and spiritual ways.

Stroke affects the family and friends:
- It is sudden and unexpected;
- It loses some of your self-image;
- It is often long-term;
- It changes family/friend relationships—forever;
- It changes stress, family support, economic resources, personality/coping styles, and relationship quality;
- It shifts ones family roles;
- We need to understand the new reality, mourn losses, accept changes, create & build a new life—in order to succeed;
- Improvements can continue indefinitely but many changes are permanent, so life is forever changed.

Common Emotional Effects:

**Survivors**
- Confusion
- Emotional liability
- Frustration, anger
- Sadness, grief
- Humiliation
- Fatigue
- Apathy, lack of motivation
- Depression, anxiety

**Caregivers**
- Helplessness
- Fear
- Frustration, anger
- Sadness, grief
- Impatience
- Fatigue
- Resentment
- Depression, anxiety
The mind is connected to the body and each affect the other, in a cycle.

Depression can lower sleep, motivation, physical health and the recovery.

Lack of sleep, alcohol use, poor physical health can lead to depression.

Also, the caregiver's and survivor's well-beings are linked together by the mental and physical health of each. If there are negative conditions on one side, the other side is likely to suffer.

Studies of caregivers show a lower immunity, increased blood pressure, and slower wound healing. Caregivers providing care AND experiencing mental/emotional strain show increased risk of mortality of 63% within 5 years.

Caregiver self-care is critical.

Each need to help the other, and create a new Life Plan. It gives resiliency and provides rewards: a new perspective and appreciation of life, increased personal strength, greater compassion, and stronger faith.

Together, We Can Do It!

Then, Elizabeth Larson, Seattle Institute of Sex Therapy, and Holly Eckert, Graduating From Guilt, talked with the caregivers on the subject “Navigating Uncertain Waters: Intimacy and Relationships After Stroke,” while Dr. Bishop presented on “Please Place the Oxygen Mask on Yourself Before Assisting Others: Caring for the Caregiver.”

For the stroke survivors, the afternoon subject was on how to keep physically active.

“What Now? Staying Active and Involved After Stroke.

by Chris Morrow, PT
Pacific Balance

by Kim Beitelspacker,
TRT
Harborview Med Center

Chris Morrow provided a handout with suggested stretches and exercises. He showed exercises that should be applicable to all stroke survivors to maintain their personal strength and physical stability. And other exercises to improve ability and avoid further loss in other physical areas.

He provided demonstrations on people who came to the front to show how they could be accomplished satisfactorily.

Chris also discussed diet and lifestyle considerations that could significantly affect your physical and mental condition.

Recreational therapy looks at how we can help people to modify or adapt/change "how" they do the activities they once enjoyed. This is not easy as you all know; stroke changes almost everything in your life, and recreation is no exception.

Kim Beitelspacker’s session was for survivors and had 3 parts:

1) "WHAT RECREATIONAL ACTIVITIES ARE YOU CURRENTLY DOING FOR FUN?" Many people raised their hands and eagerly shared a wide variety of activities: dancing, hiking, playing cards, out with friends, art, photography, ceramics, cooking and several more.

2) "WHAT DO YOU MISS DOING SINCE YOUR INJURY/STROKE?" Again, many people openly shared the many things they miss that used to bring a lot of enjoyment: talking on phone, golf, skiing, playing guitar, travel, talking with friends, driving, exercise, reading, sports, to name a few.

3) "IF I COULD, I WOULD: _____" I asked the audience to get up from their chairs, walk around the room and sign up on the sheet of 2 recreational activities they "WISH THEY COULD DO RIGHT NOW."

People eagerly found at least 2 and signed their names. Several people asked if they could do more than 2. I was thrilled with the motivation and cooperation of this group!

Right now I’m looking into community resources for all of these activities listed and will try to match them with the people who stated an interest. I am available to both caregivers and survivors via email, for those who are in need of assistance in future recreational pursuits.
tasks involving household appliances. She could not turn on a lamp, or a radio.

Today she still needs assistance from caregivers in many daily activities, but the list of what she can do grows as the list of what she can’t do shrinks. Her ability to read remains limited, but is improving. She can’t compose a letter, but she can write her name. She can’t drive a car, but she can walk around the house with a special cane. She can’t cook a meal, but she can handle most of the tasks involved with getting ready for bed. Her speech is still severely impaired, but she’s able to spontaneously say a few more words.

We have a laptop and a new iPad-reading device loaded with special software to help her communicate and practice speaking. And the other day, to the greatest surprise of her therapist, caregivers and husband, she tied her shoe. It was a small, but eye-opening achievement.

Her dominant right arm was left almost completely paralyzed by the strokes. She’s learned to rely on her left hand, and with practice is becoming more adept at using it for all the things we do with our hands without a second thought. But tying a shoe with one hand is tough.

Give it a try and you’ll see. Despite the challenge, she did it. She found a way. Fingers that once couldn’t turn on a light switch skillfully manipulated shoelaces into a knot, then stretched the loops to tighten the bow.

Somehow, brain circuitry damaged by the strokes has been rewired. It was all captured on video taken with a cheap digital camera.

What’s the moral of this story? I struggle with what to say. Awful things happen to people sometimes. There’s no fairness in it. How do you respond? But Cynthia’s answers are elegant in their simplicity.

Don’t quit, ever.

And learn to tie your shoe with one hand. «

So, you can only type with your left hand? Try “stewardesses”.
You can work with only your right hand? Try typing “lollipop”

The task of care giving is not a short term one but can be one of the most rewarding things you do. It is to be viewed through the lens of how you wish to be treated when you need care not as a ‘have-to obligation’. Having said that I want to tell a few anecdotes that make this sharing of life fun and more than that, downright hilarious, at least to me.

We have had some of the biggest laughs just grocery shopping. Just the other day in the store my wife wanted a particular type of cookie which was on the very top shelf and stacked three high. I said that I did not think I could reach them without spilling the whole pile so she cupped her hands together like she was going to lift me up to reach them and then she broke out in uncontrollable giggles. I stood there wondering what was going on because I knew she was just being silly but, lo and behold, standing behind me was a woman cracking up laughing also because she had heard the whole thing and was waiting to see my wife give me a boost to get the cookies. We got the cookies without incident.

Another time we were shopping for a dress for my wife and the sales clerk asked if she could help us. I let my wife tell her what she wanted but good old Aphasia kicked in and she was stuck after one word. She looked over at me and said ‘help me’. Then it became my turn to try to explain the type, color, style, and size (be careful here) to this very young sales clerk. The next time we went to that store to buy lingerie, that young lady went to the stock room and did not come out. Too bad, it could have been very funny watching her try to get out of dealing with me. I do not get embarrassed at anything now because the stroke patient is a person that on occasion needs assistance.

One of the big issues with my wife is she
believes people are looking at her and she thinks she looks funny to them. The truth is they are the ones that are missing out on what we are doing. We like to go to BBQ rib places, it is one of her favorite foods. Now have you ever seen how far a side of ribs in BBQ sauce can slide with minimal help? That is me trying to get the meat into manageable pieces for her to be able to chew. I have since the first time learned to request more napkins and a handwipe because I will have BBQ sauce up to my elbows and more. The good part is I get to taste a lot of different things by helping to cut up her stuff.

A key component for caring for your patient is being very conscious of the medication being taken and the schedule they are to be given. The critical thing to know is the window that the medication is working on, is it 2 hours, 4 hours, more or less. We have learned it is best to be consistent and have a set routine for the medications then the body does not get on the ‘roller coaster’ with the up’s and down’s.

Looking at the humorous side of Aphasia makes handling the situation better than building up a lot of stress that neither of you need nor want. The person with Aphasia has enough frustration to begin with, so if you can lighten it up and not put undue pressure on them you will be able to communicate better than you realize. Remember this is a two way street so learn all you can and help all you can and the care giving will reward you more than you think.

Announcements:

Dr. Jill Taylor in Seattle, November 2

Dr. Jill will focus on her personal story: why she grew up to study the brain, her research activities, and her own brain disorder.

Dr. Jill Bolte Taylor gave a TED talk in 2008, which has become one of the most viewed TED Talks to date. She was chosen as one of TIME Magazine’s 100 Most Influential People in the World for 2008.

NEWS FLASH - Sony Pictures and Imagine Entertainment are working on a feature film adaptation of My Stroke of Insight with Director Ron Howard!

The Tacoma Area Stroke group is growing by leaps and bounds. Their next meeting is Thursday, June 16th at the TACID building.

Valley Medical Center has a stroke club up and running. They meet 1 Tuesday a month from 1:30-2:30pm. Their next meeting is June 28th with speaker: Carol Blaich, M.A., Caregiver Program Specialist, speaking about "Disability Resources." The group meets in the VMC Medical Arts Center, 1st Floor, Conference Room A. For further information call 425-251-5665.

Young Adult Stroke Survivor group is having its next meeting on Saturday, June 18th at Northwest Hospital. Visit their website: http://seattleyass.weebly.com/meetings--activities.html

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