Aphasia Retreat

2nd Annual...

Save the Date!

Please mark your calendar for the 2nd Annual Aphasia Survivor and Caregiver Retreat.

Date: Saturday, April 30, 2011
Time: 9:00 AM—3:00 PM
Place: Lake City Community Center
Seattle, WA

Do plan to join us for a day with individuals and families living with aphasia:
- For Survivor AND for Caregiver
- Presentations
- Perspectives
- Sharing
- Exhibits
- Connecting

Complete information and registration forms available the week of March 14th.

Contact: SHCLINIC@UW.EDU
or, 206-543-5440 to receive a registration form.

Hosted by:
UW Dept of Speech Hearing Sciences

Kelly Scott, Aphasia Day Volunteer

Caregivers Presentation

-by Anne Nuñez, SPHSC B.S. Graduate, 2010
(Digest of her professional presentation)

People may be suddenly thrown into being a caregiver and often times:
- Have to stop working
- Lose friends
- Feel overwhelmed
- Feel cut off from the outside world
- Don’t know where to turn to get help

This affects more than 65 million Americans caring for loved ones with illness, disability, or frailty. Many caregivers needs may fall by the wayside. It’s important that they find a balance. Research has shown that if the caregiver is less stressed out, their family member with the disability is going to receive better care as well.

Many times caregivers have no recollection that they were given any information at the time of the stroke onset. It is likely that they...
At the time Arlie had his stroke in May, 2008, we had been retired and we had settled into a quiet life and one that kept us busy.

Arlie enjoyed his computer, ran his errands. We shared chores around the house. We enjoyed our grandchildren, our friends, and had time to do a little traveling. People would ask us about retired life and our response was always “it’s a good life.”

I handled Arlie’s stroke very matter-of-factly. I got him into the hospital, and with two of our children, we sat with him for 8 days, then got him home. We understood there were doctors to see for follow-up, speech therapy, etc. Speech therapists talked about working on alternative ways of communication, but naively, the kids and I sat waiting for Dad to talk again.

Our “good life” turned into a life of togetherness. Since the doctors were a little concerned about Arlie’s driving, I slipped into the role of driver. I accompanied him to speech therapy and to Doctor’s appointments. We went on errands together, to the barber shop together, to the garage to have the oil changed in the car together. This went on.

Arlie started a weekly Game Group at Northwest Rehab, and the Support Group at University Speech and Hearing. It was during these times, while waiting for him, that I could walk the Mall with a friend, have a quiet cup of coffee, or browse thru shops. I then began to realize I had space again.

I was very much aware of the term “caregiver.” My Dad cared for my mother who had Alzheimer’s. My neighbor cares for her mother who is confined to a wheel chair. But for some reason, I never thought of myself as a caregiver. It was when I began to realize I were overwhelmed with everything that was happening; the information needs to be repeated: at least at onset, at the start of treatment, and at the start of the chronic, “continuing” phase. Families are severely affected by getting discouraging information.

Encourage caregivers to have a forgiving attitude toward themselves. Make an effort to keep their own life distinct and actively search out ways to fulfill their own personal needs.

Give people with disabilities every opportunity to care for themselves as they are able to handle it. This helps give them a sense of purpose and meaning in their life.

Associate with support groups—in person or on-line. Much comfort may be gained just by knowing that you are not the only person going through the same kinds of issues.

Write a personal journal, as a way to release pent-up feelings.

Read other’s experiences.

Obtain counseling, if needed.

A suggested personal caregiver resource list:

- Personal Portfolio
- Communication book
- Maps (of local area and world)
- Picture resources
- Picture scale
- Pad and paper
- Calendar/Personal Organizer
- Leave instructions in written form
- Personalized Phone Message
- Control distractions
- Be a partner, not a therapist
- Educate themselves and others

Other resources can be found at:

National Families Caregiver Association (NFCA) at: www.nfcacares.org
National Aphasia Association at: www.aphasia.org
Family Caregiver Alliance at: www.caregiver.org

(-ed.)
needed “space,” I realized I, too, fell into this category.

At the same time, it became aware to me how very important these groups were to Arlie. He made new friends he was comfortable with, who were one in understanding his disability. It gave him a sense of belonging. I am proud of Arlie who never hesitates in trying to get his message across. He never has.

I want to be a good caregiver. Fortunately, we live in a community where we have the support to allow this. It’s important to us.

Caregiver’s Learning Curve

- by Tom Hagerty

When asked to give my perspective on care giving I thought that is easy since I have been doing it for 6 years. The truth is I have no idea what to say because the task of caring for a stroke survivor is varied as the individual involved. I do know that no one gave me any tips or ideas as to what was to come.

One of the first things was trying to learn the language of the medical team.

Next came the stark realization that there were going to be some very critical decisions to be made, the type no one wants to make and never dreams of how quickly they must be made. Decisions to perform surgery or live with the fatal consequences, not to be taken lightly.

The family unit is extremely important when it comes to helping, they make sure I eat or get some rest and they try to break up the tension. Looking back, that was the most helpful because you tend to get locked in on how the patient is doing and what else can you do. Our daughters thought that because their mother was so involved in music and enjoyed it so much they would bring in a disk player and some of her favorite music to help her come around after surgery. It was not long before the Dr. said to remove it because their mother was not trying to come out of the ‘coma’; she was too comfortable. That was a very hard decision for the girls to understand. It was the best for the patient.

Time passes quickly and now it is time to take my wife home. We go through all of the PT, OT, and work with the SLP to make certain we know what to do. I say this because shortly before doing this while in the hospital I asked my wife if she wanted a drink of water because her mouth was so dry. I drew a glass of water from the sink and gave it to her. She took a regular drink and started coughing like mad. I got her to sit up and did the old raise the arm routine and she seemed to come out of it OK. When the SLP found out what had happened she gave me the very stern lecture about never doing that unless she had okayed it. At that point I received another lesson about a term called Aphasia, and what it is. What I learned was that the receptors in the throat do not react as quickly with tepid temperature as they do with the extremes like hot and ice cold. The SLP also said that it was necessary to observe my wife as she ate to be certain that she could clear her mouth of the food she was eating much as you would do with an infant.

How do you know when you may have done something wrong? A person with Aphasia may not be able to communicate that there is a problem. My wife came home with only a ‘yes - no’ vocabulary, so I had to be on high alert for whatever it was that she was trying to say.

Outpatient rehabilitation was a god-send as it gave me a method to see progress and to ask some more basic questions. The SLP was marvelous in the way they got my wife to put together words but then it was my turn to play the game of ‘describe the term or picture’. Since we communicate faster than any computer ever built, it is unnatural to slow down for the patient. Oh, and also, the patient will get extremely tired due to the brain having to work so hard trying to ‘reload’. Reload is my term for trying to get the brain to work life as we wish for it to do. I know that Aphasia affects everyone a bit differently but I think that the goal is all the same and that is to try to have the brain function as close as possible to what it did.
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tons of “I’m sorry”. We still do not know what happened except that we did not get to eat the casserole.

The learning curve of a caregiver is absolutely vertical and unending. So just accept it and enjoy what you are given.

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My Christmas Stroke

-by Su Hagerty

It was Christmas 2004. Our family was in the kitchen talking. I was just explaining my dad’s book about World War II and his time in the Philippine Island as a master sergeant (Army) and a POW in Japan. I was crying. My dad, Chuck Humphreys, was NOT my dad; he was my ‘caretaker’. Nibs Hahn, Chuck’s best friend, was my biological father. Who knew where he was!

I was just weeping; I was so frustrated with both my dad and father. Meighan, my youngest daughter, said “Mom”. She waited for a second, looked up and said, “Mom has had a stroke!”. Tom said, “no...Su...Su...”. But she was right! I had had a stroke! “Thank you!” my eyes “thanked” her. Shawn, my second daughter, dialed ‘9-1-1’ on the telephone. I went to ‘sleep’ on the couch.

And now, I have aphasia as the result of my stroke. The brain is working at normal speed but the information does not flow to my mouth so my brain and mouth are not coordinated.

I have not lost my intelligence only the ability to express myself in a rapid exchange. I use all types of ways or things to make my brain get my thoughts organized and that is why it takes me extra time to respond. All of this extra work causes me to get very tired quickly.

A stroke and aphasia...all this in a short period of time. I struggle with these things, but I know I will accomplish ‘this long road of recovery’.

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Book Review

-by Ted Paluchowski

Passages in Caregiving: Turning Chaos into Confidence, written by Gail Sheehy (2010). According to the author, there are 65 million caregivers in the U.S., and the number is expected to double in size by 2030. As the American population ages, seniors are living into their 80s and 90s. At the same time, the pool of health providers is shrinking. Therefore, the majority of the population will be faced with the job of caring for a loved one.

When her husband was diagnosed with throat cancer she suddenly became the primary caregiver, a role she played for 17 years. Throughout the book she refers to personal stories to illustrate the text.

Through 2009 she was AARP’s Caregiving Ambassador. During the years she began to collect data about caregivers. With AARP’s assistance, she selected four cities to interview about a dozen caretakers each.

Finding common threads in the maze of data was a major challenge. The author was especially prepared for the task. She was well known for describing the changes at different points in life. Her book, Passages, was a best seller, included a comprehensive bibliography.

For caregivers there is an unpredictable series of accomplishments and remissions.

The metaphor of a labyrinth best describes the trajectory taken by caregivers. A labyrinth is an ancient device used for contemplation. There is a circular route featuring twists and blind turns eventually ending at a central point. Many churches have a labyrinth built into the floor, including one in Chartres.

According to the author, caregivers go through 8 major turning points. Overall, there is a clear message: recognize the difficulties and you can’t do it alone. With time, a caregiver changes from ‘chaos to confidence’. «

Caregivers Frustrations & Support

-by Julie B.

(‘Julie’s first article was ‘A Real Handful’ in Spring Newsletter #34. She made a presentation at last year’s summer’s Aphasia Retreat. Here is her follow-on story. -ed.)

My husband, Wayne, was very active and helpful. I’m crying because I’m remembering who he used to be.

My memories of the hospital are of him just sitting there. There was no sound. He cannot drive, he cannot go to work. He can’t talk, so he cannot use words. He only has a syllable or two. So he just says ‘we’, and ‘no’. He tries to speak and he gets very frustrated.

Too often, I don’t have enough time to really converse. We’ve got like a full schedule, a full agenda. We’re running around most of the time.

I actually started a stroke and head injury caregiver group here with the help of Nancy and Diane, so we are meeting every Saturday now. There are caregiver support groups but they’re very general, like cancer and Alzheimer’s, but stroke and head injury is very different because it’s not something like you are dealing with a terminal illness and they are going to die of it. It’s actually living today and then even getting trained to get someone better, and regain speech, and mobility, and cognitive and vocational. So I felt that a stroke and head injury caregiver group was imperative to our support and resourcing and meeting our goals and succeeding as families that have survived a stroke.

Amazingly, it’s helpful, it’s imperative, it’s vital. It really is.

I joined caregiver.com and care-giver.com and there’s a caregiver magazine, Today’s Caregiver.

On the other side, so to speak, my husband actually is quite irritated that I’ve started the caregiver group because it pulls time away from him.

“Like the moon, come out from behind the clouds!”

-Buddha «
It’s important for me to know that there are stroke survivors that feel it’s important for caregivers to find support. It’s amazing I feel like, just kind of more grounded. And maybe that’s just where I am in the cycle of our stroke, post-stroke life, but I have to think it’s a little bit of feeling like I belong. I’m not crazy for feeling what I’m feeling; other people are feeling this. It’s not just my inefficiencies or dysfunction for feeling the way I feel.

They need help, feel that they can’t afford to let go of the help and the support. They need to have that support right there.

I was part of the catalyst for starting it and I’m also a caregiver. So, yeah, it’s good. And I definitely want to make sure that I’m allowed to be a participant, that my role in it isn’t always the kind of director or whatever. I need, I want to be able to let down and be common and normal with the group. It’s cathartic, it’s wonderful, actually.

This is a passion, making sure this is right for our family and others. I said to my parents, “I have a choice to stay or go. I could leave Wayne, I could even leave Morgan. I could say, “I’m outta here, I just want to start over, this is too hard.” But, I’m choosing to stay. I’m choosing to stay with both of them and that’s my choice. I’m not stuck, I’m not a victim. I’m choosing to keep this as my life. There’s nothing else to say about it.”

Like a lot of my friends say just, “He’s alive, he’s with you. You have to be grateful for that. He’ll learn to talk again”. That’s not all that it is. It’s not just that he can’t talk. But, we’re lucky. He’s really the same person. I really feel in a way that’s it. That’s nothing compared to what some families have lost and are going through. We’ve got it easy in some ways, ya know?

I mean, I have it bad, but I don’t have it that bad.

**Going to Class, Again**

Inviting an Aphasia Support Group to attend an academic class usually excites and satisfies the Group AND THE CLASS.

The interchange encourages the Aphasia survivors to vent their frustrations, demonstrate their disabilities, and to practice and show their progress.

Though the students get academic course materials covered in profound detail, real-world examples, as provided by the Group here (March 9, 2011), can impact on and clarify the student’s feelings and understanding.

Better yet, such interaction here has often helped persuade students to select (or even change) their choice of profession to Speech and Hearing. Mutual success! (-ed.)

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

“In Search Of ...”

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