3rd Annual Aphasia Retreat

Aphasia survivors and caregivers, over a hundred of them, attended this special retreat. The occasion brought more than fifty committed volunteers, including graduate and undergraduate students, faculty and staff. They provided organization and registration, food, comfort and support, as well as the expected interchange between professional and client.

As attendees arrived and registered for the day, volunteers served continental breakfast. Everyone had time to get acquainted with one another and get settled in the Lake City Community Center.

Director Nancy Alarcon kicked off the program and welcomed attendees. She was followed by caregiver Dorrit Jensen and survivors Dennis Duva and Chris Adams-O’Coyne, with their stories.
Dr. Carolyn Baylor, Acting Assistant Professor with UW Department of Rehabilitation Medicine, presented information about a new program at the UW Hospital. It teaches medical students how to communicate with patients who have aphasia or other communication disorders. Many doctors have never received formal training in how to communicate with people with aphasia. Each person with aphasia may need to educate their doctors about better ways to communicate with patients. Dr. Baylor suggested ways to do that.

Dr. Sara Schepp, neurologist with UW Medical Center, followed with her question, “What have you always wanted to know but never had time to ask?” and provided answers to group’s questions.

Attendees took a break for boxed lunches at midday, while viewing community vendors. Vendors included stroke survivor Dawn Wass’ jewelry, survivor Mike Tran’s Stroke Determination Foundation, the Young Adult Stroke Survivors (YASS) support group, and UW audiology graduate students who provided information on your hearing health.
After lunch, survivors divided into smaller groups. Students led the group discussions and asked survivors to share what they had learned about living with aphasia. They were asked what advice they would give to someone who was a new aphasia survivor. They suggested, for example: “Get out and practice talking!”, and “Realize that progress is still possible after the doctors say that the recovery is over!” Faculty and students at the UW Speech and Hearing Clinic will summarize their advice into a pamphlet and make that available to new aphasia survivors in the community.

Meanwhile, survivors’ families and friends adjourned to the library next door to discuss their individual experiences as caregivers. Dr. Diane Kendall and Rebecca Pompon, Ph.C, facilitated the caregivers’ group and led a discussion on the challenges of caregiving and the importance of self-care for the caregiver. Each caregiver was invited to share their own resources and strategies for coping with their problems while supporting the stroke survivor.

Some words of wisdom from caregivers included: “Don’t forget to laugh and have fun with each other.”; “Take time for yourself...walk and talk with a friend.”; “Don’t feel that you alone can take care of everything.”; and “Ask others for specific help.”

At 2 pm, survivors and caregivers came back together for the day’s wrap-up and send-off.
A purpose of these annual get-togethers has been to focus and expand efforts to recognize the personal impacts of aphasia, also, to further assist survivors’ improvement and satisfaction. Based on the overwhelmingly positive feedback from attendees, planning for a repeat of the Aphasia retreat (the 4th) is already underway and will incorporate attendee feedback. (Yay!)
The commitment and intense effort of all involved in the retreat led to the reward:

“Making Your Voice Heard!”

--Many thanks for inputs to this article by Rebecca Pompon, Ph.C and Dr. Baylor

Sadness is part of the usual feeling, when a friend leaves a group and the connection dissolves. Bob Hay celebrated his 93rd year in May.
Bob has left our group - his nautical background brings up the thought of Tennyson’s “Crossing the Bar”. Bob has done so, he ‘crossed the bar’ on July 19th.
Yet, there is no “moaning of the bar” needed. He has now seen his “Pilot face to face” and, hand in hand again, his wife.
Bob’s wit, wisdom, and spirit are fond memories for us. - RLA

Us - You and Me
All survivors of strokes are we, that means us - You and Me
We want all our thoughts to say, but no words come along our way
All survivors of strokes are we, that means us - You and Me
Our aphasia’s group is meeting here to tell our stories without a tear
All stroke survivors are we, that means us - You and Me
Each telling tells a li’ bit more than what has been heard before
All survivors of strokes are we, that means us - You and Me
So our tales again are retold, but all seems newer - never old
All survivors of strokes are we, that means us - You and Me

--- Patricia M.

Nancy Alarcon:
Opened
Coordinated
& Closed

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