Our Stories Change  
— And Advance!

The Aphasia story, from each of us, is important to tell—of our difficulty and of our recovery. It reveals our imperfect understanding of our disabilities. It practices and confirms our continual advances.

It’s important for others with Aphasia—Stroke Survivors—to hear/read it. It’s just as important for caregivers—family, friends, and professionals. For their understanding, empathy, and recognition of disabilities and how we each fit into the web of troubled lives.

Our story is sad, powerful, interesting, and rewarding. To us. To others.

When new survivors feel comfortable with us (and we feel comfortable with them), we ask them to share their story. And, each school quarter, we encourage the group to reengage each of us with each other.

We used to feel that we would all hear the "same story". Now, we find that the story unfolds, and there are new, fascinating parts of each person’s story. We are continually surprised and comfortable with whatever they are willing, or now, able to share.

This is our latest "show and tell": of what happened, of our hopes and our progress:

Dennis: All right! Let’s get started!

Lowell: I had a stroke because I had a knee and that was in April 2004 and I don't know exactly what happened but I couldn't talk and I couldn't hear myself or anybody else and I couldn't say anything at first. It was just really scary. I didn't know anything about the stroke or aphasia or any of that stuff.

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The Power of Our Stories

Robert McKee is quoted as saying, “Stories are the creative conversion of life itself into a more powerful, clearer, more meaningful experience. They are the currency of human contact.”  - When I was preparing a talk for a conference this Fall, I kept feeling that my words weren't going to have much of an impact on my audience. I wanted to talk about the power of communication, how it impacts our day to day lives. The research literature was important to include, but I wasn't conveying the experience of how we're able to connect with others. I realized that I needed to make it come alive with a true personal story. Sharing a life experience made the talk come alive; people could relate to the story at a variety of levels. I could actually sense that “the listening” changed. The room became quiet.....

It is with deep respect that I quietly sit and read the amazing stories in each issue of our newsletter.

"Their story, yours and mine -- it's what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn from them."-William Carlos Williams

Join the Aphasia Registry Today!!!

Researchers at the UW are starting an Aphasia Registry. If you join, you will receive information from the UW Dept of Speech and Hearing about:

- New aphasia research studies
- Aphasia education and support seminars

Contact the UW Aphasia Laboratory
Dr. Diane Kendall, Laboratory Director
206-685-2140 or dkendall @uw.edu
I should tell you I found a hole in my heart, it went into my brain and I couldn't talk. Everything was in my mind but I couldn't put it in words. And then I found out later, that was about 3 months later in the hospital, they found a hole. It looks like two umbrellas that they put it in the hole and so now there are no holes.. Now it should be fine.

Physically, I was pretty lucky. But I couldn't read; of course, I couldn't talk. It gets better and better. I don't talk what I want to say, sometime, but it's still so much better than it was and I can read a lot more. This group really made a big difference.

**Beverley:** I had a stroke on March the 15th, 1993, so it's been a while.

I was in the hospital because I had my brain operated on. I had an aneurysm. It was my husband’s birthday. I didn’t know that I had bandaging on my head. I was insisting we go celebrate my husband’s birthday, so I was going to get out. I became so agitated they had to call a nurse and she gave me a shot. That was when I had my stroke.

I was unconscious for about two weeks. I couldn’t talk or read. In the hospital they helped me with physical therapy and I was inept in the kitchen. My husband called the nurse and said don’t ever let her in the kitchen again. (Laughing)

**Nancy:** So you didn't have to do any more cooking?

**Beverley:** Right, right.

**Todd:** It might just be me, but you have improved um, yeah.

**Stephen:** Yeah, your words go quicker together.

**Beverley:** Thank you.

**Nancy:** It was a tough journey back in ‘93. That journey became very complicated. Fortunately they got you to stay where you were. But, unfortunately, you ended up having a stroke. Thank heavens you didn't walk out of the hospital.

**Beverley:** Yeah, I was held hostage.

**Nancy:** Is there anything you wanted to add about Chris.

**Beverley:** Chris is in chemo and radiation so she won't be here all this quarter. It’s very hopeful she will be fine. She has a cancer.

**Marilyn:** Todd, could you please tell us how far you have come since being in the group.

**Todd:** I live on Vashon, in a yurt. It looks like Mongolian, but is made locally. I take a bus and then a ferry. It takes 2 hours.

Mainly, I now talk to the entire group. I laugh and I don’t feel uncomfortable, now. I will be gone for a month, I think.

**Nancy:** We are glad you can be here for a couple of sessions. That's really neat feedback for all of you about the power of the group. Isn't it amazing the support each of you offers to each other.

**Bob A:** So where are you headed?

**Todd:** Various places, Boise and Champaign, Illinois, and Tennessee, and in a van—a Volkswagen Westfalia.

**Bob A:** I was having fun coming back from a Germany trip. Most people in the back of the plane get stuck, like a sardine in a can, where you stay for ten hours and you end up with clots in your legs, or, deep vein thrombosis (which nobody really knew about until after that time).

And I had a hole in my heart. Lowell, you said it! Everybody has had one to start with, and some people still do. With a hole in your heart, a clot can flow through that hole, right up to the brain instead of the lungs.

**Marilyn:** So you have had 3 or 4 strokes now?

**Nancy:** The repair in your heart was after your 3rd stroke.

**Bob A:** Uh-huh

**Stephen:** I think a lot of us have holes in our heart. I had this first stoke when I was...
29. I was in this hospital and I was in my mom's house for 2 months. I was trying to finish my PhD, but I wasn't able to.

Then I had a second stroke in my sixties. Then I had a third one the day after that. The stroke was short, but that created a real trauma for my family. I think the trauma was worse then; my stroke was okay compared to them. Their dealing with me was really hard. You can heal from a lot of stuff, but sometimes it will hurt your family more than it will hurt you. So I've been working hard to heal from this trauma and stroke.

In terms of you guys, you have really helped a lot. I'm talking better and my mind isn't too organized yet but I only had the stroke two and a half years ago. It's hard because you need a mind to work, and sometimes the mind works and sometimes it doesn't.

I have to be really careful what I eat. If my sugar's up too high then I can't think. Most of the time I don't think about what I can't do. I think that's real important. You've got plenty of stuff you can do. Even if you can't talk, you can have love for other people and stuff like that.

There's a lot of stuff I can't do. I just focus on what I can do.

Arlie: I had a stroke about 15 months ago and I couldn't speak and my wife played flashcards, dog, cat. Northwest hospital and I slowly began to speak, not much words but spoken. I began to speak slowly. That's it.

Nancy: So gradually up, up, up. Any observations about Arlie just now?

Valerie: A lot better.

Nancy: That's nice feedback

Arlie: Yes, thank you.

Valerie: You're quicker back and forth. Your flow is easier. You don't get distracted so easily.

Bob A: I'm trying to remember how many group meetings it was before you said anything there. I think it was 3 or 4 times before you said a word.

Valerie: So you're more comfortable with the group now.

Arlie: Uh-huh.

Valerie: Basically, you're the new kid on the block.

Dennis: Hi, my name is Dennis. I'm a stroke survivor of 25 plus years. It's called an embolism. It ruptured in my brain.

Nancy: Aneurysm.

Dennis: Exactly. One of the problems was part of the brain was out. 7 or 8 months in three hospitals. I came back home and I couldn't walk, I had to use a wheelchair to the bed and back. That's about it. Little by little.

I had gone to a couple of schools. The CCR in Puyallup. It's a part of Good Sam hospital and they have a program for 6 months, it's a trial. Most of the time you can get a job and I was out for six months and I got a job in Kent schools at the library for a year and then they retired me.

I was crushed. But that's the way it is. I've volunteered at schools for 20 years. I volunteer at St. Vincent in Seattle. I volunteered and I go to the University for 16 years now.

Nancy: Really, 19. Dennis and I were just mere children when we met. Dennis has been with me for 19 years. You know I've known you for almost as long as I've known my husband.

Dennis, as you were telling your story I want to share with the group if you don't mind. Dennis has been with me for 19 years. You know I've known you for almost as long as I've known my husband.

Dennis, as you were telling your story I want to share with the group if you don't mind. Dennis, because of being 25 years after his stroke, he really went through a very different type of recovery process. What was available 25 years ago
was very different from today. Much longer stay in the hospital.

As Dennis said he was able to go down to a program in Puyallup for 6 months, it was the center on cognitive rehabilitation, it actually was one of the pre-eminent programs in the nation. We would have people in the hospital for a month, 2 months, 4 months, 6 months at 500 dollars a day on rehab. Huge, huge expenses, but amazing possibilities.

Dennis, did you go home sometimes on the weekend?

**Dennis**: Oh, yeah. That's the first time you get to go home. You have no idea where your house is.

**Nancy**: So they would send you home for the weekend so your loved ones could begin to adjust to you coming home. You'd figure out if there would need to be accommodation in the home. Did they have to rebuild some services?

**Dennis**: Oh yeah

**Nancy**: It's pretty amazing, but because of health care, insurance costs, hospital costs; there has been such a cut back on services, some of it good, some of it unfortunate. People are sent home much more quickly.

So, Dennis, a pretty amazing journey and it’s amazing because you had to retire, but this volunteering has been a central part of your life now. How many years have you volunteered for Arise?

**Dennis**: 16 or 17 years.

**Nancy**: Arise is the outpatient day program over in West Seattle. For stroke survivors.

**Dennis**: Mostly stroke survivors, a couple of head injuries. Pretty good group.

**Dewey**: I had a stroke in April 2002. I used to work as a store manager, years ago. I got out of that to become a salesman. I used to travel many miles from Seattle to Missoula, from border to central Oregon. So I spent many, many hours in the car and consequently I've gotten blood clots in my legs so the doctors gave me blood thinners.

Okay, so everything was fine until I was working in the store everything let go, stuff came on top of me. It squashed 3 discs in my back and cracked one of my bones, that was in 1987. So the doctor told me I can fix your back but you gonna die on the table because your gonna bleed to death. So you're disabled.

Consequently, here and there, mid-90s we became snow birds in Mesa, Arizona for 8 winters. Our last winter there I fell on the floor and the next day later they told me your gonna have to sign here and you’re going to go to a rehab hospital. I didn't even know what that thing was, a pen! Well, all I could do was make an X. They sent me there and December 3rd I finally came back up to Seattle.

They sent me here and Nancy has done a wonderful job. Anyway we're here and I love these people, I tell you, Nancy and her girls do a wonderful job for me.

**Nancy**: It's mutual. Thank you. Dewey has been a great proponent of audiology services because the gals downstairs take great care of him.

**Bob H**: I was trying to remember when it was I had a stroke. I think it was 2000, something like that. Anyway, I worked for the church. I was making a phone call to the secretary. I started talking on the phone and she says Bob, hang up. I thought what's the matter with her? And she hung up.

All of a sudden the front door was pounded on and I saw the biggest fireman I ever saw in my life and he took a hold of me, flopped me down and started putting stuff on me. I thought, what's wrong with these guys. There's nothing wrong with me. But, I had a stroke in my left brain. I don't speak good, and they said well it will never get perfect, it will get better. This one doctor said 5 years is about the best you can do. And I said doctor, you’re through.
I didn't know what I had until I finally found out that I had Aphasia. I'd never heard of anything like that in my life, I'd heard of a stroke, obviously. But that's what I have.

You gave me 4 different girls, 4 times, women, Nancy finally said if your good enough, you can be part of this outfit here. I said, ooh, do I want to do that stuff? You know, I could see Dennis was here and Bob was here and Ted was here. One thing I have to say about that guy, Dennis, I said to myself, if he can get along as I can, there's nothing wrong with me, for goodness sakes. Ever since then I've been better to myself because, you understand we all have the same problems, but so we get along with it.

Marilyn: Can I share, Bob(H) celebrated his 90th birthday, with 250 guests at his party.

Bob H: It’s hard for me to believe that myself.

Ted: I had a stroke about 14 years ago. At the time I was trying to complete my PhD. Looks familiar? I think there's a real correlation between getting your PhD and having a stroke.

When I first had my stroke I could barely speak. It was hard to make any sense out of it. I found out that I had aphasia. I didn’t like it. After a couple months I went through seizures, two of them, that hospitalized me.

After that I joined the clinic here. And I’ve been getting better since. Ironically, the seizures cleared my head. And that was the hard way to clear your head, let me tell you. I have progressively got better. After eight years I could read and write a book. And now I’m one of the editors of our little newsletter.

And I will tell you there are a couple people that should make a contribution to this newsletter. Lowell, you keep telling me you can read and write. We should get your contribution. Tony, you should think about it too. But you know, write your thoughts down. You have a great opportunity to share your thoughts with other people.

Valerie: I had a brain injury about 14 years ago. The brain was bounced front to back. I had a lot of things going there. But I did have physical treatment, psychologists, the speech therapy was next to nothing. If you could do Sesame Street you were fine. Frustrating.

Fast forward, about 7 years ago I had an auto accident and the airbag impacted at about 200 miles per hour and hit a heart valve loose. I had open heart surgery to repair that. I had a major stroke, the blood filtering machine let a blood clot through. Everybody was planning my funeral. I was out of it. Your body is under stress and everything else.

Then the rehab part was 14 days after the cardiologist part of it. I was home 5 months of visiting nurses, speech therapists, occupational therapists. The speech therapist was phenomenal; to get me back writing, reading, learning how to do numbers. Fantastic lady. It wasn't until I got here to the UW that I was finally making strides. The usual, no walking, not much talking, like everyone else, progression. Doing the same like everyone else in this group.

Never give up, never give in. You keep pushing, pushing and every so often you have to regroup. Step back, let yourself catch your breath. Go forward again. And always experimenting and doing new things. Not be distracted. Always have a sense of humor. And my family doesn't laugh at me, they laugh with me.

Nancy: Thank you Valerie, well-said!

Tony: I've had my stroke about 9 and a half months now. It was December 22nd, just before Christmas and then I was in the hospital until January then I went home after that.

They said I had 3 veins that were plugged in (Continued on page 6)
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my left brain. They were able to get two of them okay, but one they didn’t. That’s why I have the aphasia that you all talk about.

It’s kind of like learning how to talk again. But I remember everything. I didn’t lose anything.

One of the things with insurance. They only do so much. I did a lot of therapy at Evergreen, they only let me do 20 lessons for them. After that I have to do it myself. We looked around and found that UW also does it. That’s why we came here.

Before, I used to work in Information Technology (IT). I've been in IT for 25 years. I worked at a utility for 10 years. I started to try to go back to work 2 weeks ago. Like a project manager. For the first week I went to a lot of meetings to listen to see what they were doing.

I was very tired when I got home. Then it got better. I remember everything that they were talking about. All the projects that they were working on before my stroke they now started. They didn't do a lot of new ones that I used to do.

So now I’m trying to speak better. That’s the main thing for me: speaking.

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Our Students
in UW Speech & Hearing

Each academic quarter, we encourage and invite students to participate in our aphasia groups as a part of their clinical training, or as part of a learning project. This quarter, Doctorate of Audiology student Becky Lewis co-lead the Tuesday Aphasia Group. As part of her work, Becky provided an informative talk on the ear, how we hear, and key research on hair cell regeneration taking place at the Bloedel Center at the U.W.. Becky is actively engaged in research while completing her degree. She has been a wonderful addition to group this quarter.

Anne Nunez, a Speech & Hearing Sciences Undergraduate student, is doing an independent project with Nancy Alarcon this year. As part of her work, she is providing support to this newsletter’s Editors and Publisher. Anne, with the assistance of her husband, has created a searchable database for the newsletter. In addition this quarter, Anne presented to our Tuesday group on “Ten Principles in Neural Plasticity”—the ability of the human brain to adapt to challenges—and specifically in the presence of brain damage.

Group members found each student presentation engaging and informative. These topics encourage members to ask questions, learn new information and broaden their life experiences—a central theme of our time together in group each week.

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