



My Life After A Stroke

by *Valerie Boen*



Valerie

I am still trying to put my life back together after a stroke. This wasn't supposed to happen to me. I'm in my mid fifties and was very active at work. Okay, a little over-weight, but

nothing clogging up my blood. It all started with a fall on black ice on the first day of the New Year, 2004. Both knees were damaged, one requiring surgery. My regular doctor, Dr. Lopin, discovered a problem with my heart and ordered more tests. I got a call from the chief of cardiology, Dr. Yakovlevitch, that same night. He wanted me in his office the next day. The heart had a trauma injury, which tore the mitral valve. It was hanging by a thread. I needed open heart surgery to repair it. The operation, by Dr. Verrier, was a success! Until the doctors discovered the stroke.

Apparently, the machine filtering the blood let a clot through. Now, the doctors and nurses were fighting to keep me alive for the next four or five days. I have a large extended family. They kept the waiting room filled while I was in intensive care. They rotated in shifts to make sure I had my back rubbed, my throat wet and their voices to soothe me. They continued this when I was out of intensive care and in the cardiac unit. My husband, Jerry, stayed with me day and night in the cardiac unit to look after my needs. I had no feeling in my right arm, no vision in my right eye and little sensation in

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To come: Stories about Aphasia
-from stroke survivors
-from the family
-from survivor's clinicians««

my left fingers and arm. I could only say two words. I could not write anything! My identity was gone! I was devastated! This is how I arrived in the rehab center at the hospital.

My self-esteem was gone. I felt sorry for myself. Why wouldn't they just let me crawl into a hole and die? But, my family wouldn't let me. They were determined to get my self confidence back. The rehab center gave me the time I needed to work on my depression. My family was confined to visitor hours. I had the opportunity to work on how I wanted to deal with my new way of life.

Rehab staff's goal at Northwest Hospital was to help me function so that I could go home with my family's assistance. They had two issues to deal with. One was the physical restrictions from the open-heart surgery. Second was assessing the extent of the stroke. The staff of physical therapists, occupational therapists and speech therapists then coordinated a treatment plan. I was taught basic skills for every day living, from getting in and out of bed, dressing, showering, eating, etc. I had to have help with everything, even walking. They had to make sure I learned how to be safe and not damage anything from the surgery. Communication

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took on a whole new meaning. My social skills, like taking turns while conversing, didn't exist anymore. I now seemed "bossy" because I tended to dominate conversations. Just trying to talk, or actively listen, was exhausting. My words kept coming out wrong. I couldn't even state what the topic was that I was trying to talk about.

I had to learn to tell time again, learn to count, learn to print, all the very basics. I could read, even though my cognitive skills were slow. I had been in the middle of a good novel and just had to see how it ended. This became my personal "training" challenge. I was NOT going to let anybody do my reading for me!

My husband's devotion to me was amazing. He constantly came up with new ideas to stimulate my mind. One of them was his visual aide, in the form of an ever-changing picture wall. It was fabulous! He used the computer to enlarge pictures of our home, garden, pond, kids, pets, trip's and gatherings. He taped these 8 x 10's to cover the walls. With his and my children's help, Adam and Stephanie, my attitude gradually changed. I could fight to regain control of my life. I just had to learn the new set of rules to live by.

Eventually, I got to go home. I had in-home visits from the speech therapist and the occupation therapist, as well as nurses. My speech therapist, Jan Regier, was exceptional. She challenged me to go beyond what I thought I was capable of. She made me learn how to think, again. Write a thought down, check carefully how I phrased it, rewrite it, and then check it again. She taught me how to speak this way.

My heart was still an issue during this time. The heart beat had a condition called, irregular-irregular. It was like running a marathon 24 hours a day. I needed to be in a regulated cardio exercise class. As my health improved, I progressed to the out-patient rehab at Northwest Hospital for speech therapy and occupational therapy.

My speech therapist, Kara Beringer, also did much more than just work on my speech.

She also helped modify my behavior and try to see a different perspective in thinking. I've now moved on to the Speech and Hearing Clinic at the University of Washington that is under the direction of Nancy Alarcon. I have weekly Aphasia Group meetings as well as individual lessons with graduate student clinicians (Rebecca, Chaitee, Shanna & Abbie).

The challenge is constant for me to improve. My confidence has gradually come back. My family has continued to support me. I'm grateful for the hard work and help from everyone at the UW Speech and Hearing Clinic and everyone who has helped me during my recovery.

(We look forward to input from families of stroke survivors and anticipate some from Valerie's family and others. Their view of the difficulty can be meaningful to the survivors, to themselves, to other caregivers, and to the professionals that care for and treat them. - ed.) ««

Aphasia Goes To Class

Stroke survivors find it useful to share their experiences and difficulties with others and they periodically—"go to class."

The University of Washington Speech & Hearing Department teaches an introductory course every summer and fall, titled **Speech & Hearing Sciences 250 – Human Communication and Its Disorders**. It offers an overview, including speech, hearing, and language difficulties.



Dr. Robert Carpenter has added a unique experience to this class for over five years, inviting members of our aphasia support group to talk with students about "living with aphasia."

Students get a practical, human perspective on stroke and aphasia. And the stroke survivors work through their problems while talking with the students.

Dr. Carpenter prepares the class beforehand, may encourage specific follow-up



comments from the presenters or ask the students for their understanding of "what they just heard".

Some of the stories told may include very sad, tragic aspects.



Some are humorous.

And some can inspire sympathy.



The students can choose to become a speech-language pathologist. It is not unusual for students to come forward after class to tell the members that they have been inspired to decide on that profession.

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The Book Corner

There are a number of good books about stroke and the aphasia that often is an after-effect of the stroke. There is a huge impact on the family and friends of a stroke survivor. Here are several that deal with the impacts on the necessary caregivers. . . and what they should be aware of.

Stroke-free For Life, by David Wiebers, MD, Chair of Cerebrovascular Diseases at Mayo Clinic..

The Road Ahead: A Stroke Recovery Guide, National Stroke Association.

Living With Stroke: A Guide For Families, by Richard Senelick, MD, at the HEALTHSOUTH Rehabilitation Institute, and Karla Dougherty.

Family Guide to Stroke, American Heart Association.

And here is a book with stories of aphasia from those who have aphasia:

Talking about Aphasia, by Susie Parr, Sally Byng and Sue Gilpin with Chris Ireland

What a remarkable book! "*Talking about Aphasia*" allows us to experience "living with aphasia" through the voices of stroke survivors. From 1994 – 1996, the authors met with and interviewed stroke survivors across England to talk "about their experience of aphasia, its impact on their lives, their

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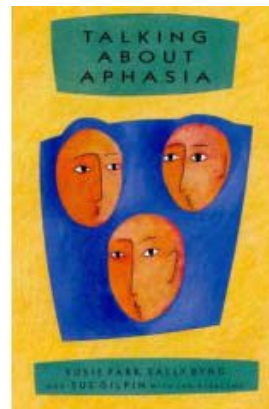
"In Search Of. . ." .

Publisher's Note —

I am most grateful to each of the individuals and families who support our educational and research mission. Each time students work with clients and subjects in our clinic, the experience enriches the education of our students and prepares them to provide best practices in the community. Special thanks to Bob and Ted for their commitment to ensure that "In Search of..." reaches out to individuals with aphasia and their families. Bob's passion for excellence, and their thoughtful insights and reflections yield an invaluable newsletter for our community. Lastly, thank you to each of our stroke survivors for sharing their very personal experiences. We continue to build awareness and sensitivity to living with aphasia.

-Nancy Alarcon

hopes for the future, the obstacles they face, and the support available to them". This book offers an extraordinary opportunity to listen to and learn from the first-hand accounts of individuals who share a very common challenge, that of living with



aphasia. The author/ researchers who live and work in London broke new ground with their project, as this is the first time a living journal of this type had been written.

Stroke survivors, family members, and friends, as well as students and professionals in the community will find this an

invaluable read. It is a powerful collection of thoughts, ideas and issues surrounding the world of aphasia. *Review by Nancy Alarcon*
Do you have a favorite book or article on the subject of aphasia or stroke? Let us know, and we will do our best to pass that information on to others who can use it. *ed. ««*

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