



## One Caregiver's Story

by **Jerry Boen**



My wife, Valerie, suffered a stroke during a heart operation and has been fighting the effects (aphasia and other related conditions) for almost three years. I retired early to help with Valerie's recovery. Together, we have been learning as much as we can

about the effects of stroke, services available to us, and how these conditions affect stroke survivors.

Our lives were so different before Valerie's stroke. We have been married for over thirty years, have adult children (one son and one daughter). Our daughter lives at home and our son lives close by. I worked for the Carpenters Union as a representative. My job was full service, and my average work week was more than sixty hours. Valerie worked for a hardware and garden center in sales. This included filling in any department position quickly and efficiently, ordering materials and directing other employees. Her job also required long hours, lots of math skills and strong communication and writing skills. Previously, she had been a competitive swimmer, a sports coordinator for the Navy and had her own business as a landscaper. This suited her personality perfectly.

She is one of the strongest persons for accepting a challenge that I have ever met. She had suffered a brain injury years earlier. She had physical therapy for that, but was on her own in devising ways to deal with her cognitive skills. She never let it stop her from working.

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*(This story continues in Spring Issue—ed.)*

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## What's Happening?

In this issue, **Jerry Boen** tells the story of his wife, and how she has suffered some sad and significant health problems. This is from the perspective of a caregiver. The story will be continued in the next (Spring) newsletter, which will feature "Caregivers" as the issue's theme.

For our previous quarter, our Tuesday Aphasia Support Group meeting was joined by two students, **Emily Blond** and **Elbereth Lorenz**. Both had just begun their two-year Master's degree program. Each provide us with their '**First Impressions**' of their monumental schedule and effort—and the real-life problems they face when dealing with people's communication problems. They both have agreed to provide additional articles about their progress through their programs. We are sure that you will be interested in how their goals and expectations might change as they gain in knowledge and experience.

We occasionally stick in a **book review** if it has something interesting or understandable about our communications problems. Here's one that does: "Family Guide to Stroke." This fits many because most people with Aphasia have suffered a stroke.

## What are we searching for?

Why are we printing this newsletter? Why are these articles in it? Why?

For every survivor we meet, questions come up and answers are needed. Every survivor's story is always the same—yet always very different. Why?

Some people have said that they still don't quite understand what has happened to them. Or why it happened. To them? NO! When it happened, it didn't happen to THEM! It wasn't to "US". It happened to ME!

I want to understand what Aphasia is, what stroke is. I want to know WHY ME! I think these articles can help me—and they may also help others.

Something happened – to ME – to my brain. It caused Aphasia in me, but that's not all it has done to me.

There are a lot of questions that need answers (they often lead to more questions.)

### —My problem—

My brain couldn't breathe—it couldn't get any oxygen. It was a stroke—it's a BRAIN ATTACK! Or, I got hit, damaged, in a wreck. Or, I was ill. What actually happened?

### —My analysis—

What caused it? Why? Who discovered it? ME? My family? Friend? Doctor?

Where and when did it **really** happen? At home? In a car? In surgery? (No? See "One Caregiver's Story.")

Was this just the current problem—did it also happen before? Will it happen **again**?

### —My reaction—

I don't have a problem, but I'm always tired. I cry! Why?

I need to be told answers to my questions. Why do people stupidly keep telling me that they have already told me, when I know that they didn't.

How am I reacting to the disaster? To the information/advice? To the system—which should have answers, but doesn't?

### —My recovery—

Who does recover? How much? How soon? Why not sooner? When do we get recovery

assistance and information? For how long?

What should we get? What CAN we get? When and how?

### —My plan—

Do I have a goal? A plan? Something is better than nothing.

What can I do? If I can't do it, who can? Who should?

As we lose capabilities, we need to compensate for it. How do I make that happen? If I turn into a hermit, I have lost my individuality, my meaning for my family and friends.

### —Help—

When a rock or something falls into a pond, the ripples go far wider; my problem affects family, friends, professional health care, the whole system—CAREGIVERS. Of course, most effects fall on those closest – the most cared for and the most dependent people.

### I care for them, I must help them, too.

*What are YOUR most important questions and the answers that YOU need now? These lead to helpful articles for YOU—and OTHERS.*

*You have some of those answers.*

*You can help by sharing your answers in articles for future newsletters. ed. ««*

### Publisher's Note—An Outsider's View

At first glance, our Winter Issue appears to be a "collection" of unrelated articles, how ever artfully connected by Bob Anderson. This issue is in fact, a remarkable account of "aphasia from the outsider's point of view." From a student's first encounter, to a lifelong partner's personal story, we witness the impact and ripple effect of aphasia beyond the stroke survivor.

As we search for a clearer and deeper understanding of aphasia and its impact on each individual stroke survivor, we can not neglect the perspectives of family, friends, professionals and the community. These viewpoints will serve as a reflection of the stroke survivor's challenges and achievements, as well as their own true measure of the ripple effect of aphasia. Each view adding to the full picture. Join us now and in the future as we continue to share personal perspectives. We invite you to send in your story to [nalarcon@u.washington.edu](mailto:nalarcon@u.washington.edu) Thank you!

## My First Impression

by Emily Blond

**aphasia** (*uh-fay'-zhuh*) *n.* An impairment of the ability to use or comprehend words, usually acquired as a result of a stroke or other brain injury.

The definition of aphasia is cold and flat, yet the people I got to know at the Tuesday morning aphasia group are warm and dynamic.

Of course I always realized that there were people behind the aphasia, but courses in neuro-anatomy and adult acquired language disorders always stressed the definitions.

Over the quarter, I have gathered stories about doctors' narrow-minded views of the possibilities for the recovery of your communication. From this I have



determined that these professionals were still only thinking in terms of those definitions, without seeing the determination, sense of humor, and bravery that can carry an individual through the challenge of regaining language.

Luckily, you ignored the ill advice and pushed yourself to reach your own goals. But how many other stroke survivors gave up, thinking that was the best they'll do? What if they had someone who encouraged them to challenge themselves? After seeing the rich lives that you all lead, it certainly seems worth making the effort. The speech-language pathologist wears many hats, and now I see "advocate" as one more. This is just one of the many lessons that I was fortunate to have learned from the Tuesday morning aphasia group.

I was led to a career in speech language pathology by the interesting definitions from medicine, psychology, and sociology that are the foundation of speech-language pathology. But what motivates and inspires me more are the amazing people I have met and the many ways I can be of help. <<<

## Book Review

**American Heart Association Family Guide to Stroke: Treatment, Recovery, and Prevention.** 2001 ed., available in Borders and other bookstores.

This book applies to Aphasia, because most aphasia is caused by strokes. It was developed by several doctors, but it is not written for professionals. It is aimed to people needing guidance and understanding about strokes and was made readable by a good writer.

Though the title says "Family" it can be useful for survivors that can comfortably read a novel.

The book is well-indexed, so we can pick

and choose to read about what we most need to understand.

It covers, in good detail and with typical examples:

- What a stroke is and its warning signs;
- What causes it and who is most likely to get one;
- How doctors may try to find out what has happened;
- How they might need to treat the problem—with surgery, medication, therapy;
- What to do after you leave the hospital;
- Suggestions for how to live with your disability;
- Suggested lifestyle modifications to prevent more strokes. ed. <<<

## Book Review next issue:

Ted will include his review of the book **"Into the Blue"**. A startling story of a caring

family, needing to help an invalid family member. But, when they need guidance and help, they find NONE available to them.

ed. <<<

## My First Impression

by **Elbereth Lorenz**



As a UW graduate student I was given a unique opportunity to work with an Aphasia group in the Speech and Hearing Clinic.

The experience has opened my eyes to the world of aphasia. It has put a human face on the topics that we learned in our

clinician schooling.

I had been taught the mechanics of the disorder, but that barely touches on its impact on peoples' lives.

But I now feel that something had been missing from our schooling. Who can better provide awareness into the client's needs? Who can suggest good ways for clinicians to approach their client? Our clients themselves can! **They** can teach the **students** about Aphasia!

There is so much more to the impairment than the anatomy of the brain and the appearance of language deficits.

The wonderful individuals who comprise the group provide much insight into the experience of having a brain injury that resulted in an Aphasia diagnosis. Their tales of fear and lack of understanding the situation made me realize how isolating it can be to have a stroke, and how as clinicians we need to make a pointed effort to provide support to our clients by teaching them ways to effectively communicate quickly.

On the other side, I've heard the remarkable stories in the group of how people were able to overcome their Aphasia diagnosis and continue to live rich and full lives, by meeting the communication challenges head on and working with clinicians to solve problems and look for ways of improving their speech.

The group also shows incredible understanding and support of each other and are accepting and kind to all of the other fellows.

The members provide unique assistance to each other through the simple understanding that the group sessions are a free place to talk with other people without having to worry about being judged by the mechanics of their speech.

I now believe that group sessions can be an invaluable tool to the aphasic patient, since I have seen first hand the benefits that can be provided.

I can say with all honesty that this group has inspired me greatly. They each bring a vastly different perspective. Every group member will have a place in my memory and heart.

I hope that as I move on as a clinician I can take their experiences and shape my practice into one that reflects what I have learned from these remarkable and inspirational folks.

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*"In Search Of . . ."*

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