

## A View from Within: Experience with Aphasia

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I wonder how many of you would understand what I mean if I said, "I feel like the man who carried coals to Newcastle in being here tonight." Let's have a show of hands first those of who have no idea of what I'm talking about. Next let's see the hands of those to whom it is perfectly clear what I'm talking about.

Would it be any clearer if I said I feel like the man who carried ashes to Mt. Saint Helens? Well tonight I feel very much like a man who did it. I am sure that every one of you experts in handling aphasics know what I mean. I am not here to tell you how to treat aphasia, I am here to tell you what it feels like to be treated.

It will be six years ago this coming October that I had my stroke. It started on a very busy weekend. Thursday after a very busy day at a conference, not unlike this one, I went home and was fixing a tall cool one (Iced Tea that is) when suddenly I couldn't see anything. I fell over a chair. My son who was in the kitchen with me, helped me up and said "What's the matter?" I told him I couldn't see.

My wife called the doctor. Naturally he wasn't home, but he'd call me back. In the meantime, my sight returned. When the doctor called back I told him what happened. He suggested that I come into the hospital the next day and have tests run. I couldn't do that. I had to introduce a speaker the next day at a conference. That was just an excuse. The real reason was that Friday afternoon, I had plans to go to Blanchard Caverns to see my daughter who was on a field trip from Texas A&M. The doctor said it wasn't exactly an emergency, and that if I came into the office on Monday it would be all right. I had my weekend in Blanchard Caverns and saw my daughter and met her boyfriend, now her husband.

Monday I went to see the doctor. Tuesday I went to the hospital and had an arteriogram. Wednesday they did an EEG and kept the electrodes on for surgery. The doctor came by and explained the surgery and the risks, which included a stroke. I elected to have the surgery since I was likely to have a stroke if I didn't have the surgery anyhow. The surgery that I had was an endarterectomy. When I woke up in the recovery room, the report that went to my wife was that I made it through surgery O.K.

When I woke up in intensive care, I couldn't move my right arm and that damned pillow on my right leg felt as if it was made of lead. I tried to say something, and it sounded like someone else was talking in a foreign language. It made no sense to me. The nurse asked me something that didn't make sense. I remember thinking I'll go back to sleep and when I wake up, everything will be all right. The next time I woke up I remember thinking I must be going to die because all my kids were home and there were three preachers. It was then I realized I'd had a stroke. I couldn't understand what people were saying to me, and I couldn't tell them that I didn't understand.

The next time I woke up it was between visiting hours, and the nurse asked me if I wanted anything—at least I think that's what she asked me. I made her understand that I'd like a cup of coffee. They didn't have any coffee, so she went into the waiting room and pretty soon my daughter Cindy came in with the coffee. But I couldn't drink it because I couldn't move my right side, so Cindy fed it to me. I like that, so I drank a lot of coffee from then on.

Then they moved me to a private room. I liked that a lot better. I could have my family with me during the day and someone stayed with me at night. I had two birthday parties in my room. One day my son and daughter-in-law came in. I had received a beautiful vase of flowers from the Lost Chord Club. Bill asked who sent the flowers. I told him they came from the society of chipmunks. He said you mean the Lost Chord Club, and I shook my head.

I was getting P.T. at the hospital and that was all, and the doctor said I should go to the hospital's stroke rehabilitation unit. I wanted to object but I couldn't. When he left, I let my wife know I didn't want to go to the Rehabilitation Unit. The next couple of days my wife checked around and decided the Rehab Unit was the best place for me. Since she thought so, that's where I went.

At the Rehab Unit I was assigned a wheelchair and a room and my wife had brought me some clothes from home. The orderly came into the room and asked me if I wanted to have breakfast in my room or if I was going to try the Mess Hall. I think I told him I would try the Mess Hall. In the morning they got me up at 5:00 to be ready for breakfast at 7:30. I needed every bit of the 2-1/2 hours to get ready. I had never tried to dress myself since the stroke, and that was some experience. I fell two or three times trying to get my underwear on, and when it came to the tie, I gave up. That's when I learned it's better to wear slip-on shoes, the kind you don't have to tie, as I went to the Mess Hall with my shoes untied.

Physical therapy: My wife asked me what I did in physical therapy, and I said I wrestled on a mat with a pretty girl. But I went back the next day, anyway.

Speech therapy: My first session of speech therapy was with a former student, and the next day I had a new therapist. Maybe I should explain that we both wanted to be boss. It was in speech therapy that I learned to dislike Bruce Porch—and comb, key, quarter, pen, pencil, toothbrush, cigarette, knife, fork and matches.

Before I had my stroke I had committed myself to make three speeches on the subject of laryngectomy. One was at ASHA, one was at the Mid-South Conference on Communication Disorders, and one was in Indianapolis. I was still in the hospital at the time of ASHA, so Joel Kahane did that one for me. The other two I tried to get out of, but neither one would let me off the hook. So my speech therapy consisted of learning to read again, learning how to put a speech together, and how to deliver it. I had to start reading at the first grade level and work my way up. My wife and I were both surprised at how rapidly I progressed.

I had no idea how to put a speech together when I started, but we started at a fairly low level and worked my way up from there. I think I delivered about 100 speeches. To my speech clinician some of them were lousy, and some of them I felt pretty good about. I got through both speeches somehow. I have no idea whether they made sense or communicated anything or not. The word communication was never mentioned.

Before I get back to speech therapy let me tell you something that startled me. At the rehabilitation unit they let you go home on weekends. I went in on Wednesday and went home on Friday. My wife put the wheelchair in the trunk of the car when we left the unit, and it was still there when we went back on Sunday. I was a little shakey on my legs but I only fell once, and that was getting out of the shower. One thing I discovered that weekend was that I had to keep my eye on my right arm if I was going to know where it was. I'll explain what I mean. One morning I tried to get up and couldn't. I tried and tried to get out of bed and was only successful in doing so when I discovered my right arm was caught on the headboard of the bed and I didn't know it. Sometime later we were invited to a formal dinner. I lost sight of my arm. I asked my wife to help me find my arm. I had it hooked to the back of my chair.

I swore I would never let myself be talked into making another speech. That happened five years ago in March. My therapist, I'm sure, inadvertently led me to believe that I was going to be my old self again. At any rate, I elected to take the summer off speech therapy and keep on with physical therapy. I still had no use of my right arm, and my right leg wasn't much better. It didn't seem as if I was making much progress.

In the fall I went to Jack Irwin, who was our acting director, and asked him if I might take therapy from Ann Haire and was granted permission. The first thing Ann said to me was that I would never be the person I used to be; but, if I would learn to communicate no matter how, I wouldn't need to be the person I was. That made sense to me; and Ann's therapy followed the same line.

This is not intended to be an advertisement for PACE therapy, because PACE had not been thought of yet. The therapy consisted of a series of assignments to communicate a thought to someone I would have contact with before the next session and report how it went. We talked about ways to communicate—often times I felt awfully dumb that I hadn't thought of it myself. I also discovered that I was communicating some things I didn't want to communicate. I have been working on my communication for about 5 years now and I'm making some progress. It has only taken me 3 months or so to get what I want to say to you down on paper—that's progress.

I think I am learning how to communicate fairly well now and prospects for doing better in the future are good.