My Survival  
— by Deb

(Deb, an aphasia survivor, was interviewed with Ted and Bob, both of whom are also aphasia survivors. In preparing this article, Ted spoke with her again, to provide important background for her severe stroke event and to emphasize Deb’s impressive recovery efforts.—Ed.)

She woke up during the night. Immediately, she was aware that something was very wrong, but she was not able to call for help. It took two hours to crawl to her mother’s bedroom and make noises. Eventually, the noise got her mother’s attention. Obviously, her mother was upset, called 911 and called for help from a neighbor. A good friend and neighbor, Kirby assisted her mother and Deb. When the ambulance came, the attendants said we will go to a local hospital. At that time Kirby intervened and insisted to go to Northwest hospital. Deb very strongly believes that the decision by Kirby to get her to Northwest was crucial for her survival.

That proved to be the right decision. At the hospital her situation deteriorated. The initial diagnosis of Deb’s condition was dismal. Some doctors said that there was nothing that they could do for her. Assorted comments included: ‘She’s a goner’, ‘The damage is too severe, it’s hopeless’, and the like. Most doctors looked and walked away.

Fortunately, one of the attending doctors said that he could save the situation. Doctor Erlich, Ph.D., M.D., a neurologist, intervened and advocated Deb’s case. Deb is absolutely certain that without his actions, she would have died that night.

By this time, Deb’s family had joined with her mother. The family wanted to do everything to help. With strong family support and consulting with Doctor Erlich, Deb was transferred to Harborview Medical Center for immediate surgery.

Severe bleeding in her skull had caused too much pressure on her brain. A piece of her skull was removed to relieve the pressure and repair the initial damage to her brain. Obviously, the surgery was a success. She spent four weeks in Harborview, then back to Northwest for therapy for four more weeks. Her speech therapist was Joan Jaeger. Eventually, Deb and Doctor Erlich were the “stars” in a presentation in a Stroke Conference at Northwest (5/23/02). Subsequently, Deb endured a second surgery. Since that time she has shown progressive improvement, has resumed her life, and flashes a feisty spirit.

Looking back, Deb wants to acknowledge three important people that made major contributions to her survival. First, her mother and her family for their continuing support when it counted. Second for Kirby, a good friend and neighbor who insisted on being sent to Northwest Hospital. Third, Doctor Erlich, whose professional expertise was instrumental and advocated for her case when others walked away.

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- by Deb and Ted

(Now, Deb’s first interview conversation… - Ed.)

Ted: Please describe what happened to you.

Deb: I…stroke…um…two years ago, almost three now…I stroke, and I, um, I didn’t know anything mattered because it just happened and my mom, she was, thankfully, was here to, and so, and she to the hospital, well, 1-1-1 she dialed the operator and the operator came and they to the hospital, and not Harborview, and first it was Northwest and then the doctors—it was really funny—because the doctors said “Oh, it’s just, not savable so go…”

Bob: Say what?

D: It’s not savable—me, so they were gonna just, die- - I know! I know! can you believe that?

T: Was that Northwest?

D: Yeah

T: Ahh! I won’t say anything! I have been up there too.

D: I couldn’t believe it. And so, um, one doctor, he said, “I’m gonna go and start Harborview transfer… um, Northwest, but you can talk a little be for the people might, um [looks in Communication book] These guys, um,

T: Your family, and friends. (note: Deb uses a “Communication book,” filled with pictures of her family and salient aspects of daily life)

D: [Nods] And mostly my son and my mom were there, they were going to do anything for me to do… they were going to do it. And so, and the hospital, the guy that we like, he said, “I’m going to go and start, um, so I can do everything and we can Harborview”, and um, the others said, “No they’re just going to go and forget it” and she said “No, I’m going to do that because, I can save me”. Do you know what I mean?

B: Your doctor said that?

D: Yes, and there was another doctor that said, “No”, and it’s just lucky that we had good people there.

B: Your mom had called 911 for you? They typically would take you to the closest, unless there was some other obvious rationale for them

D: Right, and what they did was, the brain was swelling and it was Harborview, that’s why Harborview we—to Harborview and the skull opened up. Yeah, and the um, the brain if I hadn’t done that I wouldn’t be...

You know, I don’t know much of that because I was out of it.

So I don’t know really, I know that it’s surgery really, I mean, just one hour and then surgery.

And then, pressure released. Do you know what I mean. So I was glad that… But it’s still, for me, it took me 5 days before I really kind of answered, you know, everybody else was fine, but I was out of it.

And the brain, the um, the hole, excuse me…the brain he had part of it had do um, the brain to um, they save it for um…

Um, they did it for me the brain, they set it and in what do you call it, ice, ice.

T: To put ice on to swelling?

B: So they probably did that on your head.

D: And also, had to the hole out

T: To preserve the piece of skull?

D: Yes! And put it over here for one month to and nothing had a helmet and

B: Oh, when they did that to you again, did they replace it with a bone?

D: No, the skull it, and um put it on again.

B: So the part they had taken out, they had put that, refrigerated that...

D: Yeah! isn’t that weird? And then they
went down and fixed it and about a month, and then sewed it up, you know? Well, then I had another seizure and for two years I would sleep but not very well. And my wheel chair a lot down here, instead of up and walking around, I had a wheel chair for a long time. And um, all of that, and then one more surgery, um, 6 months ago, surgery again, and for some reason, I don’t know why, it’s better, it’s a lot better. And talking better, um, surgery and I don’t know why but it’s working for some reason, so I’m glad!

(For clarification: First, Deb suffered a ruptured aneurysm that required immediate surgery. To relieve pressure on the brain, a piece of her skull was removed and preserved in ice. For a time she wore a helmet. An attempt to replace the piece of skull proved to be unsuccessful, necessitating another surgery to install a metal place.

Second, the preponderance of this interview was generated by Deb in her own words. Bob and I sought explanations and introducing new topics but Deb was quite articulate despite aphasia. I was amazed by the rate and degree of recovery between her most recent surgery and the present.

Third, Deb is very active in her recovery. She no longer relies on a taker for transportation and uses the ACESS system. Recently, she has taken a trip to Renton to visit a son and grandson. She has spoken to the Language Group at this UW clinic describing her travels and resumed her love of sailing. - Ted)

At one point of the interview, I teased Deb, “You’re pretty feisty now!”

T: Your thoughts are there, but they are spinning around.

D: Exactly! Exactly. It’s like that it’s here, but I just can’t verbalize it. You know. Oh it drives me crazy. But it sometimes it’s OK and sometimes it’s not.

T: It must be aphasia.

For more information about Aphasia or Stroke:
www.aphasia.org
www.stroke.org
www.nationalstroke.org
parents worked to provide a supportive environment that enriched our lives with reading, writing, music, history, and exposed us to a variety of cultural, religious, and political views. Additionally, due to my family’s love for language, we were encouraged to be creative and would often play around with different words and word meanings. It could be said that my family has never been at a loss for words and it is only fitting to include that I have many, many teachers in my family tree. In addition, we were taught to respect perspectives different than our own and to appreciate the differences and similarities between ourselves and those we encounter. Due to the roots of my childhood, I carry a strong love for learning and a great compassion for those around me.

Following high school, I continued to feel drawn to Speech-Language Pathology but, due to economic reasons, it was necessary for me to wait a while before pursuing my education. After working for a few years, I was hired by an employer who happens to stutter. Some days my former employer is very fluent, other days speaking is extremely difficult. During the four years that I worked for the company, I came to admire him and respected that, although fluency continued to be a challenge; he built a successful company, is respected by many others in the industry, and contributes to the community in very meaningful ways. I suppose this made such an impression because of my growing interest regarding speech and language. As time moved on, I felt increasingly compelled to learn more about the spectrum of communication disorders and to use what I learned to help others. I finally reached a position where I could pursue my education and although I still wasn’t sure exactly what life would be like as a Speech Language Pathologist, I had to find out. I was accepted to and completed my Bachelor’s degree at Western Washington University in Bellingham, Washington in Communication Sciences and Disorders. With the instruction and wonderful guidance I received during my undergraduate program, I began to build the foundation of knowledge that is essential to enter this field.

In addition to my former employer, I have known others who, at one time or another, have struggled with communication and have received help from a Speech-Language Pathologist. The reasons have ranged from needing guidance as they learned how to pronounce a couple of sounds to needing help learning to talk again following a brain injury. One dear friend continues to struggle with daily communication and through the direction of a Speech Language Pathologist, has been able to learn techniques that help ease the strain of talking with others. Through this friend I learned that there are clever tricks the casual observer may not even recognize a speaker is using. Yet those same skills can have a tremendous impact on the speaker’s independence, ability, and confidence with their communication and can dramatically change the way they interact with other people. This has further encouraged me as I continue with my education.

As a beginning graduate student in the Speech and Hearing Sciences Department at the University of Washington, I am filled with excitement and anticipation towards my future. I look forward to the experiences ahead, the people I will meet and work with, and the personal fulfillment I will feel by giving some of my life in order to positively impact other lives. At this point in time I am planning on working in the hospital setting. I am keenly interested in the medical world and I feel a special affinity for those who have acquired a communication challenge. I have eagerly looked forward to reaching this point in my training, so that I can begin working with clients. That is why I was thrilled when I received my clinic assignment for the autumn quarter. I have been assisting Nancy Alarcon, our Speech and Hearing Clinic Director, with one of the weekly aphasia groups in our clinic. Initially I thought “Oh, this will be such a good experience!” Then, an odd feeling set in. While I have looked forward to working with clients, this is my first experience as a clinician and I feel anxious about my new role. I wondered how I would apply the information from my studies to practical use. After all, reading about how to conduct speech and language therapy is much different than sitting in the therapy room with a client. I hope it is natural to feel this way. Others have told me that it is. Regardless of any uncertainty I feel about my current skills, I have confidence that my time here as a graduate student will provide me with the knowledge, training, and skills so
that I may begin my career as a Speech Language Pathologist.

— ««

Bearing Witness

These pictures are from this quarter’s Speech and Hearing Science 250 class. This class introduces students to the Speech and Hearing field and also provides points for considering this as a professional field or for continuing their search for a profession.

Dr. Carpenter periodically invites groups of stroke survivors—people with communication disorders—to one of his classes. This provides the class with real-life experiences of people with the problems described in the class study. As others have with their health problems, stroke survivors deal with their problems emotionally at one point or other. This presentation demonstrated that.

For the survivors, their stories are sometimes hard to think about—and, with aphasia, are often difficult to say. This support group has a positive attitude for their own problem—and their compatriot’s problems. They were willing to attend—and wanted to share their experiences realistically. Some of their comments were sad, some were humorous.

Deb (of the lead article, in this newsletter), Dennis (whose article appeared earlier), and others of this group, are shown. — Bob ««
the aphasia handbook
A guide for stroke and brain injury survivors and their families
US edition
Edited and adapted by Martha Taylor Sarno, MA, MD (hon) and Joan F. Peters, Esq.

The Aphasia Handbook is a unique guide designed to give people with aphasia better access to information about health issues, being in the hospital, getting the most from rehabilitation and therapy, getting support at home and in the community, finding a way through the benefits maze, support groups, rights, choices, and legal concerns.

This handbook was edited and adapted for publication in the US by Martha Taylor Sarno, MA, MD (hon), of the New York University School of Medicine and Joan F. Peters, Esq., Executive Director of the National Aphasia Association from The Stroke and Aphasia Handbook, created in the UK by Susie Parr, Carole Pound, Sally Byng and Becky Moss of Connect, the communication disability network, in conjunction with Bridget Long (information designer) and Caroline Firenza (illustrator). The authors consulted extensively with people with aphasia in the UK in planning, writing and designing the handbook, which has received international acclaim and won several awards. Revised to reflect laws and resources in the US, The Aphasia Handbook is a must for people with aphasia and healthcare professionals.

‘The Aphasia Handbook is an essential resource for people with aphasia and their families. It is beautifully clear, well-organized, and sensitively written—a most valuable guidebook to living creatively with aphasia.’
- Oliver Sacks, MD, author of The Man Who Mistook His Wife For a Hat and Awakenings.

Published in the US by the National Aphasia Association (NAA).
- NAA Response Center
  351 Butternut Court
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- Phone: 800-922-4622
- This book can be ordered at the website: www.aphasia.org

Publisher’s Notes

What an incredible journey! I never realized quite where the road would take us as we began this newsletter nearly 3 years ago. We’ve been “in search of…” the personal accounts of living with stroke, and it’s been a remarkable experience thus far.

To better understand the problems and successes of people who suffer brain attacks, we’ve asked many folks to expose their deepest feelings. “Bearing Witness” is a powerful example of that exposure. Students and stroke survivors connected on the deepest level—sharing the intensity of surviving a stroke.

My wish for the coming year? To have you share your journey as a stroke survivor, a family member, a best friend, a professional working with stroke survivors. To help us better understand the impact of stroke, aphasia and the related challenges, the obstacles and the celebrations, the worries and the hopes—the full story, the prelude, the incident, the postlude.

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“In Search Of…”

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