



Motivated to Persist

by *Ture Brusletten*

(We asked a graduate student to share her perspective on communications problems. Here is her interesting, philosophical view. —ed.)

I am a second-year student in the master's program in speech-language pathology here at the University of Washington. While I don't yet have a bed set up anywhere in a back room of the Speech and Hearing Clinic, I do sometimes feel as though I live there. Having begun this intensive program two years ago as a post-baccalaureate student, I have found it to be a demanding and all-consuming program, at times making my life seem



Ture

unbalanced. Relinquishing balance in life, even temporarily, has been a challenging aspect for me. However, I am motivated to persist. One reason for this is that from the beginning of my studies both didactic and clinical, elements of an underlying philosophy began to emerge from this professional and academic community that resonated with my own views of life and the world. I would like to share a few of these elements, as they have helped to confirm my passion to work with individuals who have communication difficulties.

I remember the first time it was impressed upon us as students that, while it was important to learn the theoretical frames with which to organize our knowledge of various disorders' etiologies, profiles and treatments, it was also important to know that most clients we would come to serve were not going to fit discretely into the boxes we had set up in our minds. This was going to be a field where the issues were not black and white, but rather where the proverbial "Grey Area" was alive and well, and demanded respect from its clinicians. I was excited to hear this. While it certainly promised intellectual stimulation, it also emphasized we would be working

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with *individuals*, not merely communication disorders. I had known for a long time that I got a charge from interactions with *individuals*—through our triumphs and challenges, we all have a story that is uniquely ours.

Another early confirming discussion regarded the World Health Organization's gradual shift from a more medical, impairment-focused model, to a current one which addresses the numerous and complex ways in which an impairment could impact an individual's life (regardless of the severity). What really impressed me was the amount of time spent devoted to discussing how an individual's *activities* could be limited by their impairment (such as using language to order at a restaurant), how his or her *participation in life* could be limited (such as dining out at all), and most of all, how a limitation in activities *did not* necessitate a restriction of participation (having aphasia did not have to preclude the enjoyment of a favorite pastime, like dining out). This was not the last time I would hear mention of or discuss what we call "Staying in the Game of Life."

I believe these discussions were inspiring to me because of their unifying themes—emphasis on the particular individual, emphasis on the whole person in the context of his or her outer and inner life, and the insistence that communication difficulties need not imply a loss of life, or a disengagement with the world. Indeed, the prospect of facilitating and witnessing an individual's process of finding himself again, reclaiming his life by finding new ways to

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communicate with the world, is a thrilling one.

Those early messages have not remained abstract philosophical discussions. Continuing on to work with a small variety of clients in the clinic, I have experienced treating a child whose language difficulties are not static or well-defined, keeping me guessing and requiring me to look outside of the framework of one disorder or treatment model to respond to the most functional needs of that individual, as they are observed. Working with a mother and her child who stutters severely has given me ample opportunity to learn about the environmental contexts in which clients live, and how treatment cannot exist in a vacuum uninformed by contextual factors.

Participating in the Aphasia Support Group has been an extremely rewarding experience. It has given me the opportunity to see different presentations of aphasia, as well as allowing me a glimpse of the individuals who have made enormous gains in their ability to communicate with one another. Each Tuesday morning, with coffee, cookies and plenty of personality in continuous circuit, these 10-14 people discuss their lives and loved ones, express their strong opinions (and their ambivalences), report on recent vacations, tease and grumble at each other, and laugh. The constant is that they communicate with and support each other. They support each other in their struggles to relearn language, but equally importantly, they support each other's individual processes of recapturing their passions and taking part in life. For some, this might mean seeing grandchildren often, or taking up a job at the bookstore. For others, traveling to visit old friends in Arizona. For others, it might include baking delicious desserts and casseroles (I can testify)! Others yet have a passion for roses (some for cultivating, some for photographing). As they continue to work on the communication challenges they face, they come together to celebrate their lives.

This last notion is a powerful one, and one that moderates the inner challenges / face in the graduate program. Looking ahead, I plan to work with a variety of clients, each presenting with a particular set of communication challenges, each presenting with a particular story that is uniquely his or hers. Without any illusions that my task will be easy or simple, I am motivated to work on the more concrete goals of improving each client's particular communication issues, in such a way that a larger goal can begin to be reached as well: that the problems faced in communication do not overshadow the client's appreciation and celebration of his or her unique story. ««

Why Go to School?

(Our Aphasia Support Group went to school again: to Speech & Hearing Sciences 250—"Human Communication and Its Disorders".



Dr. Carpenter

There were at least two purposes: Dr. Carpenter wanted his class to encounter reality by dealing with people with aphasia (and more). And Nancy, Clinic Director, wanted to offer the group members a chance to practice for their improvement—and to share their stories.

We asked three questions to the class: 1. What happened to us?

2. How does their actions and stories impact you, as students?

Here are some of the survivor's comments: - ed.)

Dewey: "I'm a stroke survivor and three and a half years ago, I was flat on the ground. My wife was handy and she called firemen; they took me to a very helpful hospital. Then, I didn't know my name, I could hardly talk and couldn't write. I was in rehab from 6am to 9pm. Then my son drove me home, to therapy here, with Nancy.



Dewey and Debbie

"I used to read newspapers a lot, but very little now. When I read a line, by the time I'm at the end of it, I've lost the first part of it."

Debbie: "Having a stroke wasn't fun, but it changed my perspective. Thank God I'm here right now. I ran motels in Florida, worked in Guam, traveled around the world and enjoyed it all. Now, I appreciate my accomplishments before.



"You go out and do it— even if you aren't sure, you can do it!

"I used to read everything. Sometimes, I turn up blank or can't find the word. Now, I am reading my grandson's books. It is not right if you don't try. Do it anyway."



Dewey, Debbie, Valerie, and Dennis

Valerie: "When Debbie went to the hospital, doctors were talking over her body, and had written her off for dead. She heard and understood that, but couldn't talk back."



"A visiting doctor said "I can save her." And did. Deb was and is a "Can Do" person.

"I've had two brain injuries. In '96, at work, a paint can fell on

my head. After a month, a doctor was still telling me that it'll go away. A neurologist got me into a year and a half of speech therapy. I was a recluse and read books, though I couldn't remember the title, author, or a lot of the context. But that encouraged me.



"After I had gotten back to driving, I had a car accident. The air bag saved me, but caused trauma to my heart. After falling on ice later, I got to the hospital to find that my heart valves were hanging by a thread. Had they come off, it would have been fatal.

"During heart surgery, I had a stroke and the doctors were fighting for my life. I could then only speak two words: Picasso and treatment. I couldn't remember my name and only could sign "X". I had to start speech therapy all over again and I focused again on reading.

"Don't write off someone, they're still there, inside their brain."



Debbie with students

Jesse is a member of the Support Group, but wasn't able to attend the class. He was an experienced, expert long-haul semi-truck driver. But then, in an accident, his truck rolled three times. This battered him and the terrible trauma to him resulted in aphasia. He of course notes that he hasn't had a stroke, but the effect of the trauma has been essentially the same.



After class conversation: Dewey with a student

Dennis: "I had a stroke 21+ years ago.

"I was a PE teacher and was teaching a class when an embolism occurred in my brain. My colleagues got me to the hospital even though I didn't feel anything was needed. I had left side paralysis and speech problems. I got 7 months of rehab when a medication reaction forced me to Harborview, then I was back in rehab again. They gave me a job for a year, then recommended that I resign. I said, "No!"

"I did retire, finally. I have been here at the UW Speech and Hearing Clinic weekly, for 14 years, and am still doing volunteer work in West Seattle.

"I can handle 6th grade materials and each week, I buy a Sunday paper. It takes me the whole week to read it."

(Oh, of course! Here was the 3d question we asked to the class:

What has triggered you into doing what you are doing now? - ed.) ««

A Phone Call Can Change Your Life

The phone message from my folks said, "She has had some bleeding in her brain." My first thoughts were "how serious is this" and "when do we need to leave." My aunt had had a stroke, but I didn't know how extensive it was. None of us had much to go on. I just knew that I needed to learn more and would eventually clear the decks heading to the Midwest to help out. I soon found myself in the midst of a remarkable journey that has forever changed my perspective on what my patients and their loved ones experience. I thought I "knew" what my families went through! How limited was the depth of my understanding, until, by this catastrophe, I was wrenched from the professional perspective to the family and caregiver point of view.

Over the course of the next two days, I learned that my aunt had in fact suffered a stroke. She had been a healthy, energetic, independent individual, with no indication that this would occur to her. As I flew to the Midwest, I thought about what I would encounter; wondering how I would react to the situation. As I got off of the elevator in the



hospital and headed to her room, I did know I was a bit anxious. However, nothing quite prepared me for my first personal view of my aunt "post-stroke." In my work as a Speech-Language Pathologist, I have been privileged to work with hundreds of stroke survivors over the years; spent many, many hours with patients and families in heart-rending sessions; and shared so many successes and challenges with these folks post-stroke. I thought I had a "real world" view of living with stroke. Was I surprised! She was sitting

in her room in the midst of an Occupational Therapy evaluation. Thank heavens she was facing the window and didn't see the tears start to well-up as I watched and listened. I couldn't believe my eyes and ears – she was sitting in a wheelchair, couldn't move her right hand, and her language was agrammatic. This was my aunt – could she be the person I always knew and loved – did she have comprehensive insurance coverage – could she go home to live on her own?? A rush of questions; a rush of emotions!

Over the coming months, I would like to share more of my personal journey. I'm also hopeful that my aunt will share some of her thoughts as well. *by Nancy Alarcon* ««

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"In Search Of. . ."

*Our lives now seem more crowded than usual with tragedies and events, with wants and needs.
In this time, we wish you all have the time to think of peace and wisdom and to plan for a better future with more satisfaction in our lives.* - ed. ««

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