

Topics In Stroke Rehabilitation

Volume 6/Number 1 ■ Spring 1999

EDITORS
Elliot J. Roth, MD and Don A. Olson, PhD

ISSUE EDITOR
Ken Akashi, MD, PhD

Higher Cortical Dysfunction in the Stroke Patient

FEATURED ARTICLES:

- Rehabilitation Approach to Patients with Unilateral Spatial Neglect *Shinsha & Ishigami*
- Rehabilitation of Executive Function Impairments after Stroke *Honda*
- Aphasia Therapy Using the Deblocking Method and Kanji/Kana Issues *J. Tanemura*
- Awareness in Apraxia and Agnosia *R. Tanemura*

AN ASPEN PUBLICATION®



Contents

TSR 6:1, Spring 1999

Higher Cortical Dysfunction in the Stroke Patient

- v **Foreword**
- vi **Information for Authors**
- viii **Letters to the Editors**
- 1 **Rehabilitation Approach to Patients with Unilateral Spatial Neglect**
Noriyuki Shinsha, MD, and Shigenobu Ishigami, MD
- 15 **Rehabilitation of Executive Function Impairments after Stroke**
Tetsumi Honda, MD, PhD
- 23 **Aphasia Therapy Using the Deblocking Method and Kanji/Kana Issues**
Jun Tanemura, PhD
- 33 **Awareness in Apraxia and Agnosia**
Rumi Tanemura, OTR
- Medical Grand Rounds Elliot J. Roth, MD, Editor
-
- 43 **Patient Participation in the Management of Stroke Rehabilitation**
Mark N. Ozer, MD
- 60 **Family Perspectives Following Stroke: The Unheard Stories**
Lindy Clemson, MappSC (OT), Maureen H. Fitzgerald, PhD, and
Colleen Mullavey-O'Byrne, MA (Hons)
- Consumer's Perspective Don A. Olson, PhD, Editor
-
- 78 **Working with Aphasia**
Paul Berger
- Ethics in Practice Kristi L. Kirschner, MD, Editor
-
- 82 **Our Disabled Communities**
Tod Chambers, PhD



Don A. Olson, PhD, Editor

Working with Aphasia

Paul Berger (as told to Stephanie Mensh)

AFTER MY stroke, I assumed that I would return to work. That was more than 10 years ago, and I was only 36 years old when an aneurysm ruptured in my brain, paralyzing my right side, and destroying my speech. When I left the hospital's inpatient stroke rehabilitation program, I was still severely disabled, needing a wheelchair, unable to speak, barely able to read—while my roommate, who was 60 years old when he had his stroke, went home walking and talking. He retired permanently, but not me.

At the time, I had a professional job for the city government in Washington, D.C., mostly analyzing, writing, and providing liaison between the government and private companies—a lot depended on my ability to communicate. I was determined to get back to my old self and back to work. To do this, I had to continue speech, physical, and occupational therapy, so I arranged almost a year's leave of absence from my job.

I made a lot of improvement that first year. I was able to say a few words, write a few sentences, and read the newspaper. I thought I was ready to return to work. My boss

allowed me to return part-time so I could continue my therapy. He had already given my projects to other staff and wanted to see what I could do before he assigned me more. Since liaison work was out of the question—my language skills were at about a third grade level—he gave me some computer spreadsheet work and filing to do. I missed the professional work, but I was happy to be in the office 3 days a week. It was my first step back. I believed that if I pushed myself with therapy, I would be “cured” in just a few more months and I would be back to work full-time and full steam.

More than 2 years passed in this part-time work, part-time therapy arrangement, with me thinking that I just needed a few more months, a few more months. But my aphasia was still too severe. I could say many more words, speak in simple sentences, write more, and read more, but not at a professional level. I had to leave my city job. That was a difficult time for me, but I did not give up my conviction that I would regain my speech and my career. Over the next 6 years, with the

Top Stroke Rehabil 1999;6(1):78-81
© 1999 Aspen Publishers, Inc.

help of the State Department of Rehabilitation Services (DRS) (and sometimes overcoming the roadblocks they threw at me), I had a series of part-time clerical jobs, some volunteer, some paying, while I continued therapy. All that time, I took speech therapy 2 days a week and had a tutor 3 days a week for almost 2 hours a session, drilling me on words and sentences. I continued to make progress, but so very slowly.

The part-time jobs were important to me—I needed the satisfaction of working, even though I sometimes felt sad knowing that just before my stroke, I had completed my second masters degree (this one an MBA)—and had been looking forward to a powerful professional career in business. Here I was doing clerical work in an accounting office—filing, typing numbers into a spreadsheet, the lowest one in the office. To make matters worse, the ups and downs in the local economy hit me first-hand. I was laid off of my last two paying jobs.

Looking for work when you cannot speak or write is a real challenge. My wife wrote my resume and cover letters, and my job counselor made calls. I had almost 20 interviews for clerical work I knew I could do, but each employer said they wanted someone who could talk. When a person with aphasia has to compete with fast-talking college grads who have also been laid off, it is very discouraging.

Then I saw an ad for contract computer work I could do at home. It used a special computer software program that was a simplified version of a very complex software program called “AutoCAD,” or automated computer-aided drafting. After 6 months, I decided that I liked the drafting part and wanted to learn more. I talked to the instructor at the local community college about his class in AutoCAD. He suggested that one

class would not be enough to get me a job—I should take a 1-year certificate program in drafting, so I could understand what I was doing with the software.

This was a major turning point for me. Many years had passed since my stroke, and despite intense speech therapy and very significant improvements in my ability to communicate, I still wasn’t functioning at a professional level. (Indeed, I am composing this article now by explaining to my wife what I want to say, and relying on her to translate, organize, and write it into grammatically correct sentences and paragraphs that you can understand. So take heart, if your aphasia is as severe as mine, there is hope, and I’m proof of it.)

I finally realized that if I was going to have a career, I would need to be retrained in a field that did not require much language skill. I had been resisting retraining since the DRS counselors had first suggested it 6 years earlier because I thought putting all my effort into intense speech therapy would “cure” me and I would not need to be retrained. I guess I had denied to myself the impact of my stroke. Now, I was giving in to the difficult concept that I was not going to get back my prestroke abilities. This was very hard for me to accept, and I am, to this day, still fighting to overcome the feelings—anger, sadness, frustration, disappointment, and disgust. I keep my sights on my goals, and this helps a lot. And having a supportive wife and family is important, too.

Going back to school was an incredible challenge. I had always been a good student, and I had retained my math and spatial relationship skills. Now I was a middle-aged man in a classroom with kids just out of high school who ran circles around me—not only because of the age difference, but because

my aphasia made me so slow in processing information and doing the course work. Everyday was a struggle for me. I hired two tutors. One tutor helped me to do the reading homework, and one helped me to learn the complex AutoCAD software. Both of these men were wonderfully patient with me and supportive.

For the first 6 months, I was so far behind, I did not think that I would ever complete the program. The instructors pressured me about my slow pace, hurting my already low self-esteem and making me feel very anxious. Eventually, I gave them a summary of the Americans with Disabilities Act, which required the school to make accommodations for me, including giving me extra time to complete assignments. Then, a funny thing happened. I guess I finally reached the top of my very long learning curve. My instructors and I began to notice that I was working faster and completing my assignments more quickly. I finally finished school, only about 2 months late.

My instructor and computer tutor helped me draft my resume and select computer printouts of my work. My wife helped me organize the printouts, letters from previous employers, and other materials into a notebook with tabs, so I could easily show it to a prospective employer during an interview. One thing I knew—if you can't speak well, you need to have good materials to show to do the speaking for you. The school's placement advisor sent out my resume to companies he knew, and I responded to ads in the newspaper.

Since I wanted to make a good first impression when prospective employers called to set up interviews, I never answered the phone! Instead, I let them leave a message on my answering machine. Then, I would call

my wife to pick up the message, read the phone number to me slowly so I could write it down, spell the person's name, and help me practice pronouncing it. Then, I would look up the phone number on a computer Internet yellow pages Web site. It would give me the full name and address of the company, and a map of exactly where they were located.

When I returned the call, I was prepared. I could say the name of the person, and I did not need to ask for the address and directions. I'm just not good enough on the phone and probably would have killed any chance for an interview if I had to get more information. I also told them that I had a "speech problem" to explain my difficulties. I used to say, "I have a stroke," but my wife thought that the word "stroke" would be too scary for a prospective employer.

And it worked! After about six interviews, I was offered my first job as a CAD (computer-aided drafting) operator for a civil engineering firm. Getting a job was one thing, keeping it was another. It just didn't work out, and a few weeks later, I found myself interviewing for another job. This was very discouraging and frightening. I questioned whether I had done the right thing, spending a year retraining for a job I might not be able to do. My father said not to let this get me down, reminding me that I had been through a lot worse!

The school's placement advisor cheered me up and sent out my resume again. I responded to newspaper ads, and had another ten interviews, using the same approach. Then, the owner of a small consulting engineering firm called me. When I returned his call, he asked me about my resume, specifically my jumping around from a professional job to clerical jobs, and now to CAD operator. I didn't know what to say at first. Every-

one had advised me NOT to put information about my disability on my resume. I decided to just tell him the truth. It wasn't easy, since my speech is so poor, but I was able to convey that a few years earlier, I had had a stroke. He still wanted me! I interviewed the next day, the "chemistry" was right, and he hired me.

I am really proud of my work. I am happy to draft plumbing, electrical, and air conditioning drawings on the computer. I am part of a team of engineers and CAD operators. The first week, I worked 50½ hours Monday through Friday—earning 10½ hours of overtime. Then, I worked half a day on Saturday. I am lucky to have the energy and stamina to focus on my work for 10 hours a day. And I am very resourceful in overcoming my severe aphasia. I always ask my supervisor to write down key information in a notebook. This way, I don't make mistakes, and I have notes to refer back to if I forget something. I am not as fast as the other CAD operators, but I know I am improving every day.

What does it take to get back to work if you have a severe disability like aphasia? My

experience tells me that you need to believe you can and will return to work. I think it helps if you can go back to your employer as soon as possible after your stroke, and do something—anything—for them. You need to assess the skills and interests you have and find jobs that use such skills. Volunteer work is a good way to explore your new potential. Retrain if you need to, even if it is hard to accept this. And most of all, do not give up. Do not listen to people who tell you it cannot be done. Keep a positive attitude and a focus on your goal. And remember, if I could do it with my severe aphasia and paralyzed right hand, you can too.

I am looking forward to building a new career. I am glad to prove that being "speechless" does not mean being "useless." And because I want others to know that it can be done, I have written a book that was published recently, *How To Conquer the World with One Hand . . . And an Attitude*, available from Positive Power Publishing. The first chapter is available on the Web at <http://members.aol.com/PosPower/>