



Mission: A newsletter for Individuals with Aphasia and for the community

Created by Individuals with Aphasia

Supported by the University of Washington Speech & Hearing Clinic

My Relationship with Music—Part 2

by Ted Paluchowski

During a visit with my neurologist I described my experience. How I felt a sudden sense of acute awareness. Abruptly, music was everywhere. It quickly became a preoccupation. I wanted to listen to every tune from the profound to the banal. It even intruded into my consciousness almost to the point of crowding other thoughts.

As I returned to a more normal appreciation of music, I was haunted by the experience. In the past, music was important in my life. After my stroke there was a time when I could not even know that I was missing it. As music returned, I wondered what else was I missing that I was not even aware of?

My neurologist was not impressed. He called it an epiphany. Apparently, my new awareness was a normal part of recovery. Then he turned our discussion to his agenda. Over subsequent years, I have experienced a number of greater or lesser epiphanies. In the scheme of things, my new found appreciation of music was a small victory. But it was a very important milestone for me.



Ted Paluchowski, a 6 year Stroke Survivor

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Later in the same year I attended a production of, “The Pirates of Penzance”. As a long time member of the Seattle Gilbert and Sullivan Society I was familiar with the work. The music was immediately identifiable. At the same time the words they were singing were meaningless; even reading the text was a major challenge.

Some years later I heard another production of that operetta. As before I could follow the music. In anticipation of the performance I read the text and now, I found it easy to read. I could appreciate the play on words, assorted puns and fractured logic of the plot. But I could not keep pace with the singers in the cast.

My difficulties during the production were symptoms of aphasia. Even simple words were confusing or lost. The accelerated pace of the score quickly overwhelmed my capacity to process input. I could follow the music but I could not understand the singers. There were too many words sung too fast. The result was a melodious but meaningless noise.

A similar problem occurs when I attend the theatre. The dialogue quickly overwhelms me. Particularly when the discourse is complex or lengthy. During a performance I miss key words and crucial passages.

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Doug Graham: A Survivor's Aphasia Story

With: Another Survivor (Bob Anderson)



Doug Graham's efforts on our newsletters and in our group meetings and his interest in the Web have shown us his enthusiasm and excitement. Doug is a Stroke Survivor with Aphasia and still has fluency problems. This article is a team effort, written with another aphasic to help him tell his story. Here it is:

Doug has had a brain attack – he was intensely interested in cars and writing - but he STILL is. He has owned 55 cars (this has got to be a record); his first was an '87 Pontiac power car. He kept switching between Ford, Chevrolet, and Chrysler to get the next technically improved car. To make it possible to quickly move on to technically better cars, Doug worked for Chrysler and Pontiac and studied business at Wayne State University and Lawrence Technological University, while becoming an ASE (Automotive Service Excellence) Master Mechanic.

His challenging jobs required much domestic and international travel and his life-long love of skiing, especially hot-dog skiing, led him to Seattle in 1992, so that he could relax within the sight of the mountains and the ski slopes.

Five years ago, in February 1998, at age 41, Doug had a stroke that was severe. The first three weeks in the hospital kept him on IV tubes for heparin to deal with

and dissolve the clot that had reached his brain. He had difficulty walking and keeping his balance, and it was very hard for him to understand speech and to say more than a few words.

Therapists helped him adjust to physical and speech problems, and he has completely recovered physically. When he left the hospital, he was tested at a twelve-year-old's vocabulary level, and was started with speaking very short, simple sentences and by reading in a 4th grade-level book. It took three years to be able to do sums, and Doug is pleased if the answer comes close (though this doesn't satisfy his wife, Sukie, who is an accountant, or of course, himself).

Doug still has difficulty retaining quickly-spoken information; a message over the phone doesn't give visual cues and can be too confusing. If the message has been left on tape, he can usually pick up the message by replaying the tape.

He had specialized in electronic test equipment involving writing technical and marketing/sales materials with his employer and with the national Equipment and Tool Institute. To work on improving his writing capabilities, he helped found our newsletters, and was editor of our first three "In Search Of . . ." issues. He enjoys the sharing that happens at our Aphasia Support Group meetings.

These Aphasia meetings and newsletters affect other Group members greatly by sparking their interests and efforts to continually improve their stroke-caused communication problems. Nancy Alarcon, the Director of the UW Speech & Hearing Clinic, and graduate students with her, are gratefully acknowledged for their support and encouragement in making this story (and these newsletters) possible. -- Bob Anderson

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(Continued from page 1)

Obviously, the play loses its dramatic impact. For those reasons I choose not to attend for now.

The same problem arises with TV programs, especially when the script calls for rapid repartee. Much of the dialogue is lost or reduced to a mumbled incantation from an alien cult. In order to follow the dialogue, I have found it useful to tape a show. With repeated replays I can eventually understand the dialogue. The process demands a block of time.

From the perspective of seven years of experience I would like to make some observations. After my stroke there was a period when I simply existed. Conversation, music, everything was a distraction. I was very happy to go to asleep. Penetrating the fog to find a known reference point was difficult. Care-takers, friends and therapists contributed to my recovery. But it was my familiarity with music that gave me a reference point to rebuild upon.

Music was instrumental in my recovery. Through music I began to be more aware. Previously, everything was confusion. My thoughts swirled without direction. Now, I had a reference. Music opened the door. I realized how much that I was missing, not only music but all aspects of language. For me, music was the trigger to language. I went from hearing noise, to music, then to recognizable language. I have to ask, would the deliberate introduction of music accelerate recovery?

I began this two-part essay with the intent of relating my experience with music and aphasia. After my neurologist heard my interrupted pattern of speech he suggested that I join a chorus and sing! Once again music may play a role later in recovery, to smooth the broken cadence of the flow of words. My ability to speak has improved. I'm not sure about my singing, but the neighbors moved.

Editors Note: The Writer's Guild edits each article as a group, with every member making suggestions. Throughout the editing process, Ted fought to keep his article from being significantly altered saying, "This is how I write." We are proud of Ted for standing up for what he thought to be important - telling his story in his own words.

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Advocating & Educating



The **U.W. Speech and Hearing Clinic** has several **stroke survivor groups**. Members of one of our groups recently spoke to students in an undergraduate course on communication disorders taught by Dr. Robert Carpenter. The course is offered through the Department of Speech and Hearing Sciences. Stroke survivors shared their personal stories about living with aphasia. Advocating for themselves, educating students, and receiving positive feedback from the students make the experience rewarding for everyone.

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The "National Aphasia Association" An excellent resource!

by Rebecca Greely

True or False?

1. *Aphasia is more prevalent than Parkinson Disease or Muscular Dystrophy.*
2. *Recovery from aphasia is usually complete within six months of treatment.*

These are just a few of the topics on the "Aphasia Quiz" that is posted on the National Aphasia Association (NAA) website. This quiz, along with countless other resources, is a way for the NAA to promote public education, research, rehabilitation and support services to assist people with aphasia and their families. Their mission includes educating the public to know that aphasia is an impairment of the ability to communicate, not an impairment of intellect. The NAA also strives to make people with aphasia, and their support systems aware of resources to "recover lost skills to the extent possible, to compensate for skills that will not be recovered, and to minimize the psychosocial impact of the language impairment".

We at "In Search Of..." encourage our readers to visit the NAA website to see all that it has to offer. Not only is it a wonderful resource of facts and information regarding what aphasia is and looks like, this website is rich in support services and community building opportunities. There is a bulletin board for those in need of answers, a pen pal program for those in need of a friend, and multiple links to other helpful resources.

With approximately one million individuals with aphasia in the United States alone, this organization has their work cut out for them. During 2002, the NAA website averaged over 7,300 "hits" per month. The Response Center mailed over 2,800 packets of educational and National Aphasia Awareness Month materials, received over 3,500 phone calls, and responded to almost 600 email inquiries. To

keep up with the financial responsibilities that these numbers require, the NAA organizes fund-raising events throughout the year. The most important of these events is the Annual Spring Benefit, being held this year on March 27th in New York City. If attending this benefit is not an option, donations will be accepted on behalf of the NAA, in order that it may continue to serve individuals with aphasia and those who love them.

Contact the NAA at www.aphasia.org

Rebecca is a student in the U.W. Speech & Hearing Sciences Master's degree program and assisted in leading the Writer's Guild this winter.

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Aphasia - What Happened to Me?

by Bob Anderson

When I had problems speaking with my family, my personal paramedic (my #2 son, Mark) took me in to the emergency room at VM. I was admitted, and the next day my son brought in a CD player and some of my CDs to keep myself busy. In listening to one, I complained that its case said "Chopin", but it was Beethoven music instead. A neurologist was watching that and remarked, "You're fortunate that you're left-handed. You weren't expected to be able to do that." I had been able to understand the title of the CD case and associate the music I heard with it. His comment seemed to say that, as I was left handed, some of my language ability comes from the right side of the brain. Good news.

There were many tests, including a CAT scan (Computerized Axial Tomography) to generate pictures of my brain. Doctors felt that they needed more information, so they put me into an MRI (Magnetic Resonance Imager) for more detailed pictures. If you're not claustrophobic, that's a nice, small cubbyhole to be stuck into.

Doctors showed me the pictures with the damage in the left half of my brain, part of what's called the temporal lobe. They said, "You

had a stroke, and, by the way, you've had two more strokes before this one." That's good news??

Then they told me I had Aphasia. I told myself, "What is Aphasia?" As I have looked up answers to my questions, I try to understand them. I am not completely sure that I do, so I look up the references and note them so that I can go back and review them later for better understanding. This is how I understand this now and why I include the references that I used (and for you, if you also want better understanding).

Aphasia is a loss of ability to understand or express words due to injury or deterioration of the brain's areas handling language. The UW scientist, Dr. George Ojemann, has shown that people can have differences in these areas however, basically, damage to three areas called Broca's and Wernicke's (named after their discoverers) and the nerve pathways between them results in aphasia. Many kinds of aphasia describe the difference in language disorders caused by different damage to the three areas.

All of these aphasias are very significant concerns to the person this happens to; some of the more common aphasias are listed below. Conduction aphasia results from damage to the above nerve pathways. Inability to speak words properly happens there and is called Dysarthria. Damage to the Wernicke's area cause receptive (or, sensory) aphasias -dysfunctions in understanding words and their symbols heard, seen, or felt. Subtypes include Wernicke's aphasia, where people speak words fluently, but have difficulty with their meanings or relationships, jumbling the words together. Alexia is the loss of ability to read words. Damage to the Broca's area causes expressive (motor) aphasias. Understanding and creating words are OK, but the ability to form and speak them is lost and weakness or paralysis on the right side usually accompany Broca's. Dysphasia is the loss of speech. If writing is affected, this is Agraphia or Dysgraphia, which can be tremendously

frustrating. If we still have good abilities with grammar and syntax, but can't name objects, that's Anomia. If brain damage is more significant and widespread, this can be up to complete loss of ability to communicate - it's called Global Aphasia.

By and large, upon being released from the hospital, my understanding of my brain's future was: "Typically, most improvement from strokes occurs in the first few days, and improvement can be expected in the next three months, but that will essentially be it and nothing else can be done. Period." I was not completely happy with that thought. I have told and repeated to my doctors "I refuse to believe that I cannot do better and will do my utter best to recover from my brain damage until they can prove to me that I can't do any better. And, any time that is the case, I don't want to waste my time and will concentrate on other things that I can do."

My concern now is to find out:

- What can be done to improve my capabilities? And
- What can be done to reduce the likelihood of another brain attack?

I've been looking for where to find my answers first; my currently most useful Internet search tool is www.google.com. A search for "Aphasia" showed 94,700 possible references (many of which could be useless or, worse, erroneous.) Searching for "Aphasia" books showed 227 on www.barnesandnoble.com; 23 at the Seattle Library; and about 450 at the Library of Congress.

References:

1. The Brain and Language, <http://faculty.washington.edu/chudler/lang.html>
2. The Merck Manual, Sec. 14, Ch. 169, Function And Dysfunction Of The Cerebral Lobes, 04-Mar-03, <http://www.merck.com/pubs/>
3. Gale Encyclopedia of Medicine, and the Gale Encyclopedia of Psychology, available at www.amazon.com <http://www.amazon.com/> and quotes available at www.google.com <http://www.google.com/> .
4. Gliesche, Sherry T., MS, SLP, "Aphasia", at www.familyvillage.wisc.edu <http://www.familyvillage.wisc.edu/> .

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Rebecca Greely, graduate clinician and assistant to the Writer's Guild this winter.

Publisher's Note

How do you synthesize all of the information that begins to describe "aphasia"? Bob Anderson and members of the Writer's Guild grappled with that issue this winter. The outcome is Bob's personal introduction to define aphasia.

Ted takes us on a continuing journey exploring his relationship with music post-stroke. His story supports the reported experiences of many stroke survivors as he recounts coming out of a "fog" with the aid of music.

From car-buff to hot-dog skier, Doug Graham's personal perspective on his stroke is shared through an interview with Bob



U.W. Speech & Hearing Clinic
Receptionist, Sara Hanel

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Anderson. This interview format sets the stage for a new section in the newsletter where we will be gathering the personal stories of stroke survivors and their communication partners for future issues. Let us know if you would be willing to be interviewed.

The creative overview of the N.A.A. offered by 1st year graduate clinician, Rebecca Greely who has assisted with the Writer's Guild this winter, highlights the value of this community resource.

This issue is much more than these stories. It represents the group's efforts to practice and develop their thinking, conversation, and writing skills; to edit and clarify their work in a supportive environment; and to hold fast to intended messages that are often challenging to convey in the presence of aphasia. This is their perspective – in their words – providing each individual with aphasia with a mechanism to challenge themselves, and the reader to begin to understand the scope of being a stroke survivor!

Nancy Alarcon, Clinic Director

Editors for this Issue: Bob Anderson, Ted Paluchowski, Rebecca Greely, & Nancy Alarcon