



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

Dennis: The Time of my Life

—This is my Aphasia story, put on the paper with help by another with Aphasia. —Dennis

My stroke has given my life a Dickens of a time – “it was the best of times, it was the worst of times . . . it was the spring of hope, it was the winter of despair”.

I have been a teacher and it is a delight to work with young kids. I taught in a Kent Junior High school and was up in front of my class when the students told me that there was “something wrong” with my speaking. That was the 20th of March, 1984. I told my colleagues that I was tired and needed to “go to sleep”, but they called an ambulance. Doctors at the Valley General Hospital performed brain surgery to correct the embolism in my brain. The doctors felt that they may have found a cause of my brain injury. Just ten days earlier than the stroke, I was playing volleyball with my school colleagues and broke my leg.



Dennis Duva

From Valley General, I went to the Good Samaritan Hospital for stroke recovery and therapy. There seemed great hope, then, more despair. There was a bad reaction to the medicine I got (Dilantin, an anti-seizure medicine). I went

into a coma and was sent to the Harborview. I was in a coma for 6 days and the Docs said they had thought that I was probably dying.

I was moved back to the Good Sam for 6 months. This was at the Center for Cognitive Rehabilitation, a community-based program. I was in an apartment there, under therapy from 8 to 5 each day, for 5 days each week. Then, from home, I went into Good Sam daily for another 6 months of therapy.

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Then it seemed a good time: my school district gave me a trial school assignment, to show my improvement. That was at the Kent district, in Soos Creek Elementary School. But, against my desire, the district retired me with a pension.

I was crushed.

And, then, with surprise — but expectation, with hurt — but satisfaction, after my wife’s complete support and care, with her daily attendance at the hospitals for a year and a half, she left me. I understood her psychological depression and that for someone so young, she needed change and more hope. We still have a very positive relationship.

I live on my own and own my home and a major part of my life is volunteering.

For 6 or 7 months, I was helped at the ARISE day program for people with disabilities. I have now been a volunteer helper at the program for over 10 years and I am there (at St. Vincent’s) every Friday. The Soos Creek Elementary School (that’s the one) has a library assistant each Monday and Thursday. Me. For over 15 years.

And, every Tuesday during a university quarter, I attend the Aphasia Support Group meeting at the UW Speech & Hearing Clinic. It is very satisfying to be with others who have Aphasia.

But my greatest satisfaction is with my daughter, Jennifer. She was 7 months old at my stroke. She is 20 now, a sophomore at Seattle University, with an English major.

Sad, but true, being independent has forced me to

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It's Not Just a Job. It's an Adventure!

by CDR JR Scott, USN

This is a personal account of my last 9 months in an adventure that has spanned over 20 years of service in the United States Navy. Last August, I was finishing up my tour as the Commanding Officer of a helicopter squadron stationed on the wonderful island of Guam. My change of command ceremony was set for August 30th. Then, with my wife and three girls in tow, we were off for our new Navy adventure. I was moving from an awesome squadron to a great new assignment at the Pentagon; life was on auto-pilot. But, an even newer assignment apparently came my way and it was an adventure that I had not planned for.

On Saturday, August 17th, I was talking on the phone with my mother around noon. As I was getting ready to say goodbye to her, I (all of a sudden) couldn't talk. I was confused and unsure what happened, so I set down the phone and went to lie down on the bed. I rolled around from side to side and tried to figure out what was happening. My wife, who had been patiently waiting for me to complete my phone call, came looking for me. She found me on the bed, laying on my front. Things started getting surreal as she rolled me on my back and asked what was wrong. All I could do was to look at her with a confused look on my face - I couldn't speak. She, unfortunately, knew immediately that I had had a stroke and call 911.

That was a touch and go night for me at the Guam Naval Hospital. The Doctors discussed medically retiring me from the Navy, but thank goodness, that didn't happen. A CT scan confirmed that I had had a left brain stroke. In the Intensive Care Unit, I tried to write down my words on paper, but I couldn't do that either. What was wrong? What had happened? It did "dawn" on me that I had had a stroke. My right arm had some paralysis, but that had resolved mostly by the next day. What else could be wrong? Well, I was given a new term that I had never heard before: Aphasia. It was a term that would change my life.

With the stroke already "finished," I was pretty much ready to get out of the hospital after a couple days. But, medically, the Doctors did not have a definitive cause for the stroke. So, my wife, the Doctors, my Commodore, and myself (as

best as I could) put together a care plan that sent me and my family to Seattle, WA to work with a talented Neurologist at Harborview Medical Center (HMC). On 29 August, we flew to Seattle to find the cause of the stroke and to begin my formal speech language therapy.

The Doctor at HMC suspected that the stroke was caused by a Patent Foramen Ovale (PFO) in my heart. This PFO is a hole between the right and left side of the heart. It can allow a small clot to travel from the right side of the heart to the left, then up to the brain. The PFO was confirmed with a transesophageal echo (TEE). This led the Doctors to look for a blood clot, and indeed, I had a small one in my right leg. To get rid of the clot, I was given a six month course of Coumadin, a well known anticoagulation medication. Fast forwarding to the end of the anticoagulation course, and I was ready to fix my PFO via open heart surgery. That happened on 28 March at the San Diego Naval Medical Center, and it all worked as advertised. With my heart fixed, I was one step closer to being back to full duty.

The aphasia side of the house has been another challenge all together and, quite frankly, the tougher of the two. While I have maintained a positive attitude throughout my recovery, I would be a liar if I said that I've always known what the outcome would be. The problem was that the outcome was dependent upon a new paradigm that needs to be understood before it can be harnessed. It is important to understand that each aphasic has a new set of individual traits that must be mapped in their brain. Luckily, a wonderful group of speech-language pathologists in Seattle were able to "map my new paradigm" and then help push me along the road to recovery.

My progress has been a slow process, especially for someone who wanted and needed a speedy resolution. Instead of being able to quickly speak, read, and write, aphasia has been a constant source of frustration as I attempted to return to my pre-stroke abilities.

The progress did occur though. Over time, I went from being unable to talk, to a word or two, then to a couple words, and finally to sentences and full conversations. My ability to write was also in question. It started out with the letters of the alphabet being a strange subject that I had to

figure out. That slowly came back as I used a dictionary to re-acquire the words that I use to know. Certain simple words, like "have" and "but," continued to be a problem, even though it was used daily. Reading a book had also been a very slow evolution, especially when I tried to read out loud. While I could read each word, it would take a while to pronounce it. Constantly reading and writing helped me to close the gap between the two.

Even with the frustrations, I was able to see small victories were evident. I worked hard to set "metrics" for myself, checking the time it took to write a paragraph or read a page in a book. The metrics, with a stopwatch in hand, helped me to "see" my progress over time. While I obviously wanted to be back to my old self immediately, I learned to realize that my old self had changed to a "new" self. This new self will always have some remnants of aphasia.

My Navy adventure will be taking another step very soon. The Navy medical folks will be checking my progress, through a cognitive test battery, to determine if my mild aphasia is within "norms." This will, for the most part, decide whether I will remain in the Navy or retire. However, I feel confident that I can effectively do my Navy job.

minimal effects. I have a lot to be thankful for. I hope that this discussion of my personal account will be helpful to others who share a common thread with aphasia. You must always continue to push yourself to do better because it is not a job, it is your new adventure. And, with the help of your family and your medical community, you can make it through your recovery and learn to adapt to your "new" self.

One last point. "The Navy Rocks" illustration was from a young lady with 10 years of Navy service. That young lady is my daughter Jennifer. She put it together for me about 4 months ago. She, along with the rest of my family, have been helping me from the start. They are very special ladies. I continue to be a very lucky guy! «



**My Aphasia Support Group
– To Help or Be Helped?**

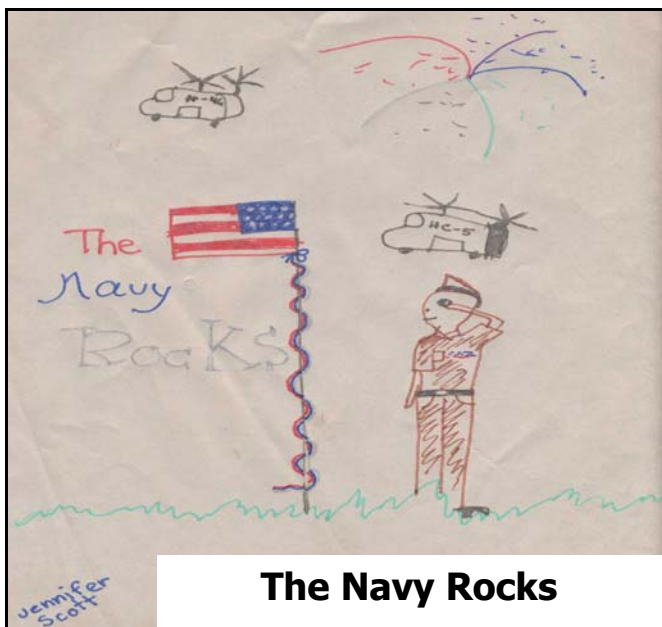
— *By Bob Anderson*

My wife and I met Beverly while 'working out' at the Washington Athletic Club two years ago. She has Aphasia, and on hearing that I also had it, she told us of the support group that she has belonged to for years. She invited Rosemarie and me to a luncheon with the group. I wanted to see if joining the group would help me.

In the group, there were humorous, interesting people holding meaningful conversations. Watching and listening to others with Aphasia, I was fascinated. It may take several tries for one to come up with the right word, or, writing letters in the air to show the word if it can't be spoken, or saying the first letter of the word if it can't be found. It may take a while to find the word, and others will wait for the speaker.

Often, while one is speaking, another may look puzzled and someone will ask the puzzled person "Do you have a question?" or may ask the speaker to clarify or repeat. It seemed to me that others had more problems than I. Would I be helped or helping? Would this be a worthwhile effort?

Some describe their writing as 'impossible' or 'incomprehensible'. Writing is staring and staring-



The Navy Rocks

My time in the Navy has been truly rewarding. I am lucky to be a part of the Navy adventure. I am also lucky to have pulled through this stroke with

Aphasia and Writing

By Ted Paluchowski

With this essay I hope to capture the challenges when writing with aphasia. In the past I have written short articles about specific topics. Now I want to focus on the process of writing itself. Before my stroke the ability to write was a given. Since that time I have aphasia. I struggle with language with uncertain results. Writing is an almost overwhelming activity. I want to review the process of writing, step by step, to bring it to full consciousness. I hope that an awareness of the process will improve my own writing and it may be of use to others.

First, the act of writing is a creative and demanding exercise. The difficulties of writing are exponentially compounded with aphasia. After my stroke I couldn't find the words I wanted. My thoughts swirled around words independent of meaning. I could not write a coherent sentence. Even a grocery list was a challenge. With time, practice and therapy I began to express my thoughts on paper. Eventually, I wrote, not like it was but functionally. But then, since my stroke everything is different. I continue to struggle to find the right word and the most appropriate expression. The product of my writing is an approximation of my intent. Close but a little unfocused. As if the words were following an echo of my ideas.

The ability to write, was and is very important to me. Beyond pragmatic and vocational application, I wanted to tell the world about my experience. I wanted to see my thoughts, my words, my ideas in print. While organizing my thoughts for this essay I was aware of leaving a record of the events that happened to me. As if the written words gave a validity to the experience and the experience in turn legitimized my choice of words in writing. At the completion of the essay, I felt as if I went through a rite of passage. Now, when I read my writing I have a sense of curiosity, surprise, almost a shock of recognition. I used to write and apparently I will do so again.

Second, as important as it was to read and write it was not enough. I wanted to learn about my con-

dition. At the beginning I could not understand the words. Never the less, I acquired a new vocabulary centered on such key words as: stroke, aphasia, neurologist, speech therapist, and rehabilitation. I wanted information about those words and the underlaying thinking that made them important to me. I wanted to know everything about my status. I emphasize everything, and I mean everything, from the trivial to the core of established fact. I think that the effort to find articles and books about stroke and aphasia was a means of coping with my own situation. I wanted an ever increasing volume of information even if I couldn't understand most of it.

With time my status began to be more clear and the associated information began more meaningful. I think I went through phases in sorting and processing the accumulated information. I found that the verb, "to comprehend", can best describe the evolution of my thinking. By definition, to comprehend means to grab ideas with the intellect. Since I have aphasia I am painfully familiar with the struggle to grab and hold a word not to mention complex ideas.

Comprehension may vary of degree. An old adage illustrates the point. Some people are active participants seeking new challenges, others are passive but aware of their environment, and some don't have a clue. Implicit in the definition there is a recognition of levels of consciousness. Eventually, I was able to fully comprehend a diverse array of information.

Third, for the most challenging aspect of writing is composition. To initiate, sustain, and complete a theme was and is a struggle. At every step of the process I have to fight to keep the topic in focus. Without a constant reminder my mind wanders in unpredictable directions.

Good composition should follow a linear progression from introduction, then to supporting arguments and evidence, ending with conclusion. With aphasia my thoughts are constantly skipping from idea to idea without completing the initial thought. The result is a clot of disembodied fragments. Rather [than] a tight grouping of related ideas my thoughts dance in a random pattern. An associated difficulty occurs with selecting an ap-

propriate sequence of ideas.

Once a clear theme has been selected it serves as a guide overall framework. For example, at one time my theme was aphasia and music. Immediately, the theme suggests an outline that includes sections about aphasia, music and the relation between them. That initial outline generated additional topics. For example: neurology, language and therapy were potential sections to include. This rough outline began the process of organizing my thoughts.

Over the years I collected a blizzard of bits and pieces of data related to my theme. In addition, I recorded short notes my personal observations, insights and fragments of intriguing ideas. The combination produced a potent but amorphous cloud of ideas.

To give form to that cloud required more structure than a rough outline. Too many ideas escaped through an open lattice design. So I turned to a process of bundling similar ideas and drafting brief paragraphs. I also selected a small number of key ideas to develop. In the process I generated a hierarchy of short outlines. Each consecutive outline refined my thinking. Over time individual thoughts coalesced into larger and more complex aggregations.

Finally, I arranged related sections in order to create a collage. All the ideas were stitched together. Inspection discovered a number of gaps, redundancies, and extraneous thoughts. Acting as my own editor I modified the text as appropriate. The result was a coherent and meaningful essay on aphasia and writing.

Before closing I want to summarize the lessons I discovered in my attempts to overcome aphasia and write. One. I found a dialectical approach worked the best. A traditional method of writing calls for a clear outline then filling in the details. I found that a outline was useful but I was constantly generating new ideas that were interesting but incompatible. I could see the big picture but the pieces were unfocused. At the same time I was able to write short vignettes and brief descriptions of my thoughts. I could group related ideas and even write connecting passages but

there was no overall direction. By combining both a top down approach guided by a clear outline and a bottom up approach using bundles of related ideas cumulated with a synthesis. The synthesis incorporated the best attributes of both approaches.

Two. At times I relied upon my visual ability to organize and sequence my thoughts. I will explain. As an academic I was familiar with the technique of recording notes on cards. Then it's relatively easy to organize and reorganize the notes to find underlying patterns. I used a similar approach. I laid out all my notes on a table top then looked for patterns. With aphasia even a small increment of input in the form of language quickly overwhelms my capacity to process it. At the same time I can immediately recognize a pattern. Therefore, I sought opportunities to use pattern recognition.

Three. I wrote rough drafts after draft after draft. Most of those drafts consisted of nonsense. But, the physical act of writing, sitting down with a pen and paper, was important. The act of writing per se kicks cognition in motion. Improvement comes later.

I will write again, but I'm not sure of the topic. My brain constantly bubbles with ideas that must be developed. I'm just here for the ride.

[Ed. Note: This is an unedited submission with the exception of 1 word-addition to clarify Ted's point] «



(Continued from page 1)

push myself further than I might have gone, for I could have become more dependent on my wife, Susan. Now, I am eminently proud of Jennifer because of her love for me and for her accomplishments and because of my encouraging and supporting her.

Her future is my goal of life now.

— Footnote: Dennis' writing is extremely hard for him. I met with him to help — so that his voice could be heard. — Bob A. «

(Continued from page 3)

at a blank page. "I want something said, but there are no words to put there."

Or in reading, "I need to turn a word over and over, to poke it and taste it and worry it to a bone until some value can be gleaned from it."

Can I be helped? Or, can I help?

I'm convinced that I have improved. But, there have been days up and days down.

I have brain problems! I feel at times that I'm really in a worse way than every other person in the group in some way or other. When I think I know what to say, I can't find some of the needed words that I used to know. I can't always 'hear' what people are saying to me, but the problem is not my hearing. My brain often just takes longer than it used to, in order to figure out what was told me. So, I lose the thread of the conversation. Sometimes, in the middle of a conversation, my brain shifts into neutral, perhaps just taking the time it needs to rest and rebuild.

My long-term trend has been positive - and it **will** continue to be positive, but improving is not as steady as I would wish for . . .

With my brain injury, to me, the 'outside', real world is like a constant war that I have to fight - like a job much more difficult than it used to be. To rest, recover, and return to the battle, one needs a place with love, peace, and safety. My wife and family provide this - and our Support Group provides this.

Can I be helped, or be helpful at a support group meeting? My answer to that question is: Yes, and Yes! I hope that I can help. Here, everybody in the group is affected by their Aphasia in different ways and degrees, and each helps each other. To accomplish what I need and want, I need a goal and guidance, like the light from a steadfast star. Each in the group provides light, shining from the hearts of the people there. And we are led by a helpful, caring guide with a strong, steady light.

"Bright Star, would I were steadfast as thou art—" —Keats «

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June is "Aphasia Awareness" Month!

Support the National Aphasia Association (NAA) by shopping at amazon.com. First, go to the NAA website: www.aphasia.org. At the bottom of their home page, use the link to connect to Amazon.com. NAA has an agreement with Amazon.com that if you connect to Amazon.com from that link, part of the proceeds from your purchases will support the NAA.

Publisher's Note: "If we keep doing things the same way, we will always get the same results!" I'm not sure who first said this, but it's a powerful phrase to live by. Change can be so uncomfortable, yet it can allow us an opportunity to grow in new directions if we permit it. Each article in this edition is a testament to dealing with change. Dennis's personal account told through the writing of another stroke survivor provides us with a glimpse into a remarkable journey of tribulations and ultimate triumphs. JR's debut article speaks to the spirit that one can call upon to deal with a sudden change in life plans. Jen's drawing captures her vision of her Dad irrespective of his stroke.

Bob has chosen to share his first impressions of joining one of our groups in the clinic. His words emphasize the uncertainty many stroke survivors experience as they venture into a new environment, and the reward of venturing into uncertain territory. "Aphasia and Writing" captures Ted's thought-provoking journey to better understand his own recovery.

As we discover new skills and challenge ourselves to grow, we have worked hard to use the chosen words of each writer. Each submission is "in their own words" with minimal team editing, preserving their personal experiences of living with aphasia.

— *By Nancy Alarcon*

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