



An Invitation for Articles

-by Ted Paluchowski



As broadcast by its masthead the mission of the newsletter is for and by individuals with aphasia and the community. Accordingly, survivors, caretakers and professional therapists has contributed, every insight helps to understand the nature of aphasia.

As a survivor I can attest to the positive consequences of putting my own words, my thoughts on paper. Even primitive scribbles are important. It is the process of writing per se that is a validity, a certain legitimacy to the underlay ideas.

In reviewing the array of articles published during recent years, I was I impressed by the range of topics. At the same time, I thought something was missing. For the most part, the authors have been drawn from one language group at the U.W. Clinic. All of its members have been classified as fluent. There are other groups that face more severe challenge. At the same time there are other groups that are not affiliated with the U.W.

Therefore, as an editor I would like to extend an invitation to such groups.

In previous discussions with the publisher, I have initiated contact with members of the non-fluent group at the U.W. clinic. Also, I have initiated contact with the Young Adult Stroke Survivors.

One member of the YASS wrote the accompanying article. I hope to involve more members, both survivors and caretakers to participated. ««

More information about Ted's visiting the Young Stroke Support group (and about our goals, and Gerrit's group) is at page 4. — ed.

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	-from stroke survivors	
	-from their family	
	-from survivor's clinicians	
	- causes and effects	««

Stricken at 48

by Gerrit Barrere

I was working at my electronics lab bench one sunny afternoon in August, 2003. I looked up at the end of the day and got a sudden sharp pain in my neck. "Oh no!", I moaned, "Another one of those muscle cricks!".

This one turned out to be pretty bad though. It was interfering with my sleep, and there was also the odd symptom that I would begin to black out if I held my head in certain positions. I didn't know it at the time, but this was a "spontaneous vertebral artery dissection" (VAD), where a section of artery lining pulls away from the artery wall like a blistering piece of wallpaper. This all happens internal to the blood vessel; there is no bleeding or cutting like the term "dissection" means in high school biology.



I made my first-ever visit to a chiropractor for the neck pain. He misdiagnosed it as muscular and (Continued on page 2)

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began twisting my head around in a "neck adjustment". This went on for three days and didn't help the pain. What it did do, however, was aggravate or tear the VAD. This formed a clot which broke off ten days later and gave me a cerebellar stroke, deep in the brain.

This was a classic stroke. At 10:30 one night as I sat answering email, my right arm went numb, then my leg, then my speech began to slur. I called 911 and took some aspirin, realizing I must be having a stroke. The emergency techs thought I was having a panic attack because I don't fit the normal stroke profile. They took their time getting to the hospital, no lights or siren, while my right side continued to die away. As I was being wheeled into the CAT scan I said goodbye to my wife and boys, thinking I was going to die as I continued to lose functioning.

Amazingly, the right side came partially back. No stroke was seen on the low-resolution CAT scan, and until a higher-resolution MRI was performed late the next day even my neurologist was guessing I might be having a hysterical episode of some sort. I experienced two more terrifying transient events in the hospital where I lost right-side functioning altogether but it returned. After four days I checked out, dragging my foot badly, unable to make a fist, perpetually dizzy, and with slurred speech. The doctors told me they did not know why this stroke had occurred, incredibly they did not see the VAD on the MRI images at the time, but they said to "take it easy".

I interpreted this to mean I could take a nap if I wanted, and I charged back into my life trying to rehabilitate as fast as I could. I was in the process of a divorce at the time and was moving out, so there was plenty of opportunity to overdo it. This I did, and three weeks later I pushed the VAD up into my brain as a result and caused a second stroke.

This second one was much different than the first. It was heralded by a day of the worst nausea and vomiting imaginable, along with extreme fatigue and exhaustion. Finally I asked my son to take me back to the hospital. I was put through a series of spurious tests (like chest x-rays), despite

my telling the doctors I had had a stroke three weeks earlier, and finally was admitted and fell asleep about 2 AM.

The next morning I awoke to find my left side completely paralyzed, limp as a rag doll. I had now experienced a stroke on both sides. I was also seeing double, vomiting at least once a day, had a buzzing in my left ear, speech like a drunk, could not swallow thin liquids, and was seeing strange crescent-shaped floating objects in my vision occasionally. I couldn't comprehend the enormity of any of this. When I noticed I was paralyzed that first morning, I said to myself, "Huh! I'm going to have to do something about that". When my wife and kids came in, haggard from fear and having spent the night at the hospital, I wondered aloud if that had really been necessary. My neurologist saw how close to death I was, but it completely escaped me.

This time the loss of function did not come back. It was several days before I could make the slightest movement of my thumb, the first thing to return. Then I could barely move my toes. Slowly, excruciatingly, movement began to return.

I also discovered that I was "emotionally labile". I could not control my emotions. The slightest sentimentality would send me hysterically sobbing. The slightest humor and I would be laughing uncontrollably. When my brother first visited and wordlessly held me, I began to cry racking sobs. After a little while of this I began to think it was a bit peculiar and my crying morphed into hysterical laughter without a pause. My brother backed away looking puzzled and asked, "What ARE you doing?". As if having a stroke was not emotional enough!

I spent a week in intensive care, a week on the medical ward, and two weeks in rehab. The work in rehab was grueling; after something like this you have almost no energy or strength. But it is extremely important. My therapists told me most of my improvement would occur in the first six months. I was going to prove them wrong, be the Superman of stroke recovery, but they were absolutely right. I think if I had not worked as hard as I did for those first six months, during in-patient and out-, I would not have recovered as well as I have.

It was after this second stroke that my new doctor saw the VAD on my brain scans from the first

stroke three weeks prior. He was very firm about what to do now that it was clear that I had a VAD, and I wonder if the second stroke would have occurred at all if the first doctors had seen this too and been as firm with me.

By the time I left rehab, I was walking very slowly with a four-footed cane and a spotter holding my belt to catch me if I fell. My speech was still badly slurred, but I could drink liquids if I was very careful. I choked on food and drink regularly. I could not raise my arm above my head and had only partial use of my hand. I used a bench in the shower. I was dizzy all the time; it felt like I'd had too many cocktails 24 hours a day.

My sister dropped her life in Santa Fe and spent three weeks with me when I got home. She cooked, cleaned, helped me with paperwork, took me out for diversions, gave me pep talks and encouraged my exercising, and listened sympathetically to my hysterical laughing and crying. My life was shattered, and I don't know what I would have done alone those first weeks without her.

I made slow but steady rehabilitation progress for the first six months. I kept a list of little milestones, like raising my arm over my head for the first time, ever-lengthening walks, being able to clip my own fingernails, and so forth. Looking back on this helped keep my spirits up. I also made a list of short- and long-term goals, things I still wanted to do. But I hit a wall at six months and suddenly stopped improving.

Not long after this I slid into a terrible suicidal depression. I really felt my life was over. I had failed in my marriage, and now I was crippled and felt like I would never love or be loved again. I could no longer play the classical guitar or piano, one of the major joys of life before my stroke. I was living a nightmare in a body which was no longer my own. I can remember one awful day, catatonic and crying inconsolably, when I was planning how to end my life. In the depths of despair, the thought occurred to me that I could "take my life, or give it away". I realized that no matter how awful my life was I could make a positive difference in someone else's, whether that meant spooning them soup in a kitchen or giving my possessions to the homeless. With little effort on my part, I could

make a big difference to others.

This was the real start of my recovery. I began volunteering in a local retirement home, reading to the old folks to help my diction and give them some pleasure. I began to donate lavishly to causes which directly help people in need. I began handing granola bars out to freeway off-ramp beggars. I volunteered for the Sierra Club Executive Committee. I began serving as the leader for the Young Adult Stroke Survivors group. I gave generously to friends and relatives. I was no longer worried about the future, and I discovered the paradoxical secret that the greatest happiness comes when you give freely of yourself with no expectations. I only regret that it took me 50 years and a near-death experience to figure this out!

Now it has been two and a half years since my stroke (I think of them as one). I walk stiffly and clumsily with a cane, and can no longer run. I have almost full motion and strength in my left arm and hand, but cannot move the fingers quickly enough for the guitar or piano. I have discovered music creation with a synthesizer and computer though, which is great fun and wonderful compensation. My diction is pretty good now, except when I'm tired. I still laugh and cry like a minor lunatic and have the equilibrium of a drunk. I am back to work full time as a consulting engineer, and very thankful that there were no cognitive effects from the stroke. I even wrote a long technical paper which has just been accepted for publication, something I never would have had time for before my stroke. Life is slower, but in some ways actually better. Oddly enough, there are times when I think this has been the best thing that has ever happened to me. ««

Why the Article by Gerrit??

- by Bob Anderson

It is from a stroke survivor, but from outside our group and the Clinic.

Ted heard about this Stroke Support Group from one of the other members of our group. He was encouraged by Nancy to attend the YASS and speak to them about our newsletter.

His response: "I'm not waiting, I'll go talk to those people."

"Since I was there; I was on the agenda – I had my turn. I wanted to have an impact. I got a reaction. For me, it was really good – it was an opportunity to address a large group. I presented my material – they reacted. I was done. I rattled their cage.

"The diversity of abilities and concerns is really, really wide. Some people went to sleep—others were jumping up and down— I thought ok, the more articulate were interested. I said fine – I explained how to contact, etc.. Now maybe others will reach out.

"That was almost an assignment – make contact with this group – I had literature with me. It was something to do.

The practicing could have been enough, Ted

"It was the content and the message. It turned out to be a way to push myself further and here is a way to take it further for all of us."

We have had a dream for this newsletter for a couple of years—to reach out, to broaden our interests, to understand ourselves better. The articles by Gerrit and Ted are part of this need to reach.

People who have strokes almost invariably are impacted differently—and by more than Speech and Hearing Disorders, though that is the primary concern of the UW Speech and Hearing Clinic.

The survivors, their family, friends, caregivers, and medical professionals are all impacted by the stroke's effects. It is more difficult for the survivors to share their needs and wants and for the supporters to understand and accept this different situation.

We will keep pushing.

We want to.

We need to.

««

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Gerrit's Stroke Group

Gerrit Barrere goes to the **Young Adult Stroke Group and Caregivers**, which meets monthly at the Northwest Hospital. Its next meeting is March 18th, from 1:30 to 3:30, at the hospital Rehab Center, Meridian & NW 115th Street, Seattle.

Driving directions:

- From I-5 take Northgate Way exit and head west-bound.
- Go 1-1/2 blocks, then right at Meridian (stoplight).
- About 2 blocks, then left at N 115th St. (Stop sign).
- A half block, then right into the NW Hospital main entrance. Parking is free on Saturdays.
- Follow the signs to the Rehab Center, there is a parking lot there.
- They meet in the **TCU Dining Room**, down the corridor from the main entry. Arrows show the way.



Publisher's Note

I'm so pleased that Ted helped us connect with one of the area stroke groups in our community. We are stronger for that connection. Our hope is to continue to reach out, increase the awareness of Aphasia and Living with Stroke in the Greater Puget Sound, and enhance services for individuals with aphasia and their families.

As a result of Gerrit's article, we'll come back to talk about living with emotional lability, dealing with depression, and finding inner strength in the face of adversity. Our next issue will be in June—National Aphasia Awareness month and we're sure to address these topics. In the meanwhile, visit www.aphasia.org for exciting activity information, including the "Speaking Out" national convention in Boston, MA June 15-17th.

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