

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 Annual Christmas Pilgram**

-by Jim



**Jim, at his aphasia group**

*Jim's article is printed here exactly as he wrote it, by hand. A few editorial comments are added, in parenthesis, for clarifications. —ed.*

It was my annual Christmas pilgram to Phoenix AZ to visit my mother. I have always looked forward to it. for a 2 wks vacation. from work @ Boeing as a instructor. I decided to take a bus. because it was a good time to put the car in the shop. Problem I decided to late to get airline tickets. It was a long bus ride, about 27 hrs.

After a long nap. I went to the store for my mom, for a couple things. It took about 10 min. on her bike. When I got there I was feeling a little wiered (funny). After about 5 min. I felt OK but when walked into the store all of a SUDDEN I relalizad my hearing had gone. Within seconds my hearing. STOPPED. I was totally DEAF. I just freaked out. I knew something bad had happened. I walked outside I jumped on the bike and rode as fast as I could. The problem was I could not hear

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-from stroke survivors	

the traffic and me equal (*equilibrium —ed.*) was not that good. Finally I got to her house and ran into the house screaming at the top of my voice. (which I did not know was so loud.).

My mom who is a retired RN. after Listening to me talking she realized my speech + the hearing promblem. That maybe I had another stroke.

Took me to the Emergicy Room. they took a CT. then the Dr. WROTE ON A piece of paper "You have had A STROKE"

I still did not know for 2-3 days. that of the results from stroke was "APHASIA" because of the hearing!!

It was when my mom wrote the note explaining what had happened. And how Asphasia WORKS. Did I understand. IT STILL DID NOT SINK IN UNTIL. I WAS ABLE TO start to hear. even in it was still NOT BACK to NORMAL hearing.

I was having trouble to find the words I wanted to say. I just could not find them inside my Brain. or in side my DICTIONARY (INSIDE the Brain). They were gone

I was NOTICING other things. (Like I

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told my mom, when we got back home after being from Christmas EVE to the 1<sup>st</sup> DAY of 2003. that I still feel that something is still wrong!

After getting TEST fom Behaviorol Phy (*Psychologist –ed.*) for Laweyrer, Against GOV for SSD (*to qualify for Social Security Disability –ed.*) other things showed. (Some again from Asphasia)

One of the things from quite a few that Asphasia can do. I seem to have a prombly with I say the opposite meaning. WORD making a bunch of Promblems Confusnig me; clerks, anyone I am talking to. They have funny looks on there face after talking to me

After 16 months I still have problem, reading composing. I have quite a lot promblem w/ conistration (*concentration – ed.*). like watching TV. trying to Read. get real tired. You are just tired the brain needs a break, like body phycaly needs break

The biggest thing that happened from the 2<sup>nd</sup> STROKE which is one of the Bad thing is the hearing promblem. The left ear has gotten worse. The rt. ear came back about 75% The Left ear came back about 25% & is getting worse. The brain is just not understanding the message from the ear to the brain. All I can hear in the left ear is just loud static. It also maken tollaly hard to figure where Sound (Direction) come from.

NOT hearing well IS a big promblem for people who have fallen into the grasps of Asphasia clutches. The promblem of not be able lisenting is a big part of conversing be ableing to understanding what the person is convaying.

Another Problem when composing or writing The first time got on the computer to write some E-mails. All of a sudden I DID NOT SPELL VERY WELL. I also when writing notes to my mom in the hospital for the 1-4 days. Spelling Stunk!! Still STINKS

*Ted and Bob, two others with aphasia, read Jim's article with him. We asked him,*

*"How were you affected by a stroke before this one?" We wrote down these notes: -ed.*

My first stroke happened in January, 2001. I was working at my computer at Boeing, and reached for a drink. The Mountain Dew can slipped out of my hand and splashed onto the floor. After cleaning that up, it happened again to my 2<sup>nd</sup> can. Going into the restroom for more paper towels, I noticed my face in the mirror and saw that the whole side of my face was slack.

I now was concerned, but managed to get home. Music that I heard was just noise. I was wondering "What happened?" I was going to try to call 911, but in trying to speak, everything came out as mumbles and grunts. I couldn't WRITE the information that the medics would need. Essentially, I gave up on trying to get to help, and lay down wondering what to do (and HOW to do it.)

I got up an hour later. . . And everything was back to normal—EVERYTHING. Three months later, I had a Grand Mal seizure, and on Christmas Eve, 2002, my 2<sup>nd</sup> stroke happened.

*We were happy to see what Jim had produced and asked him how he felt about printing it. He thought first about editing it and chose to print it "as-is".*

*We were even more pleased. People with aphasia write and speak "that way". Seeing words like this help us to recognize that we have something to improve upon. What we want to say isn't always what we do say or how it sounds.*

*Ideas take time to develop, and Jim's story idea started last fall. We look forward to more of his story (and his mother's input?). He might include how he continues improvement, how he deals with his problems and later, perhaps, if he feels differently about how he wrote this article and how he could do that.* -RLA, ed. ««

*What are the warning signs of strokes?*

*-see Pg. 5*

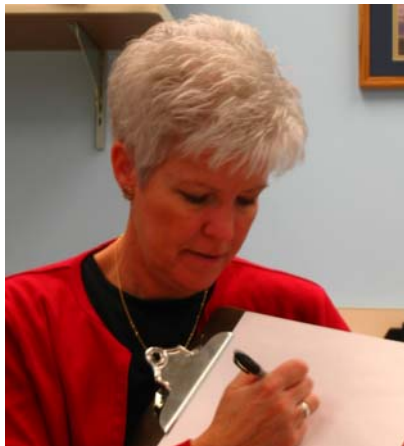
### The real 'survivors'

#### – knowing the warning signs of stroke

-by **Nancy B. Alarcon**, MS, CCC-SLP

Sr. Lecturer & Clinic Director

U.W. Speech & Hearing Clinic



*Nancy Alarcon conversing with individuals with aphasia—by writing and talking.*

"Bill" was nauseated and had quite a headache when he awoke, so he decided to stay home that day. Since he was resting quietly, his wife left for work. When she checked on him later in the morning, no one answered the

phone.

Fortunately, she decided to run home to check on "Bill". He was sprawled on the bathroom floor, unable to tell her what had happened. She immediately called 911. "Bill", 45 years old, had reportedly felt as healthy as ever. By the end of the day, his wife learned he had suffered a *stroke*.

"Mary" knew something was wrong as she pushed the grocery cart down the aisle. She suddenly felt confused and dizzy. What was happening? With her granddaughter in tow, "Mary" managed to get through the checkout stand and found a pay phone outside. Thank heavens, her husband answered the phone at work. She tried to explain that something was wrong, but as her husband reported later – "I knew it was "Mary's" voice, but she wasn't making much sense." "Mary" was experiencing a *transient ischemic attack*.

In an instant, everything can change. We recognize how precarious life can be, but assume "it" always happens to other people. For stroke survivors, they know only too well

how lives are turned upside down in an instant. A stroke or "brain attack", is a disruption in blood flow (ischemia) and a disruption in the delivery of oxygen (hypoxia) to an area of the brain. Transient ischemic attacks, or TIAs, are temporary stroke symptoms with a disruption in blood flow, for less than 24 hours, with no evidence of permanent neurologic impairment. A stroke may occur as the result of a cerebral vascular accident, trauma to the head, or other neurologic conditions. The extent of impact is in part dependent upon the location of the stroke.

An estimated 500,000 to 750,000 strokes occur each year in the United States. It is a significant cause of disability in young people and the leading cause of disability in adults. Approximately 4 million stroke survivors live in the U.S. today. As you'll note, we use the term "survivors", not victims.

The complications of stroke may include sensory and motor impairments, swallowing impairment, vision changes, the disruption of speech and language, hemiparesis (weakness or partial paralysis on one side of the body), and muscle spasticity (changed muscle tone or possible muscle spasms). These are "impairments" or physical changes which may occur. In addition, the stroke survivor may face limitations doing familiar activities, experiencing significant difficulty in daily activities such as walking, talking, listening, driving, and working.

Unfortunately, the impact of stroke doesn't end there. The stroke may physically affect the individual, but it also markedly impacts family and friends. A stroke survivor faces the challenge of reestablishing him or herself as a meaningful member of society. The success of participating in society is typically wrought with obstacles in part due to lack of public awareness of stroke and its impact on daily living. Given the incredible challenges stroke patients face – they are **survivors**.

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We live in exciting times, as researchers endeavor to unlock the mysteries of the brain. Scientific research is focusing on identifying "high risk" profiles for earlier identification of individuals who may be prone to stroke.

In addition, the National Stroke Association and the American Heart Association are strong proponents of "Stroke Awareness" with national efforts focused on raising the consciousness of American's to lead healthy lives and seek immediate medical attention when faced with the warning symptoms of a "brain attack" or stroke.

The National Aphasia Association offers education and resources to assist families and patients coping with the disruption of communication.

When a stroke happens, changes occur at the cellular level in neurons and surrounding tissue. These destructive changes are brought about by two mechanisms: the cascading effect of cell death that is part of the body's process due to injury or lack of oxygen, and chemical and electrical changes that are necessary for communication between brain cells.

The body has a natural "neuroprotective" response to stroke. Research is trying to understand the complexities of this acute response, and optimize "neuroprotective intervention". As a result of a 1995 National Institute of Neurological Disorders and Stroke (NINDS) study, the drug "tPA" has been the focus of extensive news reports for its potential to significantly reduce devastating effects of stroke for certain individuals when administered within the first 3 hours of a stroke. Neuroprotective intervention is aimed at administering agents that are most effective following the ischemic event within a critical time period.

Scientists are finding that the agents or medications must be able to move from the body into the brain by crossing what is

referred to as the "blood-brain barrier". This must happen within a specific time to be most effective, and must not have negative side effects. Our knowledge in this area is in its infancy, however the outcomes look incredibly promising.

The course of recovery for a stroke survivor and their family is arduous and often an emotional roller coaster, however research in rehabilitative medicine, as well as complementary and alternative therapies, continues to address patient and family hopes.

Constraint-induced movement therapy findings first publicized in the spring of 2000 as a result of a study at the University of Alabama, is now undergoing further investigation through a six-center National Institutes of Health (NIH) study. The thrust of treatment is rewiring the brain and recruiting nerve cells to replace the working ability of cells destroyed by the stroke.

Historically, most therapies have focused only on the individuals with aphasia. At the University of Washington, Dr. Margaret Rogers, Dr. Lesley Olswang, this author, and a number of graduate students are investigating family-based therapy for individuals with chronic or long-term language disruption (aphasia). As part of their clinical work, they are exploring the impact of aphasia on the quality of life of individuals with aphasia, as well as their communication partners.

Acupuncture is one of 200+ alternative and complementary therapies that are outside of the traditional rehabilitation model in medicine. A 1997 NIH sponsored conference suggested that acupuncture might be helpful as an adjunct therapy in a number of medical conditions such as stroke rehabilitation. Further research was recommended and is ongoing nationally.

Additionally, therapies such as the use of hyperbaric oxygen (HBO) therapy to increase the amount of dissolved oxygen in the blood, and the use of ginkgo biloba in

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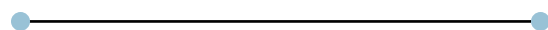
post-stroke patients to improve attention and short-term memory are being investigated.

Some of the most exciting, yet daunting and controversial scientific research happening today is the exploration of nerve cell regeneration, the identification, development, and use of nerve growth factor, and nerve tissue transplanting.

Government and private support for research in these areas will hopefully bring us closer to lessening or eliminating the devastating impact of stroke. These areas of exploration will also challenge our ethical conscience, however.

For the time being, what should we do? Neurologist, Dr. Jose Suarez, remarked in a review of acute ischemic stroke that **"time is brain"**!

It is **critical** for us to recognize and respond immediately to the warning symptoms of stroke.



### Warning Symptoms of Stroke

*Sudden numbness or weakness of face, arm, or leg, especially on one side of the body*

*Sudden confusion, trouble speaking, reading, writing, or understanding*

*Sudden trouble seeing in one or both eyes*

*Sudden trouble walking, dizziness, loss of balance or coordination*

*Sudden severe headache with no known cause*

If faced with **any** of these symptoms, get medical help—**immediately!**



- Nancy Alarcon««

### Mental Fatigue. . . So Tired

-by **Bob Anderson**

Friends at our Aphasia Group have often mentioned being tired or fatigued. In Jean's newsletter article several years ago, she said that she had often felt very tired. I have felt that way, too, and wondered why.

After my stroke, I would feel very tired and need to take naps, even though I had done little physical effort. This was not the way I had felt before the stroke, when I was in good physical shape and active.

There's more to understand about fatigue. I'd like to really find out why.

The prescription with sports injuries almost invariably seems to include rest of the injured part—and exercise, but not overdoing it.

Rest was part of recovery from surgeries I was familiar with. That clearly was not obvious to me while I was recovering from my stroke.

Now, I figure that 'rest' applies to my brain damage in the same way as "real physical injury" to body parts, like legs and arms, that do exhausting physical things.

For a long time, I have known that the brain is appallingly complicated. And that my blood temperature is higher when it leaves the brain, and our head is where we normally lose more heat.

That suggests to me that my brain requires a lot more 'effort' to do work and, to **maintain** itself.

Repairing a muscle strain or tear takes a while. It takes a longer time for repairing a broken bone (if that's possible.) So, longer time and 'effort' to repair a very complex machine, the brain (if **that's** possible.)

My energy stores are depleted much faster than expected, even though the rest of my body is in reasonably good shape, so that must mean that the 'work' tiring me so much is my brain working to repair my brain.

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Since I've been a kid, good health guidelines given to me included good rest (and, of course, good food, exercise, doing some things, and avoiding other things, but always, sufficient, good, and regular rest.)

I haven't found anything in articles on the Web about stroke that mention "mental fatigue", but there are 799,000 Web sites identified from a search for "mental fatigue". I'd like for somebody to research that and let me know the results.

Typical symptoms of mental fatigue include:

- Inability to keep fixed attention
- Impaired memory
- Failure to grasp new ideas
- Difficulty/slowness in reasoning

I need to set up a plan for myself to help set the environment for my brain to have the best possible chance for it to improve. ««

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"In Search Of. . ." .

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#### **Publisher's Notes**

"Don't get mired in the details" – how true that is! For Jim, we are most thankful that he did not get "hung up" on the details when he wrote his story. In his own words, he tells of his unique hearing loss and accompanying language difficulties resulting from his 2nd stroke. Telling one's story is a journey in itself—sometimes uncomfortable, yet often very rewarding.

Bob's wonderfully insightful piece on fatigue helps us to acknowledge and begin to understand what happens to each of us.

As we close out the 2003-2004 year at the U.W., I am most grateful for Bob and Ted's spirit and dedication to this valuable newsletter. Their tireless efforts make this possible!

*Exciting things can be happening in science.*  
News item: A mother with a stroke affecting her left arm could not even pick up a candy off the table, much less pick up her child. Seattle company Northstar Neuroscience is testing a therapy that allowed the mother to pick up her son though it is "not graceful".

-Seattle Times, 2004Aug10

*One hopes for more development . -ed. ««*



*Where in the brain does aphasia happen?*

*We're in search of answers and will share what we find.*

For more information about Aphasia or Stroke, look on the Web:

[www.aphasia.org](http://www.aphasia.org)

[www.stroke.org](http://www.stroke.org)

[www.nationalstroke.org](http://www.nationalstroke.org)

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