



Our 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

Scottish Pride

-- By Robert James "Bob" Hay

I'm Scottish and proud of it!

I'm a member of the Hay clan and have been very involved in things



Scottish. I was vice-president of the national Clan Hay Society. I've regularly gone to the annual Northwest Region Highland Games, usually with some of my children. It was a major event for me to plan a trip, with all five of my children and a grandson. We were to go to Scotland for the

world-famous event - the Annual Gathering of the Clan. It had been a long time planning for the trip and I had already gotten all the reservations and tickets.

Then everything changed!

Just ten days before we were scheduled to leave, I had a stroke. I had to cancel and only one son and my grandson went on to Scotland; I went to the hospital.

Three years ago, on July 13, 2000, I was phoning Ruby, our church secretary, asking about my volunteer assignment. I did not know that I was then having a stroke. She told me my next day's assignment, repeated it, and then said, "I'm going to hang up." I didn't understand that, because I was sure that we were conversing perfectly. Later, she said, "I couldn't understand one thing you said. You were just garbling."

She called 911 and then my neighbor. By the time I walked upstairs from the basement, there was a pounding on my back door. When I answered the door, my neighbor asked "What's the trouble?" I answered, "I don't have the slightest idea what's going on." By that time, the fire engine was driving up, with paramedics right behind it, and Ruby was

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just behind them. The paramedics got me to Providence Hospital.

After the stroke, my vision and hearing were worse and I could not read, write, or speak clearly at all. I have completely lost the ten days that I spent in the hospital. My two older daughters then kept me in their homes for several weeks until I could handle being at home by myself. I think of them as opposites that make a whole – what one can't do, the other can. It was six months before I was able to really understand that something was wrong. My life changed, with disappointment and with challenges.

My eyes have macular degeneration now and I don't know if that's due to the stroke or not. My children got for me some new computer technology that magnifies the pages that I want to read. Now I can read magazines from the Clan, for the first time in three years. I wasn't reading at all until a year ago and I'm still slow, but I'm nearly back to normal.

My speech therapy started with two or three letters, words got longer, and then in about a year, I could speak with my kids using simple words. Composition is VERY hard. I'm slow and miss (many?) words in my vocabulary. I was Chairman of a committee to write a new, updated constitution for the Clan, which I had completed just months before the stroke. Just now, it took me three slow tries to get the word 'vocabulary' out.

I couldn't write checks then, and now I can. I can walk a short distance, but have to rest to walk

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My Life as Stroke and Women who Helped Me

— By Don Risan

All started with my stroke on March 29, 1994. I was going to 40-plus office but a stroke hit me in the restroom. After that, it's blurry. I think, a technician in emer_truck, but I was not able to respond.

The Technician was going over the Overlake Hospital and meeting with Linda Mgers; very close friend, for 6 years then. I was a basket case" and I was not to speak to her. I stayed for 9 days. but all a blur to me.

I realize now, Linda "stayed a course", for me.

We changed hospital to Northwest Rehab. Technician in emer. truck took me, Linda choice for hospital for me. The Hospital for new stroke recovery was great. I stayed for 3-month. I visited Joan Leager, (Speech and Language) for 3-4 times in a week. Joan is a pleasure for me. I worked really hard with her. I'm not able to speak; garble, it best. At the 3-month finish I can speak in three/four word or sentences.

I can say, "Very important to know Joan for everything."

I was home in Seattle for 1 1/2 years. Linda introduced Peggy Armiston at Kimberly Quality Care. I worked and enjoyed for 6 hour per day for one year. She worked 5 time per week. We worked for 3-hour and we enjoyed outside for the remainder of the day.

Linda and I says "God a send with Peggy for all those times!"

We changed address in Seattle. I sold the house because limited income each year. I would going for Peggy, until one month. Next, We celebrated because I was sad but Kimberly Quality Care finished for me.

We traveled to West Seattle for Mt. Vincent Day Program for 2-3 days. I stayed in the program for 4 hours for 9 month. Dennis Duva was here to, Later on, he wrote called "In Search of..." for the newsletter.

I changed at U of W Speech Hearing Science and Nancy Aharcon is the manager. Joan Jaeger recommend for her. and Linda says "excellent school" Nancy is excellent college teacher and good person too. Nancy and myself was in class or brunch outside for total 6 years. Now right in brunch at the restaurant, myself and two friend were one day per week for 3-years, Two friend are also stroke survivor.

Nancy encourage me to write the newsletter call "In Search of..." There it is.

Concurrently, I worked in Virginia Hospital in the Rehab Center for New Stroke patients. And American Heart Assoc. Outreach. I worked one day per week. The supervisor is Marcio Wollam and the Volucenter is Barbara Bend-Howard.

Marcio and Barb are very good people in work. I was sending the new pattern about pamphlets on American Stroke Assoc and I seem to like it. I talked to the patient and respond to me, but mild stroke more sp. Easily than modify patients.



Linda is supporting my projects all the way. In the other subject, Linda and I have the time for time-share for Lake Chelan Shore for 16 years. Also, we have in Phoenix for Sheraton Desert Oasis for 3-year today. I bought the "exchange" also for that. The "exchange" for RCI, we visited on kind of The country, for the example. We saw Napa Valley for the wine country; Florida and Bahama in the Fall; winter in Canada for skiing. New Orleans in the old District; Virginia, D.C. , and Boston in Harvard University and Cape Cod. For the Civil War we enjoyed in cities, towns and rural country for R.C.I. Exchange program.

I forgot to mention; but I play golf (one-hand), sailing and skiing with ski for All I'm the membership in Ski for All in 6 years

I really enjoyed working and helping me for the women and establish for Linda.

Editor's Note: *With his approval, Don's story is in his own words—unedited. We encouraged him to allow his words to be printed as is; hopefully inspiring others to tell their story in their own words.*

Don's Stroke

— By Linda Myers

On August 8th, Don and I became a couple 15 years ago.

During our first 6 years together, we bought a home in Ravenna and watched our three children from previous marriages graduate from high school and start college. Both Don and I were very involved in our careers, Don was a structural engineer who traveled all over the world and I was in health-care as an educator as well as an advocate for health-care issues. A very busy and fulfilled life for both of us and our families.

Two months before our wedding, our world changed...totally. I received an early morning call at my office from Medic 1. Don had a massive stroke and was on his way to Overlake. After 11 days at Overlake's Intensive Care Unit, Don was transferred to Northwest Hospital Stroke Unit. His diagnosis: severe CVA—left side no speech and very severe aphasia. After many months at Northwest, we brought Don home. Along came speech therapists, physical therapists and a full time care giver named Pam. Pam became a family member 5 days a week from seven to five. She is still a very dear friend and has since become a registered nurse.

The changes in all our lives have been too numerous to list. Moving from our house because of physical barriers, cancelled holiday plans, and vacations because of medical concerns like seizures, and of course financial issues. When Don had his stroke we had 3 kids in college – two out-of-state and one in-state.

Our lives are much more routine because of Don's condition. His speech has returned – very slowly and when he tires he becomes very frustrated and confused. We don't travel as frequently or as far. Our three children have all graduated from college – we did have to bring one home where she received her degree from the University of Washington.

The impact of Don's stroke continues to challenge us as a family. We have a grandson now but Don is unable to hold or pick him up.

I have chosen not to work at jobs that require lots of traveling. Daily phone calls and medic-alert systems make going to work easier for all of us.

Don continues to amaze all of us. He snow skis, volunteers at Virginia Mason and is working on his golf game – one-arm swinging. He also is "Mister Handyman" at our house – painting, working in the yard and minor repairs.

I continue to work full time in health care. Also my faith and occasional get-aways with my girlfriends help me maintain my sense of humor when things get tough at our house. I'm looking forward to our fifteen-year anniversary on August 8th.

Ed. Note: *We are grateful to Linda for allowing us our first look at the partner's perspective.*

Speaking Out

This summer, stroke survivors were invited to meet with U. W. Speech & Hearing undergraduate students. Survivors from one of the clinic stroke groups shared their personal stories about the impact of stroke. "It's a highlight of the summer class," according to Professor Bob Carpenter who teaches an introductory course in communication disorders. By joining in the class presentation, survivors build personal confidence and speak out for all survivors of stroke!



Bad Emotional Effects — from My Stroke?

-- By Bob Anderson

"There is nothing either good or bad, but thinking makes it so."

--Shakespeare, Hamlet

Can emotion get all involved with a stroke and become a major effect of it? It sure did with me. A stroke can get your emotions involved, can take control and let--or force--you to anger, depression, or frustration or to weep. I have certainly had emotional reactions differently than before my stroke.

I have been angry with myself for not doing what I used to be capable of. I've cried with frustration when I know what I want to say. I start saying the sentence that I picked —.but can't find the most important word that fits. Recovery of my brain isn't as fast as my recovery from sickness was before—it is slow and irregular.



I cannot remember much about how often I cried or got really angry as a kid, but it probably happened normally. I do remember, though, crying when a scrape or cut was treated with the IODINE. That hurt worse! When I got into science-fiction during high school, I thought it ideal to be like a Vulcan (do YOU remember 'Spock' in Star Trek?) and control my emotions.

Post-stroke now, I'm not a Vulcan. In a group or at a restaurant, my brain couldn't pick out one voice to follow that conversation. I would intend to start on a task, but my brain-blob usually independently came up with another idea or task. And the brain repressed the first task and worked, full-bore, on the other idea. The brain says: stay

with that task until it is tired or distracted by another idea—or until someone asks me why I'm doing THAT instead of what I said I would do.

The medical diagnosis I have heard was "Expect that there will be improvement for 3 to 6 months—and that will be it." The first time that I heard that, I told them that I refused to believe (and still do) that I had a limit to my recovery until they could prove scientifically that I could not improve further. I would then devote all my effort and power into other areas that would be more fun, challenging, and rewarding.

It would have been a kinder, and truthful, alternative for the medical people to say "Most of your progress will in the first days and months. You can still make recovery after that, but understand that it may be much more slowly." Did the doctors really say that alternative, but I just failed to hear and understand it? Perhaps.

After the stroke, only working on one thought made me concentrate on brain recovery actions and not on paying attention to my wife and family. This caused more problems and frustrations for me. My neurologist in testing and talking with me, said that I must relax, let go, not push so hard. Even so, that was very hard for me to accept that and to not devote all my time to the brain recovery.

Emotions can release stress and let people adjust to a problem as a survival mechanism. It is typical for males to apologize when they cry. It can be tougher for men to let emotions go, because of a cultural male standard called macho.

I think that I have dealt better with my brain problems and the emotions caused by that. I try to be more flexible, relaxed, and even-tempered. This encouraged more help and support and I believe my progress has come easier and faster. I can do more things and give help because I got help from my family, friends, and my Support Group

Have you gotten more emotional at times after your stroke?

— "We could never learn to be brave and patient, if there were only joy in the world."

-- Helen Keller

(SCOTTISH PRIDE

- Continued from page 1)

again. When I'm tired, my brain is, too, and it takes a rest.

Sometimes I cry with frustration. My doctor had told me "You're old, and you may have improvement for a few years, but that's it." I got upset and told him that my age isn't part of the problem, and if that's the best he can tell me, I'd better get somebody else.

On top of that, I still miss my wife deeply. She survived cancer for five years before she passed on in 1996. When we recognized the limit she was approaching, we were able to share each other's thoughts in a way that we hadn't. Of our 54 married years, those were the most wonderful five years we had.

I have wonderful children; their families are close and share many activities with me. They have given me great support and they mean very much to me. I need to tell my children often that I love them and I'm so proud of them.

It is hard for me to understand what happened and why. I have been angry and frustrated at

what I've lost and cannot do now. There are times when I lose control and cry in desperation, but "What else am I gonna do?" except keep going. I should not complain – I plan to recover.

- ◆ I intend to continue volunteer work for my church.
- ◆ I will do what I can do in my garden and home.
- ◆ I don't want to leave my house. I like where I am and I'll stay as long as possible. I like myself being with myself.
- ◆ I want to find out more about genealogy (I have identified 13 generations, including my grandson). Scottish history is really interesting to me. In 971 AD, The Danes invaded and were routing the Scottish army – but the Hays joined the battle and turned it into victory.
- ◆ I expect to go to the NW Region Highland Games next year – and want to plan again to go to Scotland for the Gathering of the Clan.

"I am 18 . . . No, **84** years young."

"Thanks, Lord, I made it one more day."

— *Bob Hay was interviewed by two other individuals with aphasia, Ted Paluchowski and Bob Anderson. BobA documented his story.*



Publisher's Note: "In Search of..." is edited and published through the Writer's Guild. The guild is now 1 year old—what an amazing journey since we took our first steps last summer. If we go back 2 years ago, the newsletter started under the direction of colleague, Cathy Off, who directed one of our stroke survivors in strengthening writing skills via a newsletter as part of a therapy program. As the newsletter took shape, the workload increased and thus the job needed to be shared. Graduate student, Leslie Parker, and I brainstormed a year ago and decided to move the newsletter into a small group treatment process. The presses have been "rolling" ever since. We never dreamed of the extent of the issue you have in your hands today!

The dedication, imagination, and motivation of Bob Anderson and Ted Paluchowski have shaped the newsletter that is before you. "In Search of..." has evolved into a dynamic voice for individuals with aphasia. We are building upon people's stories—their personal journeys as they wrestle and live with the impact of stroke and specifically, with aphasia. In this issue, we have the first opportunity to hear the telegraphic "nonfluent" words of Don, as he relates his account—unedited. Don revealed that it took him 2 hours/day for 4 days to compose his article; tough going, but strong evidence of his continuing improvements in written language 9 years after his stroke. He wanted to show his skills "as best as possible," but to make perfect would have taken more time—we encouraged him to permit the article to stand on its own. We hope you will consider submitting your story too—in your own words, or with guided support from others with aphasia. The partner's perspective in "Don's Stroke" is a bold step for us. Linda Myers opens the door to share experiences that are not as frequently heard of in the literature. Her account is a testament to the strength of love and commitment, and provides a wonderful compliment to Don's story. Lastly, Bob and Ted educate and inspire us with their excellent contributions in this issue.

It's been quite a journey and we hope you'll with us, and consider contributing. Nancy Alarcon

Summer Reading

— By Ted Paluchowski

Books by stroke survivors! These are several that I have reviewed. Why don't you suggest some books that you're aware of and I'll recommend some more in the future.



My Year Off, by Robert McCrum,
W.W. Norton, 1st American ed.,(1998)

The 42 year old British editor woke to find that his left side was paralyzed. This book tells about recuperating from the physical and emotional impacts of a stroke. Quite introspective. In the past he was defined by what he did. Now he has to redefine himself. Huge challenge.

Up From the Ashes (There is Life After a Stroke), by James A. Young, C.A.P., The Inner Path Publishing Corp., Sarasota, FL, (1995)

The author was an Addiction Counselor when he had a stroke at age 54. Girlfriend, family, friends and medical assistance were important. Very strong spiritual dimension and alternative medicine. Eventually, wrote the book. Now he lectures and leads groups for aphasia and stroke survivors.

The Diving Bell and the Butterfly, by Jean-Dominique Bauby, Knopf: Distributed by Random House, (1997)

Former 44 year old editor-in-chief of French Elle magazine. Seven strokes resulted in "locked-in-syndrome", body paralyzed but mind intact. Communicated by blinking left eyelid. Dictated the book about his experience as a "vegetable". A positive affirming life book.

My Stroke of Luck, by Kirk Douglas,
Perennial Press, (2003)

An accomplished movie star and author had a stroke when he was 80. Unable to talk, felt hopeless, confused and depressed. Strong support from wife, family, friends and therapists. Returned to a

movie role and wrote book. Positive attitude and sense of humor important. The desire to help other stroke survivors was part of his recovery.

Ed Note: *Let us know if you have inspiring and informative books related to stroke that you would like to recommend to family, friends and professionals. Email the Writer's Guild via nalarcon@u.washington.edu*



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