



**June**

is Awareness Month for

**Aphasia**

We have an Aphasia Quiz

There's an Aphasia Bill of Rights, now.

And parts of it is presented in this newsletter.

There are some things that make aphasia work better. And some make it worse. And there are MANY books and articles that tell us about Aphasia. What we should know; what we might suggest to others that would help both of us.

Inside this Issue:

Page

|  |                     |
|--|---------------------|
| <b>My Dad's Stroke</b> — by daughter Peggy                                 | <b>1</b>            |
| <b>My Dad's Stroke</b> — by daughter Robin                                 | <b>1</b>            |
| <b>Book Talk</b> - by Ted Paluchowski                                      | <b>4</b>            |
| <b>Can You Take a Trip?</b> - by Bob Hay                                   | <b>4</b>            |
| <b>Aphasia DOs and DON'Ts</b> here & there                                 |                     |
| <b>NAA Aphasia Quiz</b>  | <b>5</b>            |
| <b>Aphasia Bill of Rights</b>  | <b>6</b>            |
| <b>More news, hearing from survivors, things to do and try.—next time!</b> | <b>&lt;&lt;&lt;</b> |

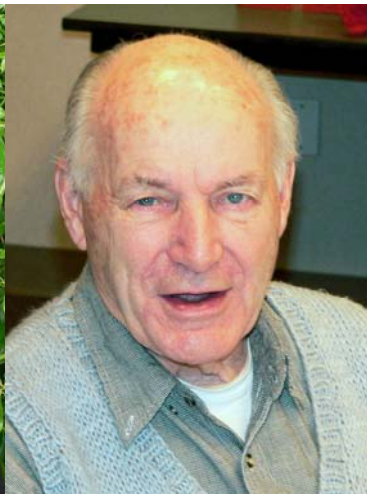
**My Dad's Stroke**  
- by Robin

**My Dad**

**My Dad's Stroke**  
- by Peggy



**Daughter Robin**



**Bob Hay**



**Daughter Peggy**

Peggy's story covers everything- she always has been the talker. What Dad went through was indeed a trial not only for him, but our entire family – children, spouses, and grandchildren. Dad has always been blessed not only with family, but with wonderful and caring friends. We believe that all have contributed to his recovery and will continue.

In the beginning Dad seemed to be uncomfortable attempting to converse with anyone. As his therapy and care progressed, his old fight came back – he wanted to be independent and he is now (maybe not 100%, but to a

*(Continued on page 3)*

It was such a gift—to take a trip to Scotland. To spend three weeks with my father and my siblings would be just as when we were children. As a family we all went places together, and now I'd see Scotland through **his** eyes! Then that terrible phone call told us that Dad was in the hospital and it brought my world to a standstill.

The doctors told us together that he had a brain attack (stroke) and would be at the hospital indefinitely, needing rehabilitation, and with a long road to recovery.

*(Continued on page 2)*



The children, spouses, and grandchildren visited the hospital, but Dad couldn't speak our names! It was a hard blow, and the Doctor said he could not travel to Scotland. He would need constant care and have to relearn his daily activities and chores.

Robin and I became his main caretakers. For weeks (and months) he stayed at our homes, and the brothers would spend time with him. The hospital started Dad on speech therapy with work assignments that we helped with. It was very difficult for him as he could not communicate. I personally got very frustrated trying to help him – sometimes we even got angry with each other. I was having to do his thinking for him and “boss” him around – he was the head of the family and that is not my nature!

He was really pushing himself to learn and it was exhausting him and his brain, but he was healing emotionally, physically, and spiritually and things came easier bit by bit.

He regained his interest in church, friends, Scottish events, and in speaking to everyone. His therapist Jan (one of his angels) pushed him to the UW Speech & Hearing Clinic to continue his therapy. He understands more, communicates more, and does public speaking more. He reads lessons out loud to the church congregation—maybe he stumbles and forgets his words sometimes, but he does it! His passion is to serve the Lord in whatever way he is capable of.

He wanted to become more independent, and he was delighted when he began driving again during the day.

All the family members rallied to help Dad. They took him to lunch, helped with projects, spent quality time with him—and listened. Listened to what he wanted to share. Now he goes to their homes, makes phone calls, and spends time with his grandchildren.

His vision got worse and changes in his glasses didn't help. The answer was: Video Eye—a machine to magnify any document

that can be placed in front of it. It is costly and is not covered by insurance, but what is your vision worth? His love has always been for reading, writing, and learning things. And he uses it for everything. Without his Video Eye, it would be devastating to him.

Dad still struggles with words and sentences, but can communicate quite clearly. The joy of living one day at a time shows in everything. He better understands what happened to his brain. He knows there are still many ‘roadblocks’, but as a ‘stubborn Scotsman’, he is up to the challenge. He is very social and comfortable in his community. He had lost part of that and many had missed that from him; now he has regained that and enjoys ‘talking to people’ again. He had a knack with writing and journalism and that is still a part that he hasn't regained completely.

The styles of care that Robin and I have contributed to his healing are different. Robin teaches him to be independent and makes him do everything himself. I want to do everything for him and try to mother him. It is very difficult for me to say “no” or deny him things!

He needs the care of both types of nurturing.

What happened to our father affected all of us. As a family we were all stunned by his stroke and some family members took much longer to accept the changes in him - and in our lives.

We have come to know our father in ways not possible before! He was always there for us throughout all our lives and now we are there for him. Giving our time and love and support to our father is healing for all the family.

He is the HEAD of the “HAY CLAN” and we love him unconditionally.

- Peggy ««

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### **Aphasia DOs:**

- Make sure that you have the person's attention before communicating.
- Minimize or eliminate background noise.
- Encourage and use other modes of communication in addition to speech



point where his self-esteem has returned). Dad still has the need for assistance in some areas of striving for independence and that is where our family will always be available for him. This is our wish for him as this is what makes him happy. Each one of us

are different in personalities and ways of doing things, but all love and respect him unconditionally.

My way of care for Dad has always been not to do for him but to make **him** do it—whether it was re-learning how to write checks, make coffee, open a can – or to get his own beer out of the refridge!

When he first was at therapy and had his home work lessons we all became frustrated – seeing your father struggle with writing his name (and sometimes forgetting parts or all of it, even in speaking or saying it) – saying or understanding even simple words. He so wanted to be back where he had been and sometimes didn't want to understand why/ what had happened. We did not change the way we treated him prior to the stroke – maybe a bit more protective and at first not leaving him alone. When he would get angry with me (and really not at me – I would just be the one in front of him at the time), I and the rest of us did not become upset – we understood his frustration as we in turn had it also. I believe his anger was a positive force in him as he began to fight to regain what he believed he no longer had. He began to push himself in his therapy, homework lessons, speaking with his friends and even with strangers at times (as all Scotsmen are a B.S'er). This area of healing was of great importance.

From day one in the hospital and through the next few months one of us were with him at all times, including children, spouses and his grandchildren. One of his good friends, Ruby, gave up time from her busy life and work time to be there for him. We are truly blessed to have her in Dad's life.

The time came to wean him from the constant togetherness and I had to be the strong one and make this decision. I felt that if he was to become independent again, then he had to start – a hard choice, but believe this was for the best. He didn't like this idea, but we stuck with the decision. Peggy and I live the nearest, Ruby lives close, and the other sister and brothers were only a phone call away – we tried a day at time leaving him at his home, checking in by phone and visits every other day or so. We would take him grocery shopping, bring him to our homes for dinner (but back home for the night) and Ruby would take him to church or lunch. After his doctor okayed him to start driving for short distances, Peggy took him on a test drive. He has been on the go ever since!

What happened to Dad, had an impact on all of us. We are recovering as well – our lives have changed along with his. As we said before, dad was always the rock and now we have to be strong for him and us. We are all so very thankful for how far he has come. Believe the stroke was much harder for our brothers to take or understand and as Dad recovers, they seem to realize the importance of sharing – they have always cared and loved but in a silent way. Something like their father!

My sisters and brothers and I are so very lucky to have spouses who are understanding and loving. If one of us are unable to do, each one is more than happy to jump in. Without them, we would all be stretched. Must have to do with our upbringing in a loving and caring home – all of us chose a spouse with these attributes and who truly love our father as we do.

- Robin ««

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### **Aphasia DOs:**

- Keep communication simple but adult. Simplify your own sentence structure and reduce your own rate of speech.
- Give them time to talk and a reasonable amount of time to respond.
- Repeat a statement when necessary.
- Encourage them to be as independent as possible.

««

## Book Talk

- by Ted Paluchowski



### Talking about Aphasia

by Susie Parr, et.al.

*(Open University Press (1997), available at Amazon.com and others.)*

Over the years this publication has sought to identify and review books dealing with stroke. The overwhelming bulk of these books contain a common theme. An individual suffered a stroke disrupting their life resulting in a long rehabilitation. Eventually, the author is able to tell his/her own story. The story is presented with a polished text.

The book currently being reviewed makes a number of significant departures from the norm. To begin, fifty (50) survivors were systematically interviewed to collect information about their experience. All of these survivors had a stroke and all of them suffer from aphasia. A broad range of degree of disability is included. With a large number of respondents the book can reinforce common themes, as well capturing the surrounding variations.

Another salient attribute of the book is its long term perspective. The book strives to include the entire spectrum of the experience. From the onset of the stroke, hospitalization, the realization that language is impaired, therapy sessions and dealing with disability. One prominent point emerges, survivors face an array of changing needs and support over time.

Finally, stories and experiences are told by survivors in their own words. There are numerous quotations to illustrate each topic. Some survivors struggle to find a single word while others are relatively articulate. The book shows the frustrations faced with aphasia in attempting to communicate.

As a concluding comment, this book contains a mountain of useful information. The inclusion of long term consequences of a stroke and a broad range of respondents fill a more complete picture of aphasia. ««

## Can you take a trip?

- by Bob Hay

"No, I can't!", I told Nancy.



"Yes, you can!", said Nancy. "You should be able to do it and you should take the trip."

So I took a trip to Scotland with my son and grandson—a dream fulfilled last August

It was a terribly long flight. From Seattle to Amster-

dam, then to Glasgow to start a tour of famous spots in Scotland and proud Hay Clan locations

It had been 20 years since I had been to see beautiful Edinboro—the castle high above on the peak, the stirring military tattoo. The Highland Games. Scottish tartans. Aberdeen—all the fishing boats relocated elsewhere to make space for oil rigs. Castles and banquets for the Hay Clan. My family all helped to get me to Scotland—son Rick pushed me in a wheelchair when needed.

I've gotten much farther than I expected since I have learned more about what had happened to me. But I've gotten less that I want.

I have regrets about my stroke—the **happening**. All of us with a stroke feel it. But we can get out of the funk we occasionally land in. By letting ourselves see others with a laugh and a positive attitude toward their tragedy (Dennis is a terrific example.)

Part of the Scottish ME always tries to test my own limits. Sometimes, while in Clinic remedial therapy, I would thoughtlessly, try other's limits as well., and try to get the clinician mad. But I never could and asked one: "Why can't I get you mad?"

Dr Miller of the Clinic clearly had been observing the session and broke into the room and told me: "You never will—we raise them



## National Aphasia Association (NAA) Aphasia Bill of Rights

On September 26, 2005, the NAA Executive Board voted unanimously to approve a Bill of Rights.

*This article lists **some** of the observations and rights found in the Bill.*

(For a complete and correct copy of the Bill, see NAA at:

**www.aphasia.org**  
7 Dey Street, Suite 600  
New York, NY 10007  
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Aphasia is a condition, usually acquired as a result of stroke or other brain injury, which **impairs the ability** to use or comprehend words, but **does not affect intelligence**.

As a result of their difficulty communicating, people with aphasia may **experience great isolation and frustration** in their daily lives, which is often **made worse by the lack of information** that they receive about their condition.

The **majority leave** the health care system **without referrals** to resources in their own communities

*The Bill specifically notes that people with aphasia have more than the rights noted below:*

**Be told**, as soon as it is determined, preferably by a qualified speech-language pathologist (SLP), both **orally and in writing**, that they have "aphasia" and given **an explanation** of the meaning of aphasia.

**Be told**, both **orally and in writing**, that there are **local resources available to them**, including Aphasia Community Groups in their areas, as well as **national organizations** such as the National Aphasia Association (NAA).

**Give their informed consent** in any research project in which they are participating.

Demand that accrediting health care agencies and health care facilities **establish requirements for and competency in caring for** people with aphasia.      ««

**Publisher's Note:** The impact of a stroke touches so many lives. Bob Hay's family gives us a glimpse into how they have coped with the changes, and loved and supported their Dad through his stroke recovery. How blessed he is to have their constant love and support. This awakens me to the point of how important it is for each of us to have family and friends around us to shore us up in challenging times—to be there in the good times and the tough times. I need to let folks around me know how much I appreciate them being there for me all the time!

Our community is so fortunate to have a number of great supports in place for those living with stroke; the various community stroke groups that meet in hospitals, community centers and homes. However, we need to continue to grow! As a stroke survivor, family or professional—let your ideas for improving stroke care be heard. Share with us your ideas and your stories. Let your voice be heard, so that others can benefit from your life experiences. Advocating for individuals living with aphasia,  
Nancy Alarcon

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- learn more about our services; and,  
- to access past issues of the Writer's Guild quarterly newsletter:

"In Search Of. . ."

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