



Patience



by Penny

Gerry, my husband of 44 years, had taken me to work at 9:00am on September 17, 2002. I rarely called him from work, but had a question for him.

It was 10:15 am when he answered the phone – confused and slurring his words. I arranged for a ride home and immediately took him the 2½ miles to Northwest Hospital ER.

I told the staff that I thought he was having a stroke. After interviews, scans, and more tests, it was confirmed – Gerry had a blood clot in his brain, causing a stroke.

Thirty days later that, Gerry came home. He had aphasia, apraxia and the right side of his body didn't function normally. Now he would learn to eat, write and dress himself with his left hand.

I had learned what I could do to care for him from the nursing staff and all the therapists at NWH Rehab. There is a delicate line between **helping and smothering** the stroke survivor, and I was walking that line.

Gerry was an attorney for 43 years – and talking with people was what he did. Needless to say, it was extremely frustrating not being able to say the words he was thinking.

Patience is the key to the survivor of the stroke and to the caregiver. We had to slow down and look each other in the eye while we communicated. Most of his speech needed to be re-learned and gestures became very important.

Speech therapy at the UW Clinic has been a tremendous help to both of us.

When Gerry first came home from Rehab I was afraid to leave him alone; afraid he would fall if he tried to get up from his chair, afraid he would panic if the phone rang or the doorbell rang and he could not respond.

Now I am able to leave him home alone for a few hours while I do errands or attend meetings.

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More CAREGIVING as a theme in future issues

He cheerfully says "goodbye" and "good luck" when I leave the house.

It is a blessing that he is comfortable being alone. He loves to play music on his CD player, work on assignments from speech therapy, play with our dogs, Pepper and Star, feed the wild birds and take photographs.

Our family is close and we see them often. They are a great support to both of us. Our son, Jason, now lives with us. Now, we know that we are not always alone in our home.

Our son, Damon, and his family came over at least once each week for over two months when Gerry first came home after his stroke. They would come over with a complete meal, which we shared. It was a great start toward getting Gerry back to a normal routine, and having lots of laughs. The grandchildren were and are wonderful.

We have had to make many changes in our daily lives, but keep remembering how lucky we are to have each other, to have wonderful memories of our children growing up and our many travels. <<

One Caregiver's Story

by Jerry Boen



(Jerry's wife, Valerie, has fought the effects of a surgery for over three years. Jerry's story started in the Winter issue (#21). This is the rest of his story. ed.)

Our lives changed in March 2004. Valerie was preparing for a simple surgery to repair her knee, when a doctor

heard a sound in her heart he did not like. She went for tests and within a few hours received an urgent call from the heart doctor who told us she needed immediate open heart surgery or she would soon die. We were assured that it was dangerous but routine enough that she would be sitting up on the edge of her hospital bed that night. Our family had no idea how much this event would reach into every corner of our lives.

The evening of the surgery is still a bit of a blur. I do recall the surgeon telling me, our family and friends that, "all went well and she should wake up just fine". I assumed things would quickly get back to normal. We took a deep breath, smiled and waited for Valerie to awaken. Several hours later, Valerie started to wake up. We realized something was seriously wrong.

For awhile, I fooled myself that it was the lasting effects of the anesthesia. Then, an attending doctor told us she had a stroke at the end of her surgery and that we would have to wait to see how bad it was. In the waiting room, our children and family must have read my face. The bad news smashed down like a hammer on our elation at the heart surgery's success. Within a blink of an eye, our lives were changed forever.

That night, when Valerie was fully awake from her surgery, we realized that she was paralyzed on her right side and could only speak two words, "treatment" and "Picasso". I think her mind picked Picasso to tell us what was going on inside. Like a Picasso painting, her thoughts were now shattered and disjointed. Now, nothing was normal and everything she saw or felt was a puzzle. For the first time in her life, I could see in her eyes that

she wanted to give up. Over the next few days she gained a few more words and asked me to help her end it all. She said she did not want to live if this is what life would be like.

After a few days in intensive care, she was moved into a heart recovery area and we were allowed to stay in her room. As a family, we took shifts staying with her and sleeping on a cot in her room. You never know how good a job you did raising your kids until they are put under this kind of pressure. Our children were wonderful.

As Valerie gained a few more words each day, we assured her that things would get better. Her attitude slowly changed and I could see the life return to her eyes. I think it was about this time when I determined that with enough time and hard work we could get back much of our former lives. I already knew Valerie was the kind of person who would do whatever it took to get the job done. My job was to help her find ways and encourage her as best I could.

After a week, Valerie was moved to the rehabilitation section at Northwest Hospital. She was dealing with two major battles, recovering from the open heart surgery and a stroke. We were no longer allowed to stay in her room. So, I brought dozens of 8x10 pictures of things she liked and made a solid wall of pictures in her room - pictures of her family, garden, dog and cats, her house, projects she had done, vacations, etc. During her stay I brought more every day.

When she left the rehab, the entire wall was covered. It seemed to encourage her and she started working hard to get back her life. At first, she needed help dressing, eating and doing simple chores. Also, she could do nothing but scribble. Her speech returned very slowly. But, she was willing to work hard. So we began the tough road back to recovery.

At Northwest Hospital, they started teaching her to walk, speak, write and interact. I know it was emotional and very difficult for someone as independent as Valerie, but she accepted the help and endured it with grace.

After 13 days she was happily allowed to go home. We started outpatient and home therapy. For several months, we had visiting nurses, occupational therapists, physical therapist and speech therapist visiting several times a week. Valerie

learned to walk again. The exercising restored some of the feeling to her right side and right hand. She got a huge benefit from all her providers but her speech therapist was exceptional. They spent many hours working on sentence structure, spelling, word finding along with math skills. Everything you might teach a child at school they reviewed and practiced over several months, several times a week, including just learning to interact respectfully with others. The goal was to get Valerie competent enough to move along to the next phase of her recovery.

My job was encouragement and grading homework.

Moving from in home therapy to outpatient therapy was happy and scary at the same time. We had grown used to our comfort zone at home.

With help from NW Hospital rehab outpatient clinic, we were referred to the Speech Clinic at the University of Washington. At the University Valerie was tested by Nancy Alarcon and her staff to determine the best way to help her with recovery. The testing was extensive and helped point to specific areas where Valerie struggled. Together Nancy, her staff, Valerie and I developed a plan of action to move Valerie's recovery along.

We also started attending a monthly adult stroke support group with people from all over the Puget Sound. I am amazed at how little people know or understand the conditions associated with strokes and brain injuries and the many different approaches to the problem.

I started the caregiver group intended to give the caregivers a chance to privately express their concerns and feelings. Caregivers have had varied experiences. We were put in a situation that we were not ready for or trained to do. So, we are learning together. Some of our partners who had strong (Type A) personalities before, now struggle to get going everyday. The run away emotions of a loved one who used to be the steady rock in our life reversed our roles so quickly. But **our** partners are the lucky ones.

Too many stroke and brain injury survivors have no one to help full time. Those who progress without a partner or family to help, are the strongest of all. But I worry about the shut-in's and isolated people who may have given up.

Valerie and I have been so fortunate in receiving help from students and professionals and our support group. I wish everyone could be treated as well as we have been.

Valerie started treatment at the University of Washington speech and hearing center three days a week to help her rebuild her ability to communicate effectively. Over the months, she has worked with many graduate student therapists in one on one and group sessions. The list is endless on the subjects that they have worked on.

The goal has always been the target based on our original plan of action. All of our interaction with the clinic has been very positive. The students are so willing and eager to help. And, the other survivors have become our mentors. It gives us real faith that we are on the right track.

Valerie's skills have improved so much that she is trying group therapy sessions only, to see if that works for her. She will still be working on her own but it's another positive transition.

Looking back to the day of the stroke, I could never have dreamed we could have come this far with such good results. Without the help of caring support groups, graduate students and professionals none of it would have been possible. <<

10 Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. **Reward yourself** with respite breaks often.
2. **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
3. When people offer to help, **accept the offer** and suggest specific things that they can do.
4. **Educate yourself** about your loved one's condition and how to communicate effectively with doctors.
5. There's a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence.
- 6 **Trust your instincts.** Most of the time they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing, and pulling. **Be good to your back.**
8. Grieve for your losses, and then allow yourself to **dream new dreams.**
9. **Seek support** from other caregivers. There is great strength in knowing you are not alone.
10. **Stand up for your rights** as a caregiver and a citizen. *From the National Family Caregivers Association*

On the Importance of Family Caregivers

by Skye Hudson



What does it mean to be a caregiver? Most of us have given or received care as either parents or children at some point in our lives, but this is expected, and follows a natural course. What happens when the cycle is interrupted, when a previously self-sufficient, fully capable teenager or adult of any age needs the kind of care normally given to an infant?

When I was seventeen, I found out I needed back surgery for scoliosis, an abnormal curvature of the spine. The surgery was extensive, and left me quite helpless and in a considerable amount of pain in the days immediately afterwards.

Though the professional care I received while in the hospital was excellent, I don't know what I would have done without my mom. She took time off work to care for me, sleeping in the hospital room on a cot that the staff had provided. Most importantly, she stood up for me when my needs were overlooked or misinterpreted by the staff.

I had been on intravenous morphine for pain after surgery, but they decided at some point that they couldn't keep the IV in, and gave me a larger dose by injection instead.

I found out then that I have an unusual reaction to large doses of morphine—my body becomes progressively paralyzed. I didn't care so much that I couldn't wiggle my fingers or toes, but it was becoming harder and harder to breathe.

I was worried that if I stopped making an effort, I might just stop, permanently... and it was late at night, and I desperately wanted to relax and go to sleep.

"Mom," I croaked, saving my breath for the important words, "can't breathe. Need oxygen. Need sleep." Laboriously, I explained what was going on. She flagged down a nurse, who checked my oxygen levels as I relaxed. Mom watched with increasing alarm as the numbers plummeted.

"Okay, Skye, you need to breathe now," she

said, as they dropped dangerously low.

Effortfully, I obeyed, but to the nurse, this meant I was fine. The levels had only dropped momentarily, then gone back up again, and she wasn't about to waste any oxygen on me if I didn't need it.

After a lengthy discussion that I would never have had the stamina for, the nurse was finally convinced. I got my oxygen, and went to sleep, but it would have been a rough night without my mother's determined advocacy.

That experience has taught me lessons about the importance of family caregivers that I will never forget.

Here are some things I learned:

1. If your loved one is in the hospital for *any* reason, whether it's minor surgery or a massive stroke, stay there with them, the whole time. No matter how good the hospital is, something unusual or unexpected could come up, with potentially devastating results.

2. Be an advocate. Your family member may be in pain, or woozy from drugs, or may have developed aphasia secondary to stroke. You know that person better than the nursing staff; you will know better than anyone if your loved one is hallucinating. The nurse may not take her "delirious" patient's statements seriously, but you know better, and you can communicate what your family member may be unable to express.

3. Just because the hospital staff are professionals doesn't mean they're always right.

The impacts of sudden helplessness can be far-reaching, both for the patient and their family. Though it's a big adjustment for all involved, family caregivers can help create a positive outcome, right from the very beginning.

Thanks, Mom.

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National Aphasia Awareness Month

June

Theme:

***"Let's Communicate . . .
About Aphasia!"***

Book Review:

by Ted Paluchowski

[Into the Blue: A Father's Flight and a Daughter's Return](#) by Susan Edsall

This book is a testament of all of the effort and dedication provided by caretakers. Most stroke related stories focus on the survivor as they cope and overcome assorted challenges.

Usually, trained medical personnel direct rehabilitation. Caretakers are normally relegated to an important but subordinate role.

After their father suffered a stroke the author and her sister flew to join their mother at their parents' home. Fearing the worst they sought information concerning their father's condition. At the same time the author had been alerted of the importance of rehabilitation.

Once "dad's" status stabilized the sisters turned their attention to rehabilitation. They eagerly anticipated rehabilitation to help dad and offer any assistance in the process. With what may be described as an understatement, the sisters found that they were disenchanted with the pace and nature of rehabilitation. Therefore, they decided to develop and implement their own program. Apparently, they succeeded. At the end of their efforts, "dad" was able to recertify his pilot's license and literally flew into the blue.

To frame the setting basic information is provided. Mr. Edsall was a very active 71-year old man. He lives with his wife in Montana. His three grown children live in remote areas of the country far from his home. He had just undergone a successful bypass surgery and was scheduled to go home.

While he was still in the hospital he had a stroke. Apparently during surgery a piece of tissue entered the bloodstream where it lodged in his brain causing a stroke. As a result, he complained of a weakness on his right side and an acutely aware awareness of the difficulties encountered with aphasia.

Critical to the story, Mr. Edsall was a pilot.

Early in this life he wanted to fly. As soon as he could earn the money he took lessons. Over the decades he owned and flown a variety of airplanes, owns his own airstrip and hangar complete with repair facilities, was well known member of the airplane community.

Foremore, his business depended on airplane access to scattered sites. Social activities centered with other pilots such as on fly-ins. For recreation he rebuilt old airplanes. It was common for him to fly another town for breakfast before continuing the day. In short, all aspects of Mr. Edsall's life involved his status as being a pilot.

His children, including the author, immediately realized how important it was to be a pilot and how devastating it would be to lose that status. Without the ability to fly, they were concerned that dad would wither and give up all hope of recovery. Therefore, the sisters decided to use every and any resource to restore dad's status.

After learning about dad's stroke the author initiated a search for information, first about the nature of stroke then concerning rehabilitation. In looking for information the sisters seemed to be well equipped for the job. They were college educated, have had professional jobs, and were familiar with the internet to find and retrieve data. In addition, the author's husband works in a hospital as a medical librarian. The sisters approached their task with dedication and skill. Nevertheless, they quickly ran into a stone wall in the form of the medical establishment.

Before leaving this review there are two enduring themes that be reinforced. First and foremost, don't wait for professional rehabilitation. If you're not satisfied, develop your own program. A bad plan is better than none. Adjust as events occur. Everyone involved will benefit.

Second, the author described her own experiences. During that period, the sisters accumulated a formidable amount of insight concerning rehabilitation. The details might help other survivors and caretakers. Hopefully the author will publish a workbook based on a successful approach.

As noted, when the sisters decided to rehabilitate dad, they made a total commitment of time and energy. Their efforts proved to be successful. At the same time there were impacts on their extended family and friends. Their barefooted assault on aphasia was inspiring, but they neglected

the impacts of their enthusiasm. Their presence soiled long-term relationships.

They began to learn and adapt to their new role as caretakers. Obviously, neither sister had significant experience with long-term disability. Moreover, they had to adjust their role while inventing a rehabilitation program. Obviously, they had a strong relation with dad and with each other. They reinforced and supported their efforts. Even when they disagreed they joined in a common goal. They remain as friends.

Helping dad sparked some unanticipated consequences. Almost from the start, the sisters were energized by the prospect of helping dad. The venture gave them a new direction and new purpose in life. The sisters benefitted, perhaps more so than dad.

Not all the consequences were positive. Mom could be classified as a casualty. Her well-ordered life suddenly underwent a series of gyrations. The household, particularly the kitchen, was mom's domain. Two adult women were scouring about, upsetting old routines, introducing new food. To an extent her role in the family was being displaced. There was a reversal in the relation between parent and children. Mom was collateral damage in the rehabilitation process. She appreciated the effort for dad, but quietly resented the intrusion.

After the sisters were well underway their brother came to visit. He is a veterinarian whose practice is in Alaska. He was appalled by dad's condition. Apparently, he saw only the negative aspects of the consequences of the stroke and aphasia. No doubt he could remember dad as a vigorous man. By comparison, dad suffered from diminished abilities. When the sisters looked at the same situation they saw real progress. The situation was relative to the observer. Their brother remained skeptical of the sisters' progress, while they remained optimistic to the end. <<

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Publisher's Note

To give care, from the perspective of family and friends, helps us recognize the impact of stroke and resulting challenges in communication on family and friends who encircle the stroke survivor with love and care.

JUNE is "Aphasia awareness month."

Thank you, Bob and Ted, for this great Issue on caregiving, for encouraging these writers to share their personal stories surrounding their own giving of care; as well as, increasing our awareness of the critical, yet challenging role each caregiver plays in the support and recovery of each stroke survivor. <<

Some Common Signs of Caregiver Stress:

- Feeling sad or moody
- Crying more often than you used to
- Having low energy level
- Feeling like you don't have any time to yourself
- Having trouble sleeping, or not wanting to get out of bed in the morning
- Having trouble eating, or eating too much
- Seeing friends or relatives less often than you used to
- Losing interest in your hobbies or the things you used to do with friends or family
- Feeling angry at the person you are caring for

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"In Search Of. . ."