

## SUMMARY OF JUDITH PARSON'S STROKE

By John Clemmer, May, 1990

Judith lay immobile, looking up at the white ceiling without the benefit of [indistinct 00:00:06] a local anesthetic. Judith could feel the vibration of Doctor [indistinct 00:00:12] Steiner, Professor of Neuro-Surgery and director of the largest Leksell Center for Gamma Knife Surgery at the University of Virginia Health Sciences Center. Drilling four shallow-bore holes into the bone of her skull. "You must not move a millimeter Mrs. Parsons, you must not move a millimeter." Into those four holes would be screwed four long carbon fiber pins, attached to a Leksell stereotactic frame, a stainless steel box framework, designed to hold the head absolutely still. Gamma knife surgery is an exacting business.

For Judith Parsons, 45, the ordeal would soon be over, but now through the pain she repeated over and over, like a mantra; "this too will pass oh God." The drilling complete, Dr Steiner put aside the surgical drill and whispered quietly; "you are very brave Mrs. Parsons, you are very brave." The road that lead Judith to Virginia and gamma ray treatment in 1989, had been a four-year walk through hell. A road to survival that was a series of fundamental choices for Judith, to go on living or not. The odds for her survival to that point, had been impossible to calculate. According to Dr James Sharp, her Toronto neuro-surgeon, it wasn't a matter of if the hemorrhage would happen again, it was a matter of when.

On April 24th 1985 Judith had suffered an inoperable subarachnoid brain hemorrhage, a bleed in the jargon of medicine. She recalls; "we were in conference, I had felt ill and excused myself from the meeting with our director, Mike Singleton, and the ministry people we were with. I fled to the washroom. I sat down and felt an incredibly hot flush creep over my body. I went to the sink and splashed water over my burning face, and felt myself going unconscious. Mike had come in to see if I was okay, I asked him to make sure that my six year old son,

was picked up from daycare. I thought I might be out of commission a day, or two. My knees were buckling. The last thing I saw was my face reflected in the mirror, slowly disappearing below the level of the basin."

Judith quickly adds, "I remember vividly, it wasn't like a dream, you know what remembrances of a dream are like? This was a memory of real experience. I felt something pressing against my shoulder, I looked. I realized I was looking down from the ceiling, it was the ceiling pressing against my shoulder. I was looking down at Mike, and other people I knew, huddled around someone lying on the floor." It would be over a year before Judith returned home to her son. Later that evening Judith's sister, Chris, wrote a note from Toronto Woman's College Hospital outlining Judith's condition. "Judith is on total life support, in a deep Judith quickly adds, "I remember vividly, it wasn't like a dream, you know what remembrances of a dream are like? This was a memory of real experience. I felt something pressing against my shoulder, I looked. I realized I was looking down from the ceiling, it was the ceiling pressing against my shoulder. I was looking down at Mike, and other people I knew, huddled around someone lying on the floor." It would be over a year before Judith returned home to her son.

Later that evening Judith's sister, Chris, wrote a note from Toronto Woman's College Hospital outlining Judith's condition. "Judith is on total life support, in a deep coma, with no primitive response of any sort. Her body is shaken with tremors, a sign of the body shutting down. The doctor prognosis is; little chance for survival."

Judith remained on life support until May 15th, at that time a difficult decision had to be made. A hole had been drilled in Judith's skull, to accept a catheter, that injected antibiotics directly into the brain fluid. Critical, because it reduced pressure on the brain. The first hole became infected, as did the second. A third hole was ruled impossible. Judith's mother, Peg, describes

that very difficult day; "we had a day to make the decision, it was not easy. The choice was to risk either an extremely dangerous operation, which would at best leave Judith institutionalized for the rest of her life. Or, to simply take her off life support, and let nature take its course. We felt that we knew what Judith would've wanted. Later that day, all the vestiges of life support were removed. Judith started breathing on her own."

The hemorrhage has left Judith clinically blind. She had severe double vision, with one eye rotated downward in the socket. But she did have full body mobility. Judith's short term memory was badly impaired; standing in her hospital room, she could not remember where the bed was. Her long term memory was partially impaired, this providentially returned and saved Judith from a life in an institution. There was a retention of visual memory, which has allowed her to fight her disability and become operationally functional. Short term memory as best described by Judith; "you turn from the sink and take a step, partway through that step you don't know why you took it. Everyone I talk to says they have done that, but it isn't the same. Forgetting what you were about to do a moment ago, within the frame of reference of having a memory is one thing. But living constantly from moment, to moment, to moment, with no recall of what you did three seconds ago, is hell."

Long term memory is the storage area of the brain where items are entered from short term memory, for example dialing a telephone number often enough to eventually remember it, are filed away for future use. All the fundamental lessons learned from cradle are stored here, how to brush your teeth, wash your face and clean up after bowel movements. If Judith had lost her long term memory she would've been in care for the rest of her life. The lifetime to rehabilitation for Judith has been her visual memory, the strongest part of the brain memory system. Without which she could not have supplemented her short term memory,

with the elaborate method of diary-keeping, note taking, and filing system that allows her to function on a day to day basis. This paper memory was devised as reconstructive therapy by Dean Dickerson, Judith's occupational therapist, at Toronto's Queen Elizabeth Hospital.

The road back; Judith thinks back with irony, to attitudes and values she held before the bleed. "I recall thinking to myself; if I could only get sick, I wouldn't have to work anymore." She laughed; "you have to watch what you ask for in life, you might get it. I was certainly fed up with the pressure of the rat race. I had been running a magazine for 15 years. 20 more years of this before retirement. And all the time this congenital malformation was ticking inside my head like a time bomb. I had always had headaches, but they were getting worse. I made an appointment with a doctor who told me; the only way to be sure about the cause of headaches, was to have a brain scan. We were in the middle of a special issue at the time, so I told her I don't have time for a brain scan right now, I'll have one after the issue is finished. That was so typical, I was always so rushed. I lived from mountaintop to mountaintop, either high or depressed."

"I flirted with suicide all my life, look at my wrists. And yet, when the chips were down and I had to make the choice, I chose to fight and live. I probably made that choice while I was in the coma, and I certainly had to make it many times since. But looking back at what I remember about my early days at Queen Elizabeth Hospital, and the fear of facing the gray amorphous mass that was the world outside my hospital room, what I had once wished upon myself was humor of the blackest kind." To Judith Dean Dickerson, her first occupational therapist at the Queen Elizabeth Hospital, was God incarnate. Slender and soft-spoken, Dean is one of those people who are not only extremely patient, a prerequisite in his business, but a good listener. With Dean, patient

progress and personal satisfaction is usually measured in the small gains.

With Judith was starting from the beginning. *"With Long-Term Memory impairment, I was 43 old baby. They had to teach me how to wash my face, I didn't know I'll have to close my eyes. They say the things you learn in hospital, after my kind of injury, are the things that stay with you for the rest of your life. That's true, with no Short-Term Memory I had to count as I rinsed the soap off my face, or I would've done it all day. Dean taught me to rinse 20 times, and I still do automatically. Not 19, not 21. I used to add it in my memory book, but now it's found its way into Long Term Memory."*

It was Dean who got Judith started on her first memory book. Dean remembers their first meeting, in the halls, at Queen Elizabeth; *"Judith could not remember from moment to moment. She would start saying something coherent, and it would drift off topic, and would wind up as a word salad, as she calls it."*

After the life support surgery her hair was short and extremely patchy. Judith thought somebody had given her a lousy haircut. She didn't know she was sick. Judith was encouraged to enter the happenings of her day in her memory book. At first it was just jotted with a lot of irrelevancy, four or five scribbles on the page. Gradually small glimmerings, as Dean called them, began to form, to outline Judith's paper memory. Where's my yellow phone, was one of the early entries; recalling a phone she had at her house. The diary entries gradually grew in length, the writing smaller and more legible, and the recording more structured. She was starting to rely on her diary. It was time for Judith to transfer the confidence she was putting into her diary, to something more functional. We sent her out into the immediate neighborhood to buy a pound of butter. It was like sending a normal person out into the world, to perform a job competently with no prior knowledge of what the job was about.

Life is a step by step process, the sum of which makes us functional. With Judith, a lifetime of steps had been erased. Her book records the breakthrough; *"I went to a local shopping district by myself, and had a cup of coffee at the new Brass Kettle."* Judith recalls Dean's formula for memory improvement; *"Firstly, remember to remember. Practice, practice recall. Focus on the moment. Concentrate. And finally, tune your observational skills. These four points have become my guidepost for day to day living."* Outgrowing the memory book she'd been using, a shopping trip had been planned to the Eaton Center, to look for a large day-timer suitable for detailed entries. A Quo Vadis was selected, and has been the basis for an elaborate system of listing that has to be done from day to day and from hour to hour. Who called, who needs to be called, and what needs to be done during the day.

Judith operates with a small subsidiary notepad for making up a working list, which she posts to the day-timer periodically. All this is backed up by a filing system built into the cupboards in the kitchen, near the phone. There are files for every aspect of her life; friends, family, personal health, the house and other matters of business. The most important file of all, and one which Judith is most protective of, is labeled past life, and is a collection of letters, personal memorabilia, and snippets of a forgotten past that friends have helped her piece together. After six months in the hospital Judith was ready to return home, and continue her hospital therapy as a day patient. Returning home in the evenings, having Fridays off for errands, and the weekends with her son who is living in Toronto with his father. At 11 years old when this was written, he believed that being a two-household child was a big benefit in this situation.

Judith remembers this time being the most difficult to cope with. To her, life was joyless and bleak. Toronto, which has a quickly changing face for anyone who lives there, was an alien space for

Judith. "So many landmarks were no longer recognizable, and I felt I had no friends. In fact, all my friends had been asked to stay away for a while, and were keeping in touch through mother, and Elaine Jacques, an old friend. All I had to look forward to was work, work, work from second to second. The smallest function required extreme concentration and effort. It was exhausting." One of the glimmerings that returned to Judith at that time was Shakespeare's "in that sleep of death, what dreams may lie when we have shuffled off this mortal coil." Out of the blackness of life with a past, and a future were being reconstructed. But, with the gradual return of the past arose the horror of her medical prognosis. "I would wake up feeling fine, and suddenly I would have this knot in the pit of my stomach, and I wouldn't know why."

*"The ceiling of ill-boding would sweep over me and I would remember afresh that I was going to die. Every single time it was like being told for the first time, that subarachnoid hemorrhages never happen once, they always return. It was cruel."* A high percentage of the people who are inflicted with memory impairment, and consider suicide, usually do it later in the reconstructive process, when they realize what they are up against. Judith, who had suicidal tendency all her life, now fought through it with more personal clarity than she had ever known. "Kent and my friends were my lifeline. I knew it was either this, living with a disability, or death. Dean says that acceptance is the key to living with a disability."

Judith experienced a second out of body experience; "I was floating in space, virtually naked except for a loose piece of cloth or cloak wrapped around my body. The earth was down to the left of center, appearing about the size of a basketball. In the blackness of space, punctuated with stars,

*I looked down at my belly which was big and light. I could see the pores in my skin. Coming out of my belly button were two thin, glowing, silver lines. One stretched off to the right, where I saw a*

*small image of my son attached to the end. To the left was a line flowing down to an image of my mother. "I don't know when that happened, but it's so vivid, it's as though it happened this morning."*

It had been planned that Judith would complete day hospital in June 1986, with her son coming home full time. The assessment of Judith's situation, by Dean Dickerson, was that with no Short-Term memory she would never operate on the same plane as a normal person, and could never return to the workforce. She would however continue to improve functionally for the rest of her life. During her time here at hospital friends had visited and Judith had begun to see glaring of sunlight, figuratively and literally. Judith described sitting in her kitchen, looking out the window on a drab overcast day, and suddenly seeing the sun burst on a roof down the street. She remembered Deans' urgings to be positive and count your blessings. This and an acceptance of the way things were for her, had finally found their way into her Long-Term memory.

Jocelyne Brault, Judith's new at-home occupational therapist, visited twice a week for the next 16 months. It was Jocelyne, who in her soft French accent, that graphically outlined to Judith what her choices in life were.

*"For you the middle road is gone. See my arms?"* Jocelyne had put her elbows together, with one forearm down, the other up. *"There is no middle road for you Judith, it's either up to life, or down. You have a choice on how you view things."* At that time Judith was still determined to return to normalcy, to have things the way they were. She recalls sitting with Jocelyne during one of her early visits, determined to remember, her fingernails dug into the palms of her hands; *"I'm going to get that job back if it kills me."*

It has now been 30 years since Judith suffered her stroke. She did not get her job back. What she did get back was a result of not



quitting. Judith's made the decision to take the up road that Jocelyne Brault had described. Judith has etched out a highly functional life for herself. With a sunny disposition that has amazed and delighted her friends. Gone is the edgy no-nonsense professional editor, but what she happily retained were her organizational instincts, and this is what has enabled Judith. The essence of the tough Judith remains, to navigate through her rehabilitation and create a new life. A functional lifestyle that included seeing her son become an environmental lawyer, and entering a new supportive relationship with her friend Don in a welcoming and loving home.

Now in her 70's Judith says true, she's not a quitter. Best told by her friends in this documentary film. The hemorrhage has not returned.