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Changes In The Sense And Perception Of Self In Individuals With Aphasia: An ethnographic study

Erline Vieira Nakano

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Changes in the Perception and Sense of Self of Individuals With Aphasia:

An Ethnographic Study

by

Erline Vieira Nakano

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science
Department of Communication Sciences and Disorders University of South Florida

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Dedication

To all the participants in the study and their families – may golf clubs, gems, guitars, weights, watercolors, books, asanas, and conversations at the kitchen table be always present and celebrated!

To my husband, Luis (Gato) Nakano, for the constant love, patience, support, laughter, and our conversations about life, the universe, and everything. I love you and I could not have made it without you!!

To my family and my in-laws for the love, the art, and the science, and the wonderful food and caring!

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And finally, to you always Dad – The Xingu is everywhere. Papaya cheers!
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Life teaches us who we are

Salman Rushdie
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Changes In The Perception Of Self In Individuals With Aphasia.

Erline Vieira Nakano

ABSTRACT

Little is known about the perceived changes in identity and sense of self in individuals with aphasia. Seminal research using qualitative methods and personal narratives has been conducted in England regarding the experience of living with aphasia (see for instance Parr, Byng, Gilpin & Ireland, 1999; Parr, Duchan & Pound, 2003; Byng, Pound & Hewitt, 2004), but the use of such methodologies is still emergent in the United States. In addition, despite the great achievements of the disabilities movement in countries such as the U.S. and the U.K., individuals with aphasia have remained largely at the margins due to the very nature of their impairment (Pound & Hewitt, 2004). How can one reflect upon and adjust to the changes brought about by a disability when one is devoid of words?

According to Brumfitt (1993), individuals with aphasia, especially during the acute stages of recovery, have the tendency to idealize their “prior self.” However are these identities transformed in relation to the acquired disability as individuals enter the chronic stages? If so, are these changes perceived in the same manner by survivors and caregivers?

The purpose of the present study was to investigate these perceptual changes in identity using a qualitative ethnographic methodology. Seven individuals with aphasia
and five caregivers participated in in-depth ethnographic interviews addressing perceived changes in sense of self after the onset of aphasia. Interview analysis resulted in ethnographic narratives in which participants and caregivers reflected on their perceptions of change and adaptation to disability. Common themes included the discovery of new identities, the gradual compromise between rehabilitation and adaptation, divergent perceptions of change, and the role of support groups during the rehabilitation process. The study was concluded with reflections from the investigator and the participants on how the results from this research could be used in our clinical practice.
Chapter 1. Introduction

“The moment of a stroke, even a relatively minor one, and its immediate aftermath, are an experience in chaos. Nothing at all makes sense. Nothing except perhaps this overwhelming disorientation will be remembered by the victim. The stroke usually happens suddenly. It is a catastrophe. (...) An explosion quite literally is occurring in her brain, or rather, a series of explosions: the victim’s mind, her sense of time and place, her sense of self, all are being shattered if not annihilated.”

Arthur Kopit.

The Stroke

“How long has it been since your stroke?”

“Nine years, going ten.”

“Almost six years.”

“I guess… About five years.”

“Three years and two months.”

“Hmm… long time…”

“A long time ago.”

“Thirty years.”
“Can you tell me how it happened?”

Vicki

Tampa, Florida, April 4th, 2001. I was home with my dog, in the morning. I think it was in the morning... You know when you have an ice cream headache and you have that rush running through you? Well... It was like that. Only that I just got the rush. I never felt the headache. I went for aspirin, and I thought, “No, I don’t really have a headache.” I felt really weird, I didn’t feel better. I don’t really know what time it was. I took a shower... I took my dog... I was taking my dog out, and all of a sudden I lost vision in my right eye... I think I threw up... My leg, weak... I went to my remote, I couldn’t figure out my remote! I had a message in my voice mail, and I couldn’t retrieve... I couldn’t remember how to do it. I looked at my dog and said, “Miles, we’ve got to get out of here.”

It never occurred to me that I was having a stroke, or call 911 or anything... I took my dog out to find a friend in the neighborhood, and I said, “Something has happened to me, and I need your help,” and she stood up and she said, “Well, we’ve known you for three years and we always thought that you needed help!” But then she looked up at me, she looked at her husband and she said, “Take Miles home (my dog) and we’ve got to get Vicki to the hospital.” She is a nurse, so she
knew that I was either in the throes of the stroke, or it had just happened... But because we didn’t have the exact time that they can have that... that I could have that shot, then I didn’t get it.

I was in the hospital for a week, and they did all the tests... At first they said it was high blood pressure... My blood pressure the day I had the stroke was 117/77. And it was... I never had high blood pressure... So they tested, you know... And all my friends, because they thought I was going to die, because it was so severe... And hmm... They finally went down my throat to check my heart, and I have a ...

From birth, I have a blocked septum in my heart, which is one valve is rigid, and the other side looks like a slack jump rope, and that’s what started the clots... So I’ve had two... I’ve had two strokes... The first one was in 2000, and I lost my taste buds and my smeller... It has never come back. And then in 2001 I had... I call it the “Big Bang”... It was... It was a Big Bang...

Larry and Susan

I drove him. I didn’t know he was having a stroke... We got as far as the fire station. Larry said “fire” and I said “station,” and the rescue squad took him to the hospital. But I didn’t know... I remember telling him, “Larry, I think you’ve had a stroke...” but he would say “No, no, no... Hospital!” And we went from there.

***
“How it happened?” she asks. “Well, he told me to turn on the light and the words wouldn’t come out of his mouth! Right here! In the hallway…”

“No… Dear, no…” Larry corrects her, gently.

“In the back hallway?” she asks in doubt.

“In… Garage!” he says.

“That’s right,” Susan concedes. “He said, ‘Turn on the light!’, and then… The words wouldn’t come! I thought… ‘He’s had a stroke… he’s had a stroke!’ Little did I know…”

Taking a breath, Susan continues,

“Your tongue got thick…”

“Oh, yes!! I…” Larry starts and pauses.

“We were going to go to a movie and… And… And we didn’t go…”

“Well… Now… What… TI…” Larry asks, searchingly.

“You had a TIA,” Susan agrees and nods. “Then in the hospital you had the stroke.”

“Stroke, two days… two days… Friday… night… Saturday” Larry mentions, trying to get his chronology straight.

“They were gonna release you on Sunday and you had a stroke.” Susan says.

“So Sunday morning… Sunday morning… the stroke has occurred…” Larry confirms. “And me, aware? No… Asleep…”

**Bob and Diane**

“Remember?” Diane asks, looking at Bob.
“Yeah…” he says, with a deep, longing sigh.

“You were traveling… you came home…” she reminisces.

“No… No… The… Friday… The plane” he corrects. “And… not a stroke, but…”

“You had a what… Remember?” she intervenes… “A kidney…”

“Ey… Stone!” he completes.

“You came home, went to bed…” she retraces his steps.

“Right… And the next day… Really early… The bed… Yeah, the stroke. The body… The arm… Not heavy, but… I don’t know…” he looks at her, searchingly.

“Numb?” she asks

“Numb! Yes, yes! And could not talk.”

***

We were on our way… This was our daughter’s… This was a, you know, a real horror story, but it’s in the past now. [She’s silent for a moment. Reorganizing her thoughts, she continues.]

We were actually on our way to our daughter’s college graduation. We were supposed to get a plane that day to go to Philadelphia. Actually, to a college reunion of Bob’s in Boston, we were going there and then to Philadelphia. I was downstairs, turning the coffee on, because we had a two-story house, and I heard this thump, and there was something about this thump that wasn’t like… You know, like dropping a cup… So I flew upstairs, and Bob was beside the bed, and I thought he was joking around.

[She looks at him and smiles.]
I thought he was playing around and joking around. I said, “Bob, come on, you know, let’s not... You know, we’ve got a lot to do, we’ve gotta, get up…” But I couldn’t arouse him at all.

I called 911, and... They... I knew it wasn’t heart, you know, I knew it wasn’t heart, because it’s not what happens in a heart attack and all... I knew... When we went out there... Because of the kidney stone in his record they thought that it was a bad reaction from the drug that they had given him the night before. I could tell by the questions... Of course, because of his age (he had just turned 51) they thought it was probably an aneurism, so they did the CT. There was no evidence. So they ruled out aneurism. They admitted him for observation because they saw absolutely nothing. So... at that point, I heard somebody mention stroke, and they asked me about a neurologist...

By that night, the neurologist managed to be there, and... Then they took an MRI. The next night the neurologist told me that... It had been a massive, horrible stroke, and... He would never do anything...

Edie and Cathy

March... hmm... Numbers... numbers... 19...95? 1995. In the morning... I have my... Kitchen...Plugging the coffee... And then something... Something... SHUMMMM! Bum!! Yeah... Bum... And... Husband is right there... Maybe ‘frigerator, or something. “What’s the mat...?" Ohhhh!!! His word, he say... He was... Because... “You have a stroke!” No wonder... I can’t... I remember the kitchen and then... Suddenly... Funny... Things... And no more... No more... Five days coma... ICU... I remember nothing.
Well, what is weird is... It happened March 14, which was a Tuesday, and I was in nursing school. Dad called me, and then I said, “Ok, I’ll meet you at the hospital.” We got there, and... [sigh]... It was clear what had happened, that she had a stroke, and in nursing school I had heard about the TPA, but it wasn’t yet approved, and... She went to a hospital in Bradenton which is a smaller community hospital. They weren’t giving it there... I asked the doctor about TPA and she said, well, it ends up causing hemorrhages and we don’t give it, and... I... At the time... That was it... They were not giving it, and... Mom... In the... In the ER... It was... Pretty clear to me that Mom knew what had happened. She doesn’t recall this, because the brain was swollen and all, but it was pretty clear to me she knew what was happening because she would pick up her bad hand.

The doctors say my husband, they say “Your wife is very sick... Be careful because maybe have a... Your wife is.... Dead...” Oh god! “Or... Is a coma... and vegetable, vegetable!!” He said “AHHHHH!!” Panicked!! Yes, I think, my husband... They say later, perhaps, but I don’t remember nothing! Slowly, five days, and then night time in the hospital, and there in night time... Dark... “Hospital? What’s the matter with me? What’s the matter with me? What happened here, what’s wrong?” And ... then... “My... My... Arm...? Hand? Oh!!!” Then suddenly! It pops in! “I have a stroke! Oh boy!!!” I couldn’t... Anger, anger, anger!!! Is very... Nobody else here! Oh my golly! It’s... The brain and... Slowly,
slowly, slowly… “Oh my god!! I can’t talk! I can’t! I… I don’t feel anything…
talking but, it’s flat… Not flat… Oh boy…”

**Tom and Erika**

Well, I had… I was on the golf course at the time… University of South
Florida. And… I had a headache… And then… Eyes are bo… bothering me… So
I… Keep rubbing eyes… So… I… Lay down… You know? No problem, hmm…
Bug bite, or something like that, a friend… You know… Three… Three hours…
Golf course… Yeah… Well, basically… Five, five hours…

***

*What happened to him…? He had a dissected carotid artery, so a piece of the
artery just broke away… Just a piece… Like, this is the artery, and a piece here broke
away and clamped it shut… You know… That’s why at the conference, when they were
talking about the two types of strokes, no, it’s not true because he didn’t have a bleeding
and he didn’t have a blood clot… Right now it’s still 100% blocked… What happened is
the blood made new pathways to go around, but the damage was done… So… Had he
gotten… In fact, he got to the hospital five in the evening; they didn’t start him on
heparin until midnight… So, I mean, it was hours and hours gone by… It was, at that
time it was twelve hours, but… I don’t think that… I don’t think it would have… If he had
gone to the hospital immediately, I don’t think anything else would have been different…
No… No… Because it was a different type of stroke. They… Say it is either hereditary or
a freak thing…

***
Looking at Erika, Tom comments,

“Nu… Number… Te… Ten minutes… Know… I didn’t… No, no… But… numbers… cell phone…”

“You couldn’t remember?” she asks.

“Yeah… Couldn’t remember!” Tom says, nodding.

“Your speech was on and off that night…” Erika recollects, “Then the next day… by the end of the next day, it was… Nothing. It was gradual… Then your boss, you were with your boss on the golf course, so he called me… He said, ‘Tom got stung by a bee or something, he’s having a reaction, I’ll take him to the hospital.’ So I thought, ‘Oh, OK, no big deal…’ I get there and you come wheeling in the chair and I said, ‘No… Something is wrong…’ You don’t remember that, do you?” she asks.

“No… I do… Some… Some… Some… Times… Flashbacks… But…” sighs,

“You know… Nothing…”

Curt and Christie

“You were at school” Christie starts.

“Oh, yeah… Yeah… University of South Florida, eating a Subway sandwich.” Curt smiles, good-humored as always. “All of a sudden, walked inside, two step, I’m almost buckled on my knees!”

“Because…” she inquires.

“Of course, I ate the Subway sandwich” he adds the important detail, and laughs good-heartedly.
“But you had a headache” she says, focusing him, as she has probably done their entire lives.

“Oh, yeah!” he nods and acknowledges.

“It just hit you real… Bad!” she exclaims.

“Almost buckled my knees…” he recollects. “I walked inside, two steps, and buckled my knee… I still ate the Subway sandwich, of course… But it hurt… And… dizzy… I didn’t know nothing.”

He stops and thinks for a while, organizing his thoughts. “I know the symptoms… I think ‘I’m having a stroke.’ ‘You’re not having a stroke’ the doctor, the nurse said…”

“They took him back to the clinic there… He had to walk to the clinic, they wouldn’t take him” Christie interjects, in quiet indignation.

“Oh, half a mile!” Curt adds.

“So he walked over there, and they didn’t know what was wrong… But they didn’t think it was anything serious… I don’t know why they finally sent you to the hospital?”

“Carrollwood hospital… I hate that hospital! It’s a small hospital!” he exclaims.

“They were almost full, or real busy at the time… So anyway, they sent him there, and yeah, it was real small… He stayed in an emergency room for about… Oh… Until about one o’clock in the morning, I guess, and he got there about four… So… They didn’t do anything… They were going to take him up to the floor and start a heparin drip on him, and by the time he got there the whole left side was paralyzed…”

“I didn’t know anything, you know? It’s weird.” He recollects.
“He couldn’t say anything.” She says, looking at him, quietly. “It was hard to say what he was understanding and what he wasn’t. I don’t think he was understanding much of anything at that time.”

“I was a messed up puppy!” They both laugh. “My two words, ‘Curt’ and ‘Christie.’ Nothing. I know what the people, but… In and out, you know?” He stops, looks at his body and says “My arm is… Limped, I don’t know what the problem is…” After a brief moment, he concludes “I made a pact with God! ‘Don’t take my life just yet…””

**Barbara**

“John went into the bathroom when we got back to the apartment and I went to the foot of the bed to step out of my sandals. As I bent down to pull off the left one, it happened. It happened so fast: suddenly I was spiraling down, head first, to the bottom of a well, spinning in perpetual, uncontrolled motion. This dizziness was far worse than the spells that had occurred that morning. It was deep inside my head, as though my brain had gone on a roller-coaster and hadn’t bothered to tell the rest of my body. The odd thing is, I never lost consciousness, and I wasn’t frightened. It didn’t hurt. There was no pain – no sense of trickling or bursting – just an overwhelming swirling, sharp drop. As my mind disengaged from my body, it separated the connection between thought and action. Everything now happened in slow motion. My body crumpled. My head hit the wooden floor with a loud thump, and I collapsed on top of it. I could feel the cold, hard planks of the floor. Then there was complete silence. I tried to get up but nothing moved. Something was very wrong. A heaviness, like a man’s hand, weighed down on my
consciousness, leaving nothing but my will. My will alone tried to pull its companion body back to its rightful place. It tugged at the limp mass and gave a noiseless command to get up. I tried. It strained to push the inert mass on the floor. But there was no mind to assist, no muscle to aid, no words to instruct. Communications were severed. My mind and body could no longer perform its commands. The connection ceased to exist. I didn’t know until much later that I had lost the ability to speak.” (Newborn, 1997, p.11).

**Literature Review**

The voices present in these narratives belong to seven stroke survivors and their families. All of the survivors have aphasia, an acquired neurogenic disorder which affects language expression (i.e. speaking and writing) and comprehension (i.e. listening and reading). In the United States, approximately one million individuals are currently living with aphasia (NAA, 1999) and 100,000 new cases are documented each year (Damasio, 1992). Despite these astounding numbers, public awareness of aphasia is still considerably low. In a face-to-face survey conducted with 978 participants in the United States, England, and Australia, 133 individuals (13.6%) had heard of aphasia, and only 53 (5.4%) had basic knowledge about the disorder (Simmons-Mackie et al, 2002).

Several factors contribute to the poor visibility of aphasia in the general population. As opposed to other stroke sequelae such as hemiparesis or hemiplegia, aphasia is not readily visible to the naked eye. As discussed by Alf in *Talking About Aphasia* (Parr, Byng, Gilpin & Ireland, 1999),

“...You can see a person in a wheelchair... he or she got no legs. Then you say: ‘Oh yes. That person is disabled.’ But you cannot see that I am
aphasic. They cannot see it, so how will they know? Have I got to have a noticeboard up and say: ‘I am aphasic’?” (p. 118)

The presentation of aphasia is further complicated by its unpredictability (i.e. language performance may increase or decrease depending on one’s level of stress and fatigue) and high degree of individual variability (i.e. no two individuals with aphasia are exactly alike). Several individuals with aphasia are themselves unclear about the nature of their disorder, and may experience a full range of conflicting emotions (e.g. anxiety, anger, frustration, shame) when attempting to explain their difficulties to strangers (Parr, Byng, Gilpin & Ireland, 1999). Of far-reaching and devastating consequence, however, is the stigma associated with the disorder. When confronted with sentences missing words or missing content, most people shy away in embarrassment, fearing either lack of intelligence or impaired sanity (Sarno, 2004; Parr, Byng, Gilpin, & Ireland, 1999). In an extreme case, Ireland (1990) discusses how she was committed to a mental institution after being misdiagnosed as mentally ill following her stroke and aphasia.

Since in most cases aphasia is “a partner for life,” how do individuals adjust to their new realities? How is their sense and perception of self redefined after such a significant life disruption? How do these changes impact their recovery and reintegration into society?

The Self, Memory, and Stories

You have to begin to lose your memory, if only in bits and pieces, to realize that memory is what makes our lives. Life without memory is no...
Questions regarding the nature and complexity of the self have permeated not only the entire history of psychology, but also several other disciplines including philosophy, anthropology, sociology, religion, the arts, and recently the neurosciences (LeDoux, 2002). Bruner (1990) refers to the “tortured history” of the self as a progressive paradigmatic shift from “essentialism,” in which the self was conceived as a preexisting substance in need of discovery, to a “conceptual self,” constructed in cultural and social interaction and constantly reformulated as a result of the dialogue between the “I” and the “other.”

Somewhere between extreme essentialism and total social constructionism lies the theory of self proposed by William James (1910). In James’ view, the self is composed of two distinct but complementing aspects: the empirical ego (Me) and the pure ego (I). As an “aggregate of things objectively known” (p. 48), the empirical ego (see Fig. 1) encompasses all of one’s material, social, and spiritual constituents, as well as all favorable and unfavorable feelings and actions aroused by them (i.e. self-preservation, self-seeking, and self-estimation.)

The pure ego (I), on the other hand, is the element of the self which confers individuals with a sense of continuity and identity over time. Differently than the feeling of transience inherent in the “Me,” the “I” provides individuals with the sense that the “Me” from the past and the “Me” from today are essentially the same, despite their constant growth and mutations.

"life at all... Our memory is our coherence, our reason, our feeling, even our action. Without it, we are nothing."

Luis Bunuel.
How can permanence and constant change coexist, however? According to James, this seemingly complex paradox is solved through the seamless fabric of our memories.

“[T]he Me of now and the Me of then are continuous: the alterations [a]re gradual and never affected the whole of me at once. …The identity which we recognize … can only be the relative identity of a slow shifting in which there is always some common ingredient retained. The commonest
element of all, the most uniform, is the possession of some common memories. However different the man may be from the youth, both look back on the same childhood and call it their own.” (p. 48).

The significance of memory in the construction of identity is reiterated almost a century later by LeDoux (2002) who states that “learning, and its synaptic result, memory, play major roles in gluing a coherent personality together as one goes through life. Without learning and memory processes, personality would be merely an empty, impoverished expression of our genetic constitution” (p. 9).

Concepts such as the “Me” and the “I” as suggested by James may be, in some ways, compared to what Kirmayer (2002) terms the “transactional” and the “adamantine” aspects of the self, which are culturally created and constrained. Thus, within the context of the Euro-American culture, individuals are expected to have a core (“adamantine”) self, which lends coherence and continuity to the fluid and ever changing aspects of the “transactional” self.

In discussing how individuals actively construct the self through the act of narration, Bruner (2002) suggests that narratives of self-making are a dialectical and cultural construct, characterized by the desire to balance autonomy and social commitment. In order to achieve such a task “we constantly construct and reconstruct our selves to meet the needs of the situations we encounter, and we do so with the guidance of our memories of the past and our hopes and fears for the future.” (Bruner, 2002, p. 64).

As attested in documents such as “medical histories, legal testimonies, psychological portraits, texts of pure fiction, news stories, autobiographies, conversations” (Young & Kay, 2001), the act of narration is pervasive in every aspect of
our daily lives. However, when regarding our own experiences, we may not readily perceive them as part of a narrative structure, given that we ourselves are embedded within the fabric of our stories (Young & Kay, 2001). According to Bruner as quoted by Young and Kay (2001), narrative is the instrument by which the mind constructs, organizes, and gives meaning to reality.

“Narrative organizes not just memory, but the whole of human experience – not just life stories of the past, but all of one’s life as it unfolds. Bruner describes narrative as an instrument of mind that constructs our notion of reality, and asserts that the experience of life takes on meaning when we interact with it as an ongoing story, as our story.” (p. 75)

The interrelationship between narrative and memory in the active creation of one’s self has recently attracted the attention of researchers in the area of neurosciences. In the article “The Neurology of Narrative,” Young and Kay (2001) discuss how the concept of self may become disrupted in individuals with “dysnarrativia,” a state of “narrative impairment” caused by focal brain damage. As evidenced in cases of global amnesia, in which one is unable to form new memories due to bilateral amygdalo-hippocampal lesions, the self may become “frozen in time, aging somatically but not psychologically [as] interests, obsessions, narrative self-interpretations and dispositions [remain] stable over decades” (p. 76). Sacks (1985) describes a poignant example of dysnarrativia in the story of Jimmie G., the Lost Mariner who suffered from a memory impairment due to Korsakov’s syndrome. As Sacks recounts in his notes, Jimmie was a “man without a past (or future), stuck in a constantly changing, meaningless moment” (p.
29), resembling in some ways a successive collection of James’ “Me’s” without the organizing presence of a governing “I.”

In cases not as drastic as Jimmie G.’s, what happens to the self when it is faced with significant life disruption? How does it heal after being shattered by illness?

_Bridging the Chasm_

_Stroke rehabilitation seesaws between hope and hopelessness._

Becker and Kauffman.

Although initially located within the realm of the body, life disruption following illness (in general) and stroke (in particular) is pervasive and systemic. As aspects of existence previously taken for granted are swept from under one’s feet in the blink of an eye, chaos and confusion ensue, accompanied by feelings of uncertainty about the future and longing for life as previously known (Becker and Kauffman, 1995). In a study investigating how a woman redefined her biography after suffering a stroke, Kauffman (1988) contended that following life-threatening illness, survivors need “to ‘repair’ and ‘heal’ the self by revising and re-creating the biography so that it makes sense in light of the current changed circumstances” (p. 217). In the seven narratives presented earlier in this chapter, stroke survivors and their family members relive the precise moment of their strokes in vivid detail, years after the fact, as they attempt to weave their memories of disruption and chaos into the fabric of their biographical time (Corbin & Strauss, 1987). As stated by LaPointe (1999), following the initial shock and confusion which accompanies the moment of a stroke,
“People begin to try to make sense of everything. They mull and ponder and ask questions about the details of how they behaved during the acute phase. They go over the events in their minds and examine in excruciating detail the events leading up to the illness to try to discover the ‘real’ cause. They ask ‘Why me?’ and finally after ruminating, they begin to accept the fact that their lives may be inexorably altered.” (p. 270)

In studying life disruptions of various kinds (i.e. infertility, midlife disruption, stroke, and old age) across groups of varied ethnic backgrounds, socioeconomic status, ages, and gender, Becker (1999) observed a pattern of recovery emerge in several narratives, characterized by a moment of disruption, a transitional period or “limbo” in which individuals lingered between two worlds, and a process of biographical reorganization, in which lives were reinterpreted in light of recent experiences. Given the pervasiveness of this pattern across such diverse narratives, Becker (1999) suggested that, within the context of American culture, biographical disruptions were seen as a violation in the thread of continuity and predictability expected to permeate one’s life. Thus, in most participants’ narratives, frequent attempts were made to bridge the past, present and expected future into a new semblance of normalcy and continuity.

In *The Wounded Storyteller*, Arthur Frank (1995) discusses a similar pattern of recovery in the form of narratives of chaos, restitution, and quest. In chaos narratives, individuals’ stories are fraught with confusion, despair, and loss of control, as the body is suddenly arrested by illness and life is thrown in disarray (Becker’s “disruption”). In restitution narratives, stories shift focus to the plight for a cure and the restoration of life and health. Restitution narratives, in some ways, are similar to Becker’s “limbo,” in
which individuals are suspended in between two worlds (i.e. past and present, health and adaptation to illness, chaos and order). Finally, in quest narratives (Becker’s “reorganization”) the plot suddenly changes and develops into a search for adaptation and acceptance of disability and difference.

In discussing the concept of illness trajectories as defined by Wiener and Dodd (1993), Becker and Kauffman (1995) state that an illness trajectory encompasses the physical development of a disease, its treatment and management, and its impact on the patient and his/her social network. In addition, illness trajectories may be interpreted through three different perspectives, including: 1) the illness as seen by the medical establishment in the form of a prognosis; 2) the illness as experienced by the patient; and 3) the “personal narrative” of the illness, constructed by patients and their families as they decide how much of the medical prognosis to incorporate into their own stories. In most cases, the degree to which the medical and the personal aspects of illness are fused into a personal narrative is highly dependent on the level of observed or perceived improvement gained from medical intervention (Becker and Kauffman, 1995; Corbin and Strauss, 1987).

In the case of stroke, one aspect of the illness trajectory which is usually shared by different survivors is the “mechanics” of treatment and rehabilitation. Following the initial hospitalization in acute care, most stroke survivors are prescribed a period of rehabilitation (including physical, occupational, and speech therapies) which may start within the context of acute care itself and transfer into inpatient rehabilitation programs, outpatient therapy, home health, nursing homes, or assisted living facilities (Becker and Kauffman, 1995). In considering whether a given patient is a good rehabilitation
candidate, medical specialists usually consider the following factors: 1) the patient’s health status prior to the onset of stroke, 2) the patient’s current cognitive abilities, 3) the level of severity of the stroke, 4) the patient’s level of tolerance for intensive rehabilitation, and 5) the patient’s age (Becker and Kauffman, 1995; Kauffman and Becker, 1986).

The role played by rehabilitation in one’s recovery usually goes beyond its more readily observed medical benefits, as it is during rehabilitation that survivors are given the first opportunity to re-establish a sense of order, routine, and predictability to their lives. As pointed out by Becker and Kauffman (1995) in their study of illness trajectories following stroke,

“Rehabilitation lent structure and meaning to [patients’] daily lives. It was important to do. It provided a series of tangible goals. They gained a sense of productivity from their efforts in rehabilitation, which diminished, to some extent, their feelings of being useless. … Rehabilitation gave shape to the trajectory.” (pp. 176-7)

Although the primary goal of rehabilitation in the United States is to reduce disability and help individuals attain a level of functional independence upon discharge (Sarno, 2004, Becker, 1994), rehabilitation is still seen by most patients and families as a source of cure and restitution to the self as previously known (Becker and Kauffman, 1995). In addition, when participating in rehabilitation programs, patients are expected to demonstrate high levels of motivation and desire to recover, which are two of the greatest predictors of success in rehabilitation, as perceived by healthcare providers (Becker and Kauffman, 1995). Thus, certain expectations and responsibilities are implicitly placed on
the patients’ shoulders, such as compliance with rehabilitation, a positive outlook on therapy, and acceptance of the therapist’s role as the expert (Pound et al, 2002; Alexander, 1990). Within that context, limited space is given for the expression of feelings of grief, anger, or loss experienced by both patients and their families as a result of disability (Becker, 1994; Pound, 2004).

“… The expression of distress is not culturally sanctioned in the United States. In the United States, there is an underlying ideology, born of puritan beginnings, that values communication through mental rather than bodily activity, that values thinking more highly than feeling. Bodily and emotional expression is suppressed. Indeed, the lack of acknowledgment of embodied distress heightens the difficulty people have in giving voice to bodily disruptions; embodied distress may be difficult to access through language and may remain muted and unarticulated.” (Becker, 1999, p. 11).

When considering individuals with aphasia the challenge is compounded: How can one attempt to communicate his or her inner turmoil when communication itself is one of the sources of distress?

**Language Rehabilitation**

*Neurology is largely a veterinary business – it deals almost exclusively with what can be measured and tested; hardly at all with the inner experience, the inner structure, the subjectivity, of the subject…. It excludes mental states, consciousness, because they are “subjective” and “private,” and cannot be verified or validated in the conventional way. No*
“persona” terms are allowed in neurology ... We do not have any
“neurology of identity.”

Oliver Sacks.

Within the current system of medical rehabilitation, speech and language
pathologists are the professionals most directly involved in the assessment, treatment, and
rehabilitation of individuals with neurogenic language disorders. During the nineteenth
century, however, the few individuals with aphasia who survived stroke or brain injury
were “re-educated” primarily by neurologists (Howard & Hartfield, 1987). It was only
after the advent of the two World Wars that rehabilitation programs started to be
developed throughout the United States and Europe (especially in Germany, the U.K. and
Russia) to accommodate the needs of wounded soldiers who had sustained gunshot
wounds and other brain injuries (Hinckley, 2002; Howard & Hatfield, 1987). As pointed
out by Sarno (2004),

“Aphasia rehabilitation is indebted to the field of rehabilitation medicine
for its philosophical foundation and its contemporary adoption of a
functional perspective for assessment, treatment goals, and outcomes.” (p.
21)

Delivery of speech and language rehabilitation services in the United States is
currently constrained by the policies and procedures of managed care. The Social
Security Act Amendments of 1983, in particular, had profound effects for the fields of
speech pathology and audiology. With the creation of the prospective payment system
(PPS) and reimbursement based on diagnosis-related groups (DRG), hospitals were
encouraged to increase service efficiency. In practical terms, however, PPS translated
into shorter hospital stays and “late or reduced inpatient referrals, fewer inpatient sessions, downsizing of staff, or reluctance to contract new services” (White, 2001, p. 216).

Traveling the never-ending maze of insurance coverage is a heroic task in itself. Overall, evaluation of language disorders is more readily reimbursed than treatment and inpatient therapy more so than outpatient. Psychosocial aspects of disability, including “depression, self-esteem, stigma, relationships, role changes, impact on carers, psychological effects, disability, identity, functionality and lifestyle changes” (Parr, 2001, p. 266) being perceived as “maintenance” aspects rather than objective deficits, are rarely addressed directly in therapy and are not covered by insurance (Sarno, 2004).

In a system built to work as a well-oiled machine, where patient care is meant to be delivered as economically and efficiently as possible, little space is reserved to the personal experience of illness (Frank, 1995). As mentioned by Sacks in the quote above, healthcare professionals (not only neurologists!) are trained to document and treat mostly the aspects of a patient’s illness which can be analyzed objectively. In fact, within the realm of speech pathology, addressing a patient’s personal narrative may be seen by several therapists as something “essentially wrong,” which steals time away from real therapy (Holland & Beeson, 1993, p. 582).

In considering her experience as a speech and language therapist, Pound (2004) reflects

“Initially, as a therapist, I felt … my job was to help patients understand their condition, improve their speech and language as much as neurological damage allowed, and somehow support them to ‘come to
terms’ with their changed lives (which of course I could only glimpse from my therapy rooms in the hospital or rehabilitation unit). Looking back, I cringe at some of my clumsy attempts to speed realistic adjustments to limitations on the part of patients and families. I also, retrospectively, question decisions about the timing and allocation of time to different parts of the rehabilitation process. How little option I gave clients in how they divided their precious therapy time, and how unclear I was in setting out the different components of therapy. For example, it was not difficult for me to listen to language errors and tales of determination. But to listen to the repeated stories of chaos and confusion and to develop therapeutic interventions appropriate to learning to live with difference – these offered therapeutic challenges of a quite different dimension.” (p. 36)

Although not common in the U.S., identity and narrative based therapies are being developed and implemented in countries such as the United Kingdom (see Pound et al, 2002). Despite the stark differences in healthcare systems between the UK and the US, one cannot help but wonder: Is there a place for personal narratives and identity-based therapy in the context of aphasia rehabilitation in the U.S.?

**What Is It Like Inside?**

*Arthur, when am I going to be me again? This is not what I had in mind for ‘me.’ After some more rehab will I be me again?*

Arthur Kopit’s father as mentioned by LaPointe in
In his preface to *Wings*, Arthur Kopit (1978) comments,

“In the spring of 1976 … my father suffered a major stroke which rendered him incapable of speech … [I]t was impossible to know how much he comprehended … As best as I could, I tried to understand what he was going through. It seemed to me that, regardless of how reduced his senses were, the isolation he was being forced to endure had to verge on the intolerable; clearly, he had not lost all comprehension – the look of terror in his eyes was unmistakable. Yet, not only did he tolerate this state; every now and then, if only watched carefully enough, something escaped from this shell that was his body and his prison … something which I felt possessed a kind of glow or flicker, rather like a lamp way off in the dark, something only barely perceptible. I took these faint flashes to be him signaling … [I]t seemed to me (indeed, seemed irrefutable) that in some ineffably essential way, reduced as he was, he was still the same person he had been. This thought was both heartening and frightful. To what extent was he aware of what had befallen him? What was it like inside?” (p. viii)

In an attempt to understand his father’s inner struggle after his stroke, Kopit wrote *Wings*, a play portraying the story of a female pilot who suffers a stroke and aphasia. As a source of inspiration for his main protagonist, Kopit interviewed and interacted with two women with aphasia he met at Burke Rehabilitation Center in NY, where his father had been transferred after his stroke. By investigating his father’s world through analogy, the playwright metaphorically translated the experience of aphasia as a pendular movement...
from the “inner self” to the “outer self,” in a progression which emerged from fragments and chaos to a new order and sense of cohesion (Kopit, 1978).

In discussing the topic of self in stroke and aphasia, Brumfitt (1993) contends that following a stroke, most survivors may idealize their “prior selves” while mourning for their losses, thus creating the need for the development of a new and transformed identity. During this process, the acknowledgement of the individual’s prior self is of great significance, as it allows survivors the opportunity to reconnect their present and past selves, thus reinstating a sense of biographical continuity. Herrmann, Johannsen-Horbach, & Wallesch (1993), however, point out that in several cases, the act of acknowledging the past may be misinterpreted as an attempt to cure and restitute the self as previously known, thus further compounding the problem of adaptation to living with disability.

Most of what is currently known regarding the experience of living with aphasia is based on personal accounts of survivors. However, as pointed out by Sarno (2004) “in-depth studies using the methodologies of the social sciences designed to identify and assess the nature of personal suffering in aphasia have been limited.” (p. 22).

What the reader will find in the following pages is an attempt to re-construct the transformations and reformulations of self as experienced by the seven individuals whose lives were suddenly arrested by a stroke and aphasia. Interwoven within the fabric of their narratives are the voices of their family members as they rediscover their loved ones as well as themselves in the new roles they assume. In order to re-construct the biographies of the seven participants, a qualitative methodology was used.
Chapter 2. From Science to Art (Or Somewhere In Between)

Qualitative Methods

Although relatively new to the field of speech and language pathology and aphasiology in particular (Damico & Simmons-Mackie, 2003; Parr, 2001; Parr, Byng, Gilpin & Ireland, 1999), qualitative research has a long and well-established history within the human sciences. Traditionally grounded within sociology and anthropology (Parr, 2001; Denzin & Lincoln, 2000; Damico et al, 1999), the primary goal of qualitative research is to “seek answers to questions that stress how social actions and social experiences are created and sustained” (Damico et al, 1999, p. 651).

In its primordial days, qualitative research was conducted by investigators (i.e. ethnographers) who traveled to foreign and exotic lands to do fieldwork and artifact analysis, in hopes of understanding the reality of the “other” through naturalistic and “objective” observation (Lindlof & Taylor, 2002; Denzin & Lincoln, 2000; Ellis & Ellingson, 2000; Wolcott, 1999). During the past century, however, qualitative methodologies have undergone significant theoretical reformulations, giving rise to a historical continuum which extends from the realism of the positivistic sciences to the multiple layered meanings of literature and the arts (Ellis & Ellingson, 2000).

Considering that all research is essentially interpretive in nature, an investigative approach (or, in this case, the researcher’s point of entry along the qualitative continuum) is influenced by one’s ontological (“What is the nature of reality?), epistemological
(“What is the relationship between the inquirer and the known?”), and methodological
(“How do we know the world, or gain knowledge of it?”) beliefs, which, taken together,
constitute a “paradigm, or an interpretive framework.” (Denzin & Lincoln, 2000, p. 19).
Thus, depending on the researcher’s position along the qualitative continuum, social
phenomena may be approached as: 1) an objective reality, existing independently, which
may be investigated linearly and documented objectively; 2) the result of socially
constructed human interactions, of which the investigator is part; 3) the interpretation of
lived experience through the eyes of the researcher himself/herself (Ellis & Ellingson,
2000).

Various strategies (e.g. case study, ethnography, participant observation,
grounded theory, life history, clinical research) and methods of data collection and
analysis (e.g. in-depth interviewing, observation, artifact and document analysis, focus
groups, textual analysis) may be employed in conjunction or isolation by qualitative
researchers (Denzin & Lincoln, 2000). As insightfully summarized by Damico et al
(1999),

“Qualitative research does not favour one single methodology over any
other. The choice of data collection procedures and preferred methods of
analyses depend upon the social phenomena under investigation, the
questions that are asked and the contexts within which the phenomena
exists. … As such, whenever this research paradigm is utilized, it produces
a bricolage – a kind of pieced-together but carefully constructed set of
practices and strategies that provide solutions to a problem in a concrete
situation.” (p. 652)
Selection of strategies and methods of data collection and analysis is largely dependent upon the investigator’s view of social phenomena. As explained by Ellis & Ellingson (2000), while naturalistic research may be more likely to use research tools traditionally linked to quantitative research (i.e. hypothesis testing, randomization, deductive reasoning), interpretive research may draw from methodologies rooted in the social sciences and the arts, including biographical methods, participant observation, ethnography, autoethnography, interactive interviewing, and narrative analysis.

Standing somewhere in between both extremes one may find what Ellis & Ellingson (2000) call the “middle-ground researchers” who combine aspects of “scientific rigor” with “artistic imagination” (p. 2289). Middle-ground researchers may resort to methods of data collection such as semistructured interviews, participant observation, fieldwork, textual analysis, or focus groups. Sampling of participants may be done in a “snowball” fashion (Ellis & Ellingson, 2000, p. 2290, referencing Reinharz), in which participants themselves identify other potential participants. Middle-ground methods of analysis traditionally include sorting and classifying, various kinds of coding (e.g. open, axial, or selective coding), as well as memo writing (Ellis & Ellingson, 2000, p. 2290).

Currently, various disciplines make use of qualitative methodologies, including education, business, medicine, nursing, communications, and social work (Ellis & Ellingson, 2000; Denzin & Lincoln, 2000). However, it has been only recently that the field of speech and language pathology has started to use qualitative methodologies in the study of language disorders (Simmons-Mackie, Damico, 2003).
Qualitative Methods and Aphasiology

Historically, researchers in aphasiology have employed experimental or quasi-experimental designs in the study of neurogenic disorders to obtain accurate and verifiable data and establish scientific credibility (Parr, 2001; Damico et al, 1999). During the 1980’s, however, following Holland’s seminal work on pragmatics and language functions (Holland, 1982; Holland, 1980), several researchers started to identify the need for more qualitatively based methodologies in order to gather more “authentic, functional and naturalistic data on aphasia” (Damico et al, 1999, p. 652).

Over the past two decades, investigators in the United States, England, Australia, and Canada have started to use qualitative methods (i.e. conversation analysis, case studies, participant observation, and interviewing) to investigate the complexities of communication in real life contexts (see for instance Cunningham & Ward, 2003; Lindsay & Wilkinson, 1999; Simmons-Mackie, Damico & Damico; 1999; Simmons-Mackie & Kagan, 1999; Simmons-Mackie & Damico, 1997; Simmons-Mackie & Damico, 1996; ). Researchers in England in particular have studied various aspects of life with aphasia using qualitative methodologies (Parr, 2004; Parr, Duchan, & Pound, 2003; Parr, Byng, Gilpin & Ireland, 1999; Parr, 1994). Still, within the broader research community, qualitative methods continue to be regarded as unscientific, or merely descriptive. According to Denzin and Lincoln (2000),

“The experimental (positivist) sciences (…) are often seen as the crowning achievement of Western civilization, and in their practices it is assumed that ‘truth’ can transcend opinion and personal bias. (…) Qualitative research is seen as an assault on this tradition” (p. 8)
In shifting parameters from quantitative to qualitative approaches, researchers are confronted with numerous practical, theoretical, and logistical challenges. Some of these are discussed in the following section.

**Challenges in Qualitative Research**

**Recanting Authority**

“*What am I looking for? Sometimes I get a nervous pang in my stomach when I think to myself that fieldwork is so undirected (...) I must admit that I would feel better if I knew where I was going... (…) I feel like I am floating now.*”

Graduate Student Quote from Kleinman, Copp & Henderson (1997).

As expressed by the student quote above, qualitative research requires investigators to approach social phenomena with no (or very few) pre-conceived notions (i.e. *a priori* knowledge, or hypotheses), thus relinquishing their posts as all-knowing authorities. Doffing their roles as detached observers, investigators are invited to immerse themselves in social phenomena and take a learning (rather than testing) stance by asking “What is going on here?” (Damico et al, 1999, p. 653). While this perspective may seem exciting on the one hand, it is anxiety and fear generating on the other, as researchers gradually realize they have much less control over their “variables” from this standpoint. As expressed by Kleinman, Copp & Henderson (1997) qualitative research requires one to “lose control to gain control.”
Learning by Doing

Since qualitative research is not based substantially on *a priori* knowledge, it requires a lot of time and investment on the part of the researcher in experiential learning tasks (i.e. fieldwork). In order to conduct fieldwork and become a participant observer, researchers need to gain access to a given social group and take part in their “daily activities, rituals, interactions, and events” so as to learn “the explicit and tacit aspects of their life routines and their culture” (DeWalt & DeWalt, 2002, p.1). As a consequence, the process of qualitative research usually involves a “kind of on-the-job training in the field or through an apprenticeship system” (Damico et al, 1999, p. 658). Currently, in the area of communication disorders, the paucity of mentors with a strong background in the use of such methodologies makes the process of apprenticeship particularly challenging.

Describing Before Theorizing

While immersed in participant observation, qualitative researchers develop rich, detailed, and contextualized fieldnotes (i.e. thick descriptions) which are taken during (or immediately after) fieldwork. As expressed by Kleinman, Copp & Henderson (1997), at the beginning of a qualitative project “everything is data.” (p. 473). As the investigators revisit their fieldnotes, transcribe the voices of their participants, and attempt to code their data in a variety of ways, patterns begin to emerge. Thus, it is during the process of writing and reflecting about what was observed and lived through experience that theories about social phenomena start to take shape, thus guiding future directions of the investigation (Richardson, 2000; Kleinman, Copp & Henderson, 1997). As explained by Damico & Simmons-Mackie (2003),
“... rather than establishing a research hypothesis, designing an experimental study to test this hypothesis, and then moving directly to collecting data and applying various statistical analyses, the ethnographic investigator collects and analyzes data with the intention of identifying phenomena of interest; then this researcher continues to collect and analyze data to progressively narrow the investigation and hone in on the phenomena of interest. As a result, a particular phenomenon of interest emerges and then is focused upon for greater investigation” (p. 137).

**Laminating and Triangulating**

"Validity is subjective rather than objective: the plausibility of the conclusions is what counts. And plausibility, to twist a cliché, lies in the ear of the beholder."

Lee Cronbach.

Since qualitative and quantitative methods are based on widely different conceptual paradigms, establishment of reliability and validity in both realms differs substantially. Take, for instance, the case of experimental and quasi-experimental designs. Within this research methodology, a hypothesis is tested based on pre-determined dependent and independent variables which are controlled for variance and experimenter bias. Randomized sampling and matched controls are used in order to ensure that participants constitute an unbiased and representative sample of the population under study (Ellis and Ellingson, 2000). Within this framework, results are valid and reliable as long as they are replicable (Damico et al, 1999).
In qualitative research, however, “extraneous variables” are incorporated rather than controlled, as the primary goal of social inquiry is to try to understand how the patterns and the exceptions fit together within the context of human interactions. Qualitative research does not require a large number of participants (even though nothing precludes it from working with several participants), but it demands keen observation, description, and documentation of how individual participants interact, behave, and see the world within the context of their daily lives. Thus, as discussed by Damico et al (1999), “there is a trade off between the power of detailed and unique description (which may later result in a deeper understanding of the phenomena) and the convenience of grouping data” (p. 659).

In qualitative methods, issues of reliability and validity are usually addressed by means of verification techniques such as data triangulation and lamination. Data triangulation can be defined as the use of “different data collection and analysis procedures across occurrences and locations so that the researcher can compare and contrast the different data obtained across the different events over different occasions” (Damico & Simmons-Mackie, 2003, p. 137). Similarly, during the process of lamination, “The researcher analyzes the collected data and forms tentative conclusions. Once this is done, the conclusions are verified through a different type of cross-comparison process; the researcher may ask the participants in the ethnography what they believe was happening when certain … behaviors were observed. In this way, the researcher adds another layer of interpretation to the data so that the actual results or
findings can be cross-referenced” (Damico & Simmons-Mackie, 2003, p. 137)

Thus, during the process of lamination, researchers attempt to bridge the gaps between their perceptions and that of their participants “so that findings reflect the meaning of the people whose lives were examined.” (Ellis and Ellington, 2000, p. 2290)

If approached from the perspective of life histories, personal narratives, and especially autoethnography, issues pertaining to validity may take yet another twist. As expressed by the narrator in Bochner & Ellis’ (2000) autoethnography piece,

“To me validity means that our work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible. You might also judge validity by whether it helps readers communicate with others different from themselves, or offers a way to improve the lives of participants and readers even your own.” (Ellis & Bochner, 2000, p. 751)
Chapter 3.  The Search for Stories

Who Are The Survivors?

When the theme of “the self in aphasia” started to take shape as a research project, the names of four stroke survivors immediately came to mind. They were Bob Lombard, Curt Mathes, Larry Smith, and Tom Boyle, or “The Four Musketeers” as they have entitled themselves.

I first had the opportunity to interact with the Four Musketeers as a graduate clinician during my third semester in graduate school. I was inspired by the strong and solid bond of camaraderie and support that they share, as well as their healthy competitiveness in therapy and golf. The more I thought about them, the more I wondered about how they had learned to adjust to life with a disability.

My curiosity just intensified during the Speaking Out! Convention in Tampa, Florida in June of 2004, when The Four Musketeers made a powerful and moving presentation about living with aphasia and the benefits of group therapy. Their presentations were a turning point for me as a student and future clinician, and a moment of affirmation in my decision to carry out a research project using a methodology (and a topic!) that raised some eyebrows.

It was also during the Speaking Out! Convention that I had the opportunity to meet two of the other participants: Barbara Newborn (who was delivering a presentation about her book Return to Ithaca and her experience as a yoga instructor for individuals
with disabilities) and Vicki Gray, a survivor who had previously attended sessions at USF but had been discharged before I started in clinic. I had first seen Vicki in a video recording presented to us by our clinical supervisor, Miz Cheryl Paul (note that the “z” is not a typo, but rather a personal signature). In that video, Vicki described in vivid detail what her experience of aphasia was like, making a strong and permanent impression in my mind. When I happened to run into her in one of the restrooms during the Convention, I could not help but ask her to participate in the study.

Finally, I was introduced to Edie Dungan, the beautiful impressionist artist, through other participants in the group. Although she was also present at the Speaking Out! Convention, we did not meet until about two months later, when I attended a meeting of the Sarasota Memorial Hospital Support Group.

**Exclusion Criteria**

In order to participate in the study, survivors needed to be at least twelve months post-onset in order to avoid the period associated with reactive depression (Währborg, 1991).

**How Was Data Collected?**

In order to investigate how the seven participants perceived changes in their sense of self after aphasia, a qualitative ethnographic methodology was used. Data collection was done primarily within the context of in-depth interviews, which were audio and video recorded and transcribed verbatim. Other methods of data collection included participant observation, artifactual analysis, and investigator diaries.
According to Parr (2001), one of the advantages of using in-depth interviews is that they have the potential to “allow systematic exploration of the ‘insider’ perspective, the subjective and changing aspects of illness, from the point of view and in terms of the people who have it.” (p. 270). In this study, interviews included not only the participants with aphasia, but also their family members (when available). Four spouses (Diane Lombard, Christi Mathes, Susan Smith, and Erika Boyle) and two daughters (Courtney Mathes and Cathy Harper) participated in the study. Interviews were conducted mostly at the participants’ homes and varied in number from two to five meetings, depending on participants’ availability. Topics addressed during interviews included: 1) The participant’s life story prior to the onset of stroke; 2) The story of their stroke; 3) Their life story post-onset of aphasia. Questions were open-ended in nature and used primarily as suggested topics of discussion rather than fixed guidelines. Examples of questions included: 1) Tell me about your life story until the onset of your stroke; 2) How would you describe yourself prior to the onset of your stroke: what did you consider to be some of your most distinguishing characteristics? 3) Tell me the story of your stroke: How did it happen? Where were you? What was your hospital experience like? How did you view therapy? 4) How did your stroke affect your social dynamics? What were the social implications of your stroke? The same questions were addressed by survivors as well as family members.

Participant observation was conducted during aphasia group meetings at the USF speech clinic as well as the Sarasota Memorial hospital monthly meetings. The description of interactions and observations made during the Speaking Out! Convention were also included in several narratives.
During interviews, participants commented on the value and meaning of various esteemed items such as personal journals, calendars, photographs, paintings, and objects (i.e. guitars, micrometers, etc.). The participant’s comments about such items (as well as copies of some of the artifacts) were incorporated within the fabric of their narratives as much as possible.

Finally, throughout the process of the data collection, the investigator kept a diary with fieldnotes, reflections, and observations about the interactions with each participant. Notes were taken primarily after each interview, and were incorporated within narratives as appropriate.

**How Was The Information Analyzed?**

The process of analysis and data collection occurred concomitantly in most instances. Following each interview, recordings were transcribed verbatim and analyzed for patterns. As the investigator identified possible leading themes based on comments made by the participants and their family members, questions were written down and addressed during subsequent interviews. In most cases, leading themes were later transformed into sections or subsections of their stories.

The final product of this study consists of seven individual ethnographic and biographical accounts of the lives of the participants and their family members. Rather than being told in one single authoritative voice, the seven narratives include not only the voices from all of the participants, but also the voices from their own texts (e.g. books and journals in Barbara Newborn and Larry’s case, and a speech and language therapy report in Vicki’s). Traditional “language errors” were never corrected in transcription or
in quotes extracted from participants’ journals and presentations. Rather, as expressed by Parr, Duchan, and Pound (2003), they were seen as “poetic licence and legitimate expression” (p. 5). As a result, rather than being homogeneous in shape, the narratives resemble a quilt, in which different voices, perspectives, and points of views are included.

During the process of “writing up” each ethnographic piece, participants were actively involved in deciding what should and should not be included in their narratives. They were also given the option to use their real names or a fictitious name in the final narrative, for the sake of confidentiality (all but one participant decided to use their real names).

**Why Stories?**

As discussed in the previous chapter, the process of “making sense” of the illness experience involves the telling of one’s story. As expressed by Ellis and Bochner (2000),

> “Personal narrative, the project of telling a life, is a response to the human problem of authorship, the desire to make sense and preserve coherence over the course of our lives. Our personal identities seem largely contingent on how well we bridge the remembered past with the anticipated future … The narrative challenge that we face as narrators is the desire for continuity, to make sense of our lives as a whole.” (p. 746)

Within the area of the neurosciences, A. R. Luria was perhaps the first scientist ever to delve into the personal experience of individuals with neurogenic disorders. With the creation of a new genre termed “romantic science” (Luria, 1968), Luria opened a
space within the scientific literature for the personal experience of the “deaf, the blind, the stroke victim, the amputee,” thus allowing us to “understand them as human beings, coping or failing to cope with the human condition rather than simply having ‘a medical problem.” (Bruner, 1987). Following in the steps of this tradition are writers such as Oliver Sacks, who was deeply influenced by Luria’s desire to understand the lives of those affected by neurologic conditions from “the inside.”

Thus, borrowing from Sack’s preface to *An Anthropologist on Mars* (1995) the seven narratives that follow are presented as “seven narratives of nature – and the human spirit – as these have collided in unexpected ways. (...) they are ‘cases’ in the traditional medical sense – but equally they are unique individuals, each of whom inhabits (and in a sense has created) a world of his own” (p. xviii).

**How Were The Stories Sequenced?**

Bearing in mind the narrative types illustrated by Frank (1995), the seven stories that follow were organized in a continuum from tales of restitution to tales of quest and transformation. Thus, in chapters one and two, Vicki and Larry describe their efforts to return to the status quo and resume their prior level of function after the onset of their strokes. Chapters three and four illustrate the journeys of Bob and Edie and the profound transformations they experienced within the fabric of their family lives and their very selves, as they grappled with the consequences of their strokes. In addition, Bob and Edie’s stories investigate how perceptions of survivors and family members may be widely opposed, and how that may affect the way in which the self is reformulated. Chapter five illustrates Tom’s story and how he discovered new facets of himself as
confronted by his disability and love. Finally, chapters six and seven portray the stories of Curt and Barbara Newborn, as they look into the past, make their peace and move along with the journeys of their lives.
Chapter 4.  God’s Little Joke

Ladies room of the Hyatt hotel during the Speaking out! Convention, 2004.

With my hands dripping and looking for paper towels, I see Vicki coming into the restroom. Without a second thought, I run to her.

“Excuse me, you don’t know me, but I know you!”

“I’m sorry?” she startles, between puzzled and worried.

“I’m a student at USF in the Communication Disorders Department,” I explain, “and I saw you on a videotape in one of our classes! You were in one of the aphasia groups.”

“Oh, yeah! With Cheryl Paul!” she laughs, as the pieces of the puzzle slowly fit together.

“I watched you talk about living with aphasia, and I never forgot it. You really made an impression on me!” In between the hustle and bustle of the conference, I quickly explain that I was starting my thesis project and would love to interview her. Helpful as always, Vicki smiles and agrees to see me. “Call me anytime, hon! Here’s my phone number” She left-handedly writes it, quickly and neatly.

“Thanks! I sure will!”

***

Sometime later in July.

Without knowing exactly what to say, I dial Vicki’s number and wait for the tone.
“Hello, Vicki?”

“Who’s this?” she asks, in an attempt to match the voice with the face.

“This is Lini from USF. We met at Speaking Out!…”

“Oh! Hi hon! This is my cell phone. Call me at home. Here’s the number.”

I find her quick and straightforward talk amusing and endearing. Even though we barely know each other, I feel comfortable around her. We talk briefly over the phone and agree to meet at the Panera for a cup of coffee.

***

Looking over every booth and every table, my eyes search for Vicki, but I can’t find her. “Could she be late?” I wonder, my eyes traveling searchingly to the pastry section. “Maybe I’ll have a muffin and a cup of coffee in the meantime.” I let my eyes and nose guide me towards the register and place my order. As I start walking toward a table, muffin, coffee and all, Vicki finds me. “Hey! So that’s where you are!” She had spotted me from her table, where she had been sitting the whole time with a friend. The table was slightly hidden behind a plant, where my eyes and my height didn’t allow me to see. We look for a separate table for the interview. As I set my gadgets she asks:

“Is this your cell phone?”

“No, this is my recorder! Would you mind if I taped our conversation?”

“No, not at all!” she replies. Without further notice, she goes straight to the heart of the matter: “I never thought it was going to get me down; I was too pissed off!”

I smile again. Why beat around the bush when we can get straight to the punch line?
Vicki Gray, a 56-year-old female, was seen on -/-/200- at the Communication Disorders Clinic for a communication evaluation. Ms. Gray reported she has suffered two strokes. The first stroke was mild and never diagnosed until she had her second stroke. She recognized a loss of smell and taste, but doctors consistently attributed her symptoms to sinus problems or allergies. On -/-/200-, Ms. Gray suffered a second stroke diagnosed as a left posterior parietal cerebral vascular accident (CVA).

Sitting across the table, Vicki’s two tiny, pitch black eyes look inquisitively at me through her delicate spectacles. I notice she has a large cast on her arm. She explains:
“It happened on Sunday night, and I don’t know how I did it. On Monday afternoon, I hiked myself up to my regular doctor and said, ‘I want you to look at my arm’. The nurse said, ‘Oh my god!’ I saw the doctor and I said, ‘Can you lance it?’ If they lance it… because of the Coumadin levels they won’t because they were afraid I would bleed to death…”

A friend of hers comes by, and she excuses herself to say hello. As she turns her back, I notice the large bruise, on her elbow. I imagine it must be painful, and shiver at the image of a bleeding death. Vicki, however, talks about her arm, her life, and her stroke matter-of-factly. “I wouldn’t want to stroke out again, so I take my Coumadin, and I go get my blood levels checked. I go every 10 days, sometimes I have to go every 14 days, sometimes I get to go once a month. I take my pills like I’m gonna have another stroke. And I don’t want one.” Matter-of fact, down-to-earth, and strong as a bull.

Figure 3. Vicki’s calendar, one month after her stroke (May, 2001).
Testing Behavior

Ms. Gray arrived early to the evaluation, and entered the testing room with no sign of apprehension. She was friendly with the examiners and responded to the testing situation with a sense of humor. She cooperated with all tasks presented by the clinicians; however, Ms. Gray appeared to be experiencing stress during the evaluation. Her posture was sometimes inadequate for proper breath support. [I have asthma!] She demonstrated significant attention to detail (e.g. interrupting in conversation, brushing her hair during the evaluation). Ms. Gray reported “I don’t know what I would do if I didn’t go to speech therapy”. This suggested anxiety about changing her routine and transitioning out of therapy. All of the tasks completed by Ms. Gray went smoothly and quickly. She often questioned the examiners about her performance on tasks, asking questions such as “So, did I flunk?” Overall, Ms. Gray attempted all tasks, and generally did not appear to be frustrated by them. Adequate samples of her speech, language, voice, and fluency were obtained for a reliable assessment.

***

“When did you realize what had happened to you?”

“I don’t know… At the hospital, I guess… I didn’t know I was having a stroke! I was 54! Come on! I have 1500 books in my house and I had a stroke! It was God’s little joke on Vicki!”

Therapy Marathon

I worked on it.

Day and night.
Probably 12, 15 hours a day.

Because I couldn’t do anything. I went to speech therapy every morning. I couldn’t do anything except work on speech, so that’s what I did. I would take naps, and I’d go back... and my speech therapist in the hospital gave me Xeroxed copies, and I worked on it.

Day and night.

I saved, I saved it all! This is all the stuff I saved, from speech therapy. I started out with these things. I couldn’t say, I couldn’t write my name... I couldn’t do anything. And these are all.... from the beginning. As I got better... I got... bigger words.

Every day! She gave me all these things, and I would say them all day long! And as I got better and better I could put these away!

This is my... these were my... these were my Post-it notes! All over the house! My friend came and she was here for a week, and she wrote everything down, so they were all over the house! There’s a refrigerator, a light switch, and cleaning products, and sponges... we had post-it notes, she put post-it notes all over, so I could get these words out... and I couldn’t say these things... and then when I got better, I finished the post-it notes. I did it from 5/31/2001 to 8/16/2001, and then I didn’t use them anymore!

I couldn’t say ABC, I couldn’t say 1-10! I couldn’t... It was unbelievable!
I couldn’t… I couldn’t say, I couldn’t write my address… I could screw up the zip code.

Camera, camera, camera, camera… write, write, write, repeat.

I couldn’t say… look… my address! In the beginning… I always screwed those up [zip code].

Over, and over, and over…

And I still do, I’ll reverse… I had to learn how to write my name, and my address, and then when I got to “Tampa, Florida” I would always screw up …

Here is more, and more… oh, and my telephone, my SSN… because I would screw that up too! I had to learn how to write my name, and my address… Several times! I couldn’t get it, because always 336… 33…467… something like that… that… here it was… 33447… 33744… 37474… whatever…

I couldn’t say the word “stroke”… I couldn’t say… that I had a stroke! And I had to learn how to say “stroke”! Because I would say “what happened to me.” It was a “strake.” Strake? And then it was “stoke.” I couldn’t… And I said… write it down, so I can get that out when I tell somebody that I had a stroke!

I couldn’t do my months… I couldn’t do the days of the week… I couldn’t say happy birthday…
Two months with my speech therapist... I went everyday, for 2 months... and then he came to... she came to my house for 2 months, and then... for 2 more months it was 3x a week, and then... and then I went into speech therapy at the clinic.

Phone, phone, phone, phone... I worked on it till I could get it... till I could write it! Phone, apparently, was really hard for me!

Lots of repetition! Spoon, lamp, book... everyday stuff! Everyday stuff that I couldn’t do... amazing, huh?

***

I take a sip of coffee and try to convince myself that the strong-willed and talkative woman, sitting across the table from me, was once devoid of words.

“I was by myself,” she continues. “I didn’t have a spouse who could speak for me, I had to get better! My life was go back to California, because the neurologist said that, you know, I was never going to say another word. ” I wondered why she dreaded the transition to California so intensely. She replies, as if reading my mind.

“My lot in life was go back to California and have my daughter speak for me.” She has a daughter? I’m surprised! Was she ever married? Questions rattle through my brain. Vicki continues.

“That was a fate worst than death. She didn’t need me, a burden, and… because I’m so … de… independent… I had… I couldn’t… I had to do it, I had to do it. Otherwise, I would just… slit my wrists…”

I tried to picture Vicki’s daughter, her age, what she was like, what mother and daughter were like together. I wondered how old she was. Maybe Vicki was a
grandmother? I could not tell. She did not volunteer much more information about her family on the first interview. I didn’t ask.

My mind drifts to the images she evokes, always so poignant, so strong. Would she really kill herself if she could no longer speak... if she became dependent on someone else? I wonder... Are doctors aware of what may go through the mind of a patient with aphasia when they deliver their cold and shattering prognoses at bedside? Maybe in medical school residents learn to be detached and distant to manage the possible shock and sadness of losing a patient they cared for. For so many survivors, as for Vicki, the initial prognosis seems like an indelible scar, which resurfaces every time the stroke experience is relived through narrative. Some survivors exhibit the scar proudly, others with resentment, but seldom with indifference.

Vicki mentions that despite her discouraging initial prognosis, there was one speech therapist who did not give up on her. “Her only regret was she never recorded me, as I got better, you know? From the beginning to the end!”

*I Love You and I Hate You*

I would see Sharon, my speech therapist. There were times when... There was one time when I was just... I was so frustrated that I grabbed her little cheeks and I said “You’re such a bitch”, and she said, “Nobody has ever told me that I’m that in my whole life!” It was so hard! And it was so frustrating... The only things I could say were the words... curse words!
Oh, God, I hated this so much! And I loved it so much... I was so conflicted, because it was ughhhh!! I hated it! But I loved her, you know?

Sharon, my speech therapist. She helped me with my... balance checking account, because somebody would have to help me do that for 2 months... now I do my checkbook... I never use a pen... anymore.

It was overwhelming.

My other clinicians? I love them! I loved them!! I wanted to glean... I... I just wanted to take... and... and get everything back you know!! I loved them!

One of them, the first one was the... It was the black chick... What was her name? I loved her!! And she loved me! I asked her, every... I made her... Xerox everything... I wanted everything... The other... the... the... the... second one was... a little blonde who was so... shy... that she had no idea... how to relate to me... But then we became friends, and she sent me all the... the stuff in the internet with... with... the crossword puzzles, and math, and all that kind of stuff... and I loved her... and then the last semester there were two of them... and hmm... and they just ....cranked... ganged up on me! And it was great!! And Cheryl Paul would, you know, she sits in that little room [observation room], and if I would say something, she would respond! I always knew that she was there.
I was... so... so bent on... getting better that... there was... there was no stopping me... you know? And... and at some point, you know, there... I had to stop because... they couldn’t help me anymore... I was done, you know? But I would have continued doing it, as long as it took, to get my speech back...

Figure 4. Vicki’s calendar, two months after her stroke (June, 2001).

Dear Ms. Gray,

It was a pleasure meeting with you on ?/?/200?. Your primary concerns included whether to continue communication therapy and maintaining your communication skills. In order to assess your abilities, several test[s] and measures were administered. A summary of our findings and recommendations is reported below.
A battery of tests was administered to determine your strengths and areas of concern. (...) An evaluation of your oral structures and functions revealed that they were appropriate for speech production. An informal assessment of your voice revealed hoarseness and inadequate breath support, related to posture and vocal behaviors. Pragmatic language usage during the evaluation revealed frequent interruptions and occasional difficulty with word choice during conversational speech. When presented with functional mathematical problems, your strengths included calculating tips and percentage-off sales. Your critical thinking skills were also assessed. Results indicated that your critical skills were appropriate for daily living. Assessment of your receptive, and expressive language skills revealed strengths in following simple directions and everyday commands. You demonstrated adequate reading skills by correctly identifying a medication and how often it should be taken. Overall, you appeared to use language effectively for everyday living situations. Still, you expressed some anxiety regarding transitioning out of therapy.

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“I got riffed”

“Riffed? What’s that?”

“Reduction in force.” She laughs, with some sarcasm. “I was kicked out. I was riffed from my job after thirty-four years. And I got riffed from speech therapy.”

I look at her somewhat confused, not really knowing how to interpret her. She continues,

“I would like you to see my final evaluation, because it pissed me off so bad… It was very clinical, you know? ‘She brushed her hair all the time…’ Oh my God! Who
cares how many times I brush my hair? It was…” She sighs. “I never showed it to anybody, because it upset me so much…”

“What do you mean when you say ‘so clinical’? What was so upsetting about it?” I ask, feeling defensive and worrying that somehow, in my diagnostics practicum, I may have offended my clients or their families, and not even known!

“It was so black and white,” she explains, “like I was a case study. There was no… room… How much you… you’ve changed, and how much you’ve improved! It was so clinical that I read it and I put it away… I never… I showed it to my friend, the one who took me to the hospital. I showed it to my speech therapist, Sharon, and she said… She said that would piss her off too… She said, ‘Don’t worry about it because you know who you are.’ But it was one of those things that… It just… It takes your breath away, that it was so cut and dry. I didn’t want a pat on the back… but… I worked for 3 semesters, and 4 months… That’s how I felt about it…”

She pauses for a brief moment and then adds, “When you read it, you might not feel the same way I felt about it. But I thought… It was to the point that… I didn’t want to help anybody for a couple of months. I was just pissed off. How can this be so clinical that you don’t have any room for… To make… to tell somebody that…”

I notice she was really indignant. “I’d like to… I want you to read it… because it’s one of those things that if you’re going to go into speech therapy you have to give the people who are improving on a daily basis, the, the, the… motivation to … to get better! I don’t know how many people go through that. They get so much better that… they get dismissed.”

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Vicki’s reactions to the report caught me off guard. I was surprised to notice I felt defensive. I had just finished the clinical practicum she was describing (DX II: diagnostic evaluations), and I started listing in my head all the reasons why our reports were so clinical: insurance companies, accountability, reimbursement, treatment coverage. I had always been taught that reports had to be objective. That was the space for facts, not emotions. After listening to Vicki, however, all my excuses paled.

Several months later that I came across a beautiful defense of Vicki’s cause in an article by Simmons-Mackie (1998). While discussing the issue of “plateau” and discharge in speech therapy, Simmons-Mackie comments

“Issues related to adjustment to aphasia, social participation and psychosocial well-being have been relegated to a grey area on the fringe of aphasia management; an area in which counseling and education were considered the treatments of choice. Perhaps the term ‘psychosocial’ has provided an excuse for neglecting responsibility.” (p. 233).

Neglecting responsibility. As I read those words, the full meaning of Vicki’s comments hit me straight in the face, as an awakening punch. Who are we treating, as professionals? Or rather, what are we treating? In our current impairment-based model of rehabilitation, we have long lost sight of the “person the disease has,” as quoted from Sacks (1995), and have focused on the impairment that consumes them instead. Reminding us that communication is a “social and emotional endeavor,” Simmons-Mackie continues,

“Perhaps discharge is viewed with distaste by some clients because we have not overtly addressed a major aspect of their communication. We
assume that, if information exchange improves, then social interaction will improve. This constitutes a narrow view of the interactive process of communication, which requires opportunities, discourse management strategies, confidence, collaboration and face-saving expertise in addition to raw linguistic skill.” (p. 234)

The problem, however, seems to have deeper roots. The philosophy underlying traditional therapy approaches assumes an asymmetrical relationship between client and clinician (Hinckley, in press). Clinicians stimulate, clients respond, clinicians provide feedback. From our all-knowing positions, our professional authority is reinforced. We know what clients need and clients comply. The situation is ironic, however, in most settings, as several clinicians are much younger than most clients. Accepting the possibility they might know their needs better than we do requires a leap of faith, a willingness to approach therapy as a road to discovery not only for the client but for the clinicians themselves, as competencies and strengths of individual clients unfold. As mentioned by Hinckley (unpublished), taking such a leap of faith requires a paradigm shift, in which clients become the experts. Are we ready, however, to take that leap?

***

As I returned home from my last interview with Vicki, a deep feeling of disappointment in myself invaded me. With a sigh, I listened back to my recording and went over the high points of the interview in my head. There were so many doors Vicki directed me to, but did not let me open just yet. I wondered about her growing up, her family, and the topics of the 1500 books she said she has in her house. I waited until I had
my first transcription done and contacted her again, hoping for a second interview. This time, we met at her house.

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The directions lead me to a quiet neighborhood and a house close to the pool. A petite but charming tree was at the entrance, with wind chimes and bird feeders. I knock at the door and Vicki greets me. “C’mon in, hon. Where do you wanna talk? Kitchen OK?” Falon, Vicki’s dog (a large and loving black poodle) was protective at first. After a couple of sniffs, we became good pals. I leave my camera, tripod, and recorder on the kitchen table, and my curious eyes start to wander. I notice the art on her walls, the glass sculptures, and the several bookshelves, replete with thick books.

“You like Miró!” I comment, looking at the dining room walls.

“Yes, I do!” She responds. “And Kandinsky… And I love glass…” she adds, noticing my looking at the glass sculptures.

I smile and say “I can tell! They’re beautiful!”

She shows me one of the paintings in the living room, “And this is ah… original… I can’t remember the… but it’s all… it’s… nursery rooms… nursery, nursery rhymes…” I look at it closely. It’s an intricate painting, in black and white. It reminds me of primitivist paintings and tales of folklore. “I tried to figure out all of the stories” She continues. “This is the… this is like Diane in Wonderland…This is the… There was an old woman, who lived in a shoe… this here is the children… this is the three pigs… and this is Jonah and the whale.”

Turning to the other paintings on the wall, Vicki continues,
“This is Kandinsky. And this is also Kandinsky.” She looks at a curious painting in blue overtones. “This is called ‘The village’ and if you look close enough you will see 8 faces and bodies. There is a whole village up the stairs… and there is a body here… and there is a body over here…”

I look at the bodies who suddenly transform themselves into buildings and ask “Were you always interested in art?”

“Yeah… well, my… second cousin was… Jackson Pollock… the painter… and my brother is a literature professor.” As we settle ourselves in the kitchen, Vicki allows me to approach and open some old family doors.

**Social**

*Ms. Gray stated that she enjoys spending time with her friends and that she likes to stay busy. She stated that she has a multitude of friends who are very helpful in supporting her through her stroke by taking turns reminding her to take medications. She reported that she used to enjoy reading, but she “gets bored too easily” now. Ms. Gray explained that a typical day for her includes getting up, taking the dog out four times a day, working on vocabulary and math, watching T.V., and going to dinner or another social event with friends and/or family.*
What Do You Wanna Know About Me?

Originally? California. Southern California. Upland... it’s about 35 miles... east of Los Angeles, and then I ended up in Thousand Oaks, which is about 35 miles north of Los Angeles, between hmm... Los Angeles and Santa Barbara, and then... I came to Tampa in... 96... I lived in California for 50 years and then I moved to Tampa. So I’ve been here 8 years. But I moved... I have... I moved 11 times. Total 11 times.

I’m a Jewish Mexican. My mother was Mexican. My father was a Jew, so... I’m a Jewish Mexican. They met at Berkeley, they were going
to school. They knew each other for 4 weeks before they got married, and they were married for 52 years. Well, it was in the... It was in the 40’s, you know, or in the 30’s, I don’t know when it was, because I was born in 46.

My father was a nursery man. My father was a farmer. Probably my father was... my father was a botanist... A botanist. He had a lot of money and then lost a lot. He lost everything... with bad investments. They never tried it again. My mother went back to work when she was 70... 56 years old. She was a... librarian. I think she went to school to be a... an English teacher.

I don’t know anything about my Mom and Dad. That was the generation that kept everything... secret. They kept all their secrets... My mother never told me all her things that bothered her with her husband, or... they... they... they just didn’t share... So we really didn’t know our parents very... well, but... you know, I know that I was loved, that I was... I was the apple of their eye. We’re all dysfunctional. It’s just a matter of degree...

Brothers. I have two brothers. I’m the little girl, little sister. I have a brother who’s a professor of literature, and he was dyslexic, and he couldn’t read or spell. And he went through... not speech therapy, but a tutor. And my other brother must be 62 now, but we really don’t talk. When my mother passed away he was horrible to me,
and I... I just, I haven’t talked to him. I haven’t seen him since 1992, and I’ve only talked to him half a dozen times in 15 years. He doesn’t know that I even had a stroke... ever called... As far as I’m concerned, he’s a sociopath. He never... he doesn’t have any regard for anybody else. He’s... he’s... only interested in... his... life... and ... he’ll take your life with you... with emotion if he had to... I just, I don’t need it, I don’t need it in my life... I don’t need, I don’t need it in my life... I don’t need to be hurt again.

_Growing Up_

Everybody in the house was... literate.

Artists... we had artists... I told you that...

Jackson Pollack is my cousin.

That’s how I grew up. It probably molded me. Everybody is real literary! I grew up with nothing but books. My parents had artists for friends.

There’s a picture of my mother that one of her, an artist friend, charcoaled her... her face... and that’s the only picture I have of my mother.

Everybody that I grew up with, my mom and dad’s friends, they were people that ... It was the... during the time of... Communism. My
uncle went underground because he is a communist, he was a communist. It’s an amazing story…

It… shapes you as you grow up to be the kind of person that you are, and the things that you believe in. I never wavered from the kind of person that I am… I never wavered…

My father was Jewish, and my mother was a Catholic until her mother died when she was 14. But we grew up with everybody in the family is Jewish, and everybody, all the friends were Jewish, so we… we… celebrated Hanukkah and Christmas, and because there was no… really… religious… up… upbringing… I don’t go to church… I am more Jewish than I am Christian.

I’m Jewish, everybody was Jewish. In the 40’s and the 50’s it was whatever it is still is, but, hidden. People … they’re such hypocrites and people are so mean, and there’s so much hatred in the world… We were… we were sheltered from that.

I had never heard the n-word. It’s not a word that I use… it’s such a horrible word that I’ll stop anybody from using it because it’s so… latent with hate…

I take everybody as they… as they are… I don’t say anything about the Indians, I don’t say anything about the blacks, I don’t say anything about Jews, because I am… and Jackson Pollock was my dad’s cousin, second cousin.
I wonder if I should ask her. The amorphous image of her daughter lingers in my memory. I see pictures of children in her kitchen. Could they be her grandchildren?

“Yes, they’re my grandchildren.” She answers, after I realize that I have actually asked her what I thought was just my own internal dialogue.

“Can I ask you more about your daughter?” I attempt.

She looks at me for a while. “Sure hon. What do you wanna know?”

“I don’t know… tell me about her.”

***

_A fate worse than death_

She’s thirty eight years old, and she has two kids.

She does everything right, and I do everything wrong

I guess...

But we’re OK...

It’s just bizarre...

She’s a stay-at-home mom...

Whatever she has to do to get through life

Is fine

You have to let go

Cut those apron strings at some point
And let them go on

To be whatever they’re going to be...

You have to do that

Otherwise

They cling... and I’m not a clingy person!

So you just have to let them go.

That’s, that’s... the grand-scheme of things in life:

Just letting people go.

I have two grandchildren. They’re wonderful!

But I don’t get to see them. They’re in California.

I talk to my daughter 3x a week

But I haven’t seen...

My little grandson is going to be 2, and I’ve only seen him twice.

My granddaughter is 4 and I’ve seen her 5 times in my life.

It’s hard to get there...

My daughter is...

I love her to death, but...

She’s a control freak!

She controls everything!

She controls drinks of milk that I give to them.
It’s hard...

My parents weren’t like that... My daughter got to do Everything!

She went to the beach every week, and she got to...

Enjoy...

She enjoyed herself. And now it is...

She controls... everything... with her kids...

Controls every...

It’s very hard... it’s hard for me.

She’s very religious, and I’m not... and was not...

To me...well... now she’s very religious

Everything is about Jesus.

The kids are going to Christian schools...

Sometimes you can be a zealot

She is a real zealot with religion.

And I’m not...

And it bothers her

That I’m not
I don’t follow the Lord’s path.

When you’re dead, you’re dead!
You’re done!
They don’t talk to you anymore!
You’re done!!
Whether you’re 15 years old
If you’re 7 months old, or if you’re 55 years old!
You’re dead!!!

Something is going to get you...
Whether it’s this elbow
Or it’s your heart
Or it’s your lower back
Or it’s a shoulder

Something is going to get you
As you get older you just
You just know that these things are going to happen
But it isn’t because I got a direct line to Jesus Christ...
I just want it fast...
I don’t want to have another stroke
I would like to lie, die in my sleep
But that’s what everybody wants!

Let me be who I am!
Don’t try to...
You can’t...

But they’re...
What they...
They’re supposed to spread the word....
They’re supposed to tell everybody about Jesus Christ

Don’t do it to me!
I’m your mother!
Let me be whoever I am

You do whatever you have to do to get through your life
And there’s nothing I can do about it
Except deal with it.
Whatever way I can deal with it...
Just be who you are!

But let me be who I am!

***

“Do you ever feel afraid?”

“Sometimes.” She stops and thinks for a while. “If I get a real bad headache, I always think that I’m going to get another… that I’m going to stroke out again… and then I just start talking more. Because… Oh God! That I would lose that… I mean… What a loss! It was such a loss… for so long… And… you just… take it… Completely different path… When something like that happens to you, because you can’t equate it… Nobody knows what you went through. It’s like a death. It is a death. It’s a death and a re… a rebirth. And it just makes you a stronger person. A better person.”

“Is it like a scar, that won’t go away?”

She pauses. “I don’t think it is a scar. I think it as just another… Something I had to deal with. You know?”

I nod. “When you say it was life changing… Do you feel you’re the same person you were before?”

“I think… If somebody pulls into you while you’re driving, I just let them in. It’s one of those things… If you want in that bad, get in… If you have a red light, run it… you know? I’ll always stop… Because people are in such a hurry, always… They’re so impatient, and they honk their horns, and they bitch at people. Why? You don’t even have a clue what’s gonna happen to you tomorrow! You know? And for me, I had
another tomorrow. I had a tomorrow. A lot of people didn’t think I was gonna have a
tomorrow. I didn’t know that… that it was so… life threatening for me.”

***

*Based on the results of testing, the diagnostic team recommended that you continue therapy to address pragmatic language and vocal behaviors. Additionally we recommended that you consider counseling options including vocational rehabilitation or other community re-entry assistance.*

***

![Vicki’s calendar four months after her stroke (August, 2001).](image)

Figure 6.

*Who am I?*

*I’m Vicki!*
I’m the same person I’ve always been!
I’ve never changed!
I’ve never changed my philosophy, the way I react to people.
It was just another journey
You get curves in the road
That was a curve in the road, you know?
I always thought I was a pretty good person anyway
And I think I still am.

Why I read? Because I want to know EVERYTHING.
I want to know A LOT about EVERYTHING.
I have 1500 books in my house and I couldn’t read!
It was God’s little joke on Vicki!

I started reading again. Two weeks ago.
I started back with the mysteries I love.
But I didn’t read for 3 years
Because I was so pissed off.

When I stroked out
And I knew I couldn’t read
I still went to Barnes and Noble
And bought books. I always have new books

It makes me who I am.

I can study people.
I know exactly what kind of person they are
Maybe 6 months later
They turn out exactly how I told they were gonna turn out.

I don’t give advice.
I wouldn’t say what you need to...
What you’re supposed to...
People don’t wanna hear that!
And who am I to...! Judgment!

If they asked me, I say
“This is what I would do... If it was me.”

I have too much stuff that I want to read now.
And write!
Write a book with my brother
Or be a motivational speaker
You just have to give back!

It might just be my journey, you know?
But I had fun!
I had a good run!

When I die
Don’t grieve.
Have a party
On my behalf.
I really like my life!

***

“What do you think of yourself, how do you see yourself!”

“How do I see myself? I don’t know… I think I’m pretty cool!”

“What makes you tick?”

“What makes me tick? I don’t know what makes me tick. I just know I’m still ticking!” She laughs, with pleasure.
March 18 2005.

I knock on Vicki’s door and Fallon immediately announces my arrival. Vicki and I do some small talk, and she mentions she could not read the transcriptions of the conversations from our previous meetings. “I just hated all the ‘hmms’ and ‘ahs’… I was pissed off… So I didn’t even finish reading it. It just brought all the aphasia back. I thought I was over it.” Upset with myself for not being sensitive enough to edit the hesitations beforehand, I apologize to Vicki. She asks me not to record this meeting, and silently I promise myself never to do the same careless mistake again.

I tell her I had finished writing her story, based on our interviews, and she agrees to have me read it to her. I was pleased and exhilarated when I noticed that, throughout
the reading, she nodded in agreement, and at times, finished my sentences! “It’s good that I always tell my story the same way, isn’t it?” She comments, laughing “at least that way people know I’m not lying!” When the reading was over, Vicki exclaimed “You have to show this story to my speech therapist! She’ll get a kick out of it!” She goes to her kitchen and writes down her therapist’s phone number. I feel happy and relieved she forgave me, and I can see that she had liked the final narrative.

I pack up my things and we go outside. Fallon is excited, playing catch with her ball. “Can I hug you?” I ask Vicki. She looks at me and smiles, “Sure hon! Come here!” As Fallon returns with a battered tennis ball in between her jaws, I pet her and say goodbye to Vicki.

Figure 8. Vicki’s calendar six months after her stroke (October, 2001)
Chapter 5.  Diamonds are a Girl’s Best Friend

Through the Looking Glass

First semester of graduate school, summer 2003.

Amid the usual hustle and bustle of clients and clinicians in the speech clinic, I thumb through the old schedule binder in search for an adult treatment session to observe. I scribble down a few room numbers and check my watch from the corner of my eye. The timing is tight, but with some luck I will be able to find an empty seat in one of the observation booths.

I try the first doorknob and take a peek inside: empty. Relieved, I enter the small room, put on a set of earphones, and open the mini-blinds into the session.

Through the one-way mirror, I see a grey-haired gentleman working intently on a spelling task with a young clinician. His voice is paused and deliberate, marked by a soft but steady cadence. From time to time, I notice his semblance wrinkle in frustration as the quickness of his mind stumbles on the deliberateness of his speech. However, the lines in his forehead are usually relieved by his sharp and refined sense of humor, which opens the gate to a broad and truthful smile.

A few minutes later, the door squeaks softly as the clinical supervisor comes into the booth to take her notes. I pass her a set of earphones, and we both watch the remainder of the session quietly. As it draws to an end, I break the silence and ask her about the history of the client. She smiles and replies,
“Larry? He is our jeweler. He just passed his gemology recertification exam a few days ago. It was a great achievement, we were all ecstatic!”

I take one more glance through the looking glass. I feel the desire to enter the room and congratulate Larry for his achievement, but I stop myself. The one-way mirror had allowed me a glimpse into a world to which I did not yet belong, and all the information I had learned was to remain confidential. For all intent and purpose, I had never been there.

The following year I would frequently run into Larry in the elevators and hallways of the department, and I would wonder how he was doing. It was not until I became a student clinician, however, that we were formally introduced. We never worked together in individual therapy, but I would always see him during groups. As he was quite advanced, he frequently worked as a mentor, guiding other participants who needed more assistance.

At the end of the spring semester of 2004, as we were finishing our reports and completing our assignments, Larry found out he was graduating from therapy. The formal announcement was made on our last group session, and everyone demanded a speech. It was a very emotional moment for all of us. I tried my hardest not to cry, as I had promised myself I would be professional while saying my goodbyes. I saved face with some grace with all other members of the group, but my mask fell as I hugged Larry and his wife Susan, tears rolling down my cheeks. What was it, in the eyes of this experienced jeweler that disarmed my carefully constructed shield?

***

Summer, 2004 – end of the first year of graduate school.
I dial Larry and Susan’s number and cross my fingers tightly, hoping catch them at home. After a few beeps, I hear Larry’s voice on the other end of the receiver, and we exchange our warm hellos. As we catch up on our recent news, I tell Larry I had started working on my thesis project and ask him if he would be interested in participating.

“Sure!” he obliges. I thank him profusely and I can hear him chuckling softly.

“You have directions?” he asks me after we schedule our first appointment.

“Don’t worry! I can probably figure it out.” I reply self-confidently.

“You sure?” Larry double checks, knowing I had not been driving for very long.


“Sure!”

New Driver on the Rainy Road

July 20th, 2004. Sure enough, on the date of our scheduled interview, Tampa was greeted by profuse and torrential summer storms. As the wipers dance frenetically on the windshield, I stretch my neck and search faithfully for the yellow line on the pavement to ensure I would not pay an unexpected visit to the lane on my right.

I find the correct exit off the interstate and drive around in circles before realizing that my good internet directions were not that good after all. Swallowing my pride, I reach for the cell phone.

“Hello?” Larry answers.

“Hi… It’s me… You were right, I guess I’ll need directions…”

Larry laughs warmly and guides me to the correct route. A few minutes later, I arrive safely at their door.
Larry’s Journal Entry.

Larry and Susan welcome me warmly to their home. As I place my recorder on the coffee table and take the informed consents out of my bag, I notice the traditional and harmonious decoration, which is nicely complemented by the soothing background music. Pictures of family members are carefully arranged on the walls and on a side table across the hall.

We all sit comfortably in the spacious living room and briefly catch up on news from school and the clinic. I ask Larry how he has been keeping up after his graduation from speech therapy. He laughs and says,

“Well… hmm… busy and not busy… Because… hmmm Susan … 3 or 4 times a week…”

“I work about 3 days a week, every morning…” Susan explains.

“So I have… I guess I… fortunate… I… seeing the news or, Fox channel… News worthy… Clean up the house, vacuum…” Larry continues and smiles gallantly.

“You’re a lucky lady! Don’t we all wish for such a devoted husband!” I say. With a smile, Susan adds,

“Well, there’s also your therapy homework!”
“Yes, therapy!” Larry nods. “Two or three days at school. Now, graduation, changing the pattern. But I have homework to do, repeated homework, so… I have hmm… interspersed therapies, news, golf… and… sports… Saturday, Sunday… I… stay busy… and exercise… periodically… treadmill garage… and golf… So it’s boring and… unboring…” he concludes.

“Actually,” Susan mentions, “Larry really wants to get a job. We’ve been working with the Easter Seals, and I think something is going to happen very soon! We have an appointment this afternoon…” Larry looks at her lovingly and nods in agreement.

“Really! That’s very exciting news!” I exclaim.

“Yes!” Susan continues. “They’ve been very positive, you know? He’s going to see what happens. It’s been a long process because of the doctors, and you have to have forms filled out, it goes on and on… but I think we’ve gone through that part now. We’re at another level.”

Larry listens quietly, acknowledging. After a while he intervenes,

“Hmmm job interview, I guess… Job Etcetera… Job Etcetera… Job Etcetera is sponsored by the state and federal government to get jobs for physically disabled… And I, three or four months, Job Etcetera, and … hmm… the … agency is now Easter Seals. So, I have two… one appointment and two appointments now… set.”

“Tell her about the interview you had!” Susan says.

“Well… I interviewed the… occupational therapists interviewed me to… hmm… because I hmm… was up and about… and knowledgeable, you know?… Five years of college, ten professional degrees, and active… So she said… I would like to… attempt
to… attempt to get you to… hmm… PT tech… here… because… hmm… an office… but… then… last week… the hmm… the job is unlisted because budget… So… but hmm the… advisors… indicated volunteer and then… budget… comes … two months… so, I don’t know, it’s… But… courier … bank courier is number one… or chauffer… chauffer disabled people… but… poor incomes…Volunteer, yes, but…”

Noticing the hesitation in Larry’s voice I comment, “Volunteering is very rewarding, but after a while I think you start to long for something else.”

“I guess it reaches a saturation point…” Susan nods.

Larry sighs and adds, “But anyway… Is invigorating because… I definitely job search…”

_The Mother of all Gems_

5/8/02 – WED.

_CLARITY MEANS A DIAMOND’S INTERNAL OR EXTERNAL BLEMISHES. ONE OUT OF FIVE THOUSAND DIAMONDS ARE FLAWLESS. THE REMAINDER OF THEM HAVE FLAWS. COLORLESS IS THE TOP RANGE ON THE DIAMOND SCALE. ONE OUT OF TEN THOUSAND DIAMONDS POSSESS THE COLORLESS QUALITY. THE REMAINDER OF THE DIAMONDS ARE VERY SLIGHTLY YELLOW TO TRAINED EYES, TO YELLOWISH TINT TO UNTRAINED EYES_

Larry’s Journal Entry.

I was… born West Virginia… My father died when I was five years old.
Pneumonia and flu... flu and pneumonia... Thirty-six my father died... Before... hmm... penicillin. My mother... inherited jewelry store... I guess my father owned it 29 to 36, and I was born December 1930. I have a sister, Peggy, four years older than I am. I looked more like dad, and Peggy more like mom.

Tell her what your mother did before all of this happened...

Mother was school teacher...

Hmm... She was a school teacher who became a jeweler... She was a woman's lib before the word ever existed!

Well... But... Mother's mother passed away when she was nine, and four of them, four of them... four siblings... hmm... Mother and sister youngest, and two brothers. So she was the female of the house. Nine years old!! So my mother is... hmm... hmm...
guess… hard work all her life… and
the third one died at the age of 13
because appendicitis… and hmm…
she was… always handling family, so
difficult all her life. Then father died…
hmm… I guess nine years of marriage
and then widow… I was five… Peggy
was nine…

Peggy was the same age your mother was
when she lost her mother… They were
both nine… I had never thought about it
until you just said that…

Yeah… So… so… I was a… a…
hmm… chaperone, and, hmm…
caregiver, so… my mother is all I have
ever had… She never remarried.

She had many opportunities, but she
never…

She said, ‘I love…’

She loved Larry’s dad…

‘…Larry’

His name was Larry
See, first five years, or six years, I was
Sonny… Sonny… and I guess my
father died in March, and then she
called me Larry…

***

5/10/02 - FRIDAY

THE CARAT WEIGHT IS ONE-FIFTH OF A GRAM. THE WEIGHT OF
THE GRADED DIAMOND IS STATED IN CARAT AND HUNDREDTHS
OF A CARAT. THE CUTTER IS COMPLETELY IN CHARGE OF
CUTTING THE DIAMOND. THERE ARE GUIDELINES FOR CUTTERS
TO FOLLOW. A PORTION OF THE CUTTING IS SACRIFICED FOR
SIZE; THEREFORE, SIZE AND BEAUTY ARE OFTEN LOST. CUTTING
IS THE MOST NEGLECTED OF THE 4 C’S BY MANY JEWELERS.

Larry’s journal entry.

During our aphasia group meetings at USF, we frequently had the opportunity to
go on outings. As I listened to Larry’s family history, memories from group started to
emerge. Trying to organize my thoughts into a coherent question I ask,

“Larry, remember when we went to that pottery place with the aphasia group?” I
ask.

“Yes!” he replies.

“I noticed that you decided to paint different styles of gems on your tile. You even
brought your stamps, remember?”

He laughs “Yes! Yes!”
“How did that passion start? How did you discover the world of jewelry?”

Larry smiles, thinks for a moment and then answers,

“I guess I remember hmm… Daddy… hmm… was… sick bed and then… I remembered… eight or nine years old, hmm … watch making, watch making… I had a watchmaker employee of my mother’s and I used to sit down, or stand up and watch… hmm… him work… So I said, ‘No way was I going to ruin my eyes…’ I said, ‘I don’t want to be a watchmaker.’ Daddy is a… hmm… elder in watch company… he was schooled… hmm in the 30… 30’s… no… 20’s! Schooled as engraver and watchmaker, so… I said, ‘No way I was going to be able to… repair watches…’ So I guess I gemologist…”

*From Bridges to Business and Counter Intelligence Core*

In the beginning, I wanted mechanical engineering… build bridges… But I… recanted junior year in high school and I started to… University of Cincinnati, Ohio accepted me… in the college of business administration… I have hmm… feelings about leaving Mamma alone at the store.

*You did a… co-op… Tell her… co-op…*

Co-op… hmm… first year… then…
hmm… ten months schooling… then
ten months… business… no… 10
months… no, no, no…

One semester…?

No… Hmm… ten weeks of…
employment and three… hmm three…
two… hmm… ten… hmm… ten…
and… weeks of school, and… for four
years, and I was employed by my
mother… So I have college job
experience! Twenty-one weeks of
school and hmm… Thirty months of
hmm… work.

There are very few schools in the US that
offer that kind of program, but the
University of Cincinnati is one of them.
It’s called the co-op program. You get a
balance between school and work
experience.

Hmm hmm

And after that…?

After that?
After that... Tell her about what you did in the Army. I’m very proud of you for that...

Hmm... I was privileged to become an ROTC graduate... November 30, no, November 15, I... hmm... 1953... I was... commissioned in the Army. So the fighting was all over, but I was a Korean War Veteran. But I fought the battle from Nashville.... [laughs] But hmm... anyway. I... bashful... hmm... 35 years... hmm... No, thirty years... No, twenty-five years... Bashful...

Hmm... Friend of mine’s shadow... [laughs], but later I... was in the CIC, the Counter Intelligence Core... So I had to... Blossom out. Two years after qualifying for CIC, I... Field agent, fourteen months. Army with civilian clothes. Everybody thought I was an FBI agent! But I was investigating top secret clearance for hmm... anybody who had a top secret clearance...
hmm… in the Washington area. So I
was the Super Duper Pooper Scooper
[Laughs].
Then I was… was engaged to a girl,
and I married… two years later.

Match Made in Heaven and Two Angels to Go with It

5/5/02 – SUNDAY

DIAMOND’S ARE A GIRLS BEST FRIEND.

FRIEND

IN 1840, THE DUKE OF BURGANY, AUSTRIA, PRESENTED HIS
LOVER A DIAMOND RING.

BECAUSE OF THIS, THE ENGAGEMENT RING BECAME SYMBOLIC.

Larry’s Journal Entry

With my full attention devoted to the story, and trying to anticipate the next turn
of the plot, I ask,

“So that’s when Susan entered your life?”

“No, actually I’m Larry’s second wife” Susan replies.

“Really?” I ask, surprised.

“Hmm hmm…” Larry answers. “First wife, Liz. Married seven years. We had two
girls, Amanda and Sarah. But when Liz have second baby… hmm… hmm…
hemorrhage… didn’t stop… and hmm… three hours later she died… she never saw…
baby. I, thirty-two… Liz thirty… I widowed.”
“You had to grow up fast, huh?” Susan says and smiles.

“Fast, yes!” Larry chuckles and softly holds Susan’s hands. After a pause he continues,

“Anyway, I suddenly became a man and housekeeper. Imagine myself supporting a baby, big responsibility! I… cared for them at home… In hospital… hmm… hmm… hmm… the baby was in the hospital a week, then I have a… I… recruited a… you know, caregiver… so… hmm… My sister… was a nurse… and she would… fortunately the… hospital and… the… caregiver, and… and… the… was… all three blocks from the nurse… oh, no… Anyway… she was… able to pick up the caregiver… then I… would have six o’clock arrival and hmm… then… hmm… caregiver… fixes dinner and then… the girls and I go… hmm… give her a ride home.”

Amazed by how they harmoniously weave their sentences together, I ask,

“So… How did Susan enter the story?”

They laugh and Larry answers,

“Blind date!”

“No kidding?”

“Hmm hmm…” Larry confirms, “I… was widowed, two and a half years… and hmm… my best buddy… hmm… golfing… and hmm… two days of golf. And hmm… friends… anyway, he said, 19th hole… you know…” he chuckles and continues,

“Friend said, ‘Larry, hmmm… Johnny’s girlfriend… has… has… a… girlfriend… and … I would like to… hmm… hmm… bring her… so you have a date…’ and so… hmm… I guess… six weeks occurred… and hmm… the hmm… Labor Day
weekend, I had a date two… for two days. Saturday night… and Sunday night… and… and Monday. And… we fell in love!

“Right away?” I ask.

“Right away!” Susan confirms. “It was love at first sight! And two little children to go with it!”

With a proud maternal smile, Susan adds, “They were… two… and… four… When we got married they were two and a half and five and a half. They are beautiful children! Just beautiful!! I’m so proud of them!”

The Making of a Jeweler

5/13/02 - MONDAY


Larry’s journal entry.

I have hmm… Fourteen months

Nashville, Tennessee corresponding

with Liz… So I… started to… to…

corresponding with… hmm…
diamonds, and... gemstones. With
the... Gemological Institute of America
– GIA. So I... am proud of that.
Then... Liz had died two and a half
years I... Set out to begin a certified...
Thesis... and I became... hmm...
Certified gemologist in... Three
years... With Susan... Then I,
advanced degree at... hmm... well...
1963... hmm... I became a certified
gem appraiser.

1983... they didn’t have the title until 82...
so it was 83.

Yeah... So I had three degrees... and
certified... hmm... so I... and after, in
63, we bought our... store two.

Hmm hmm... No... in 68...

68?

Hmm hmm... We weren’t married in 63...

Oh! Right... And hmm...

So you bought store two in 68, store 3 in
82.
And close them all...

And then we closed all three.

***

Several months later, when I return to Larry and Susan’s home to show them the first draft of the chapter, Susan describes the complex process of becoming a Certified Gem Appraiser in greater detail.

“First, you graduate from the Gemological Institute of America or GIA” Susan explains. “After that, you become a Registered Jeweler and finally a Certified Gemologist, both through the American Gem Society, or AGS. In Larry’s case, he graduated from the GIA and became a Registered Jeweler through the AGS when he was in the Army. Then, after Liz died, he became a Certified Gemologist. Years later, in 1983, the American Gem Society created another title level called the Certified Gemologist Appraiser, which is used for courtroom purposes. There are only about three hundred Certified Gemologist Appraisers in the United States and Canada, and Larry is one of them. The complication of that title is you can only use it if you are affiliated with a business that holds the AGS title. So nowadays, when Larry does an appraisal, he signs it the Gemological Institute of America. He has to go back in his level because he’s not currently affiliated with any stores. However, if he were to be in a courtroom, he would be there as a Certified Gemologist Appraiser. It is really complicated!”

Thinking back to the beginning of the chapter, I wonder which one of his several certifications Larry was renewing at the time. As if reading my mind, Susan continues,

“What you described in the beginning of the chapter was how Larry renewed his Certified Gemologist Appraiser Certification. He has to take that exam every year. It is a
really complex exam, and you need to have a lot of schooling behind you to answer even the first question. And Larry did it, aphasia and all!”

From Santa Claus to the Budweiser Bubble

“Larry, you must have so many interesting stories of proposals and engagement rings from when you had your stores…” I comment.

He nods.

“Can you tell me a couple?”

“Sure… I guess I sold an engagement ring to St. Claus once!” He smiles.

“Really?”

“Yes. He was a college age student but hmm… hmm… hmm… Santa Claus is outside the… counter line and I sold him an engagement ring!”

“Was he dressed like Santa Claus?” I confirm.

“Oh, yes, yes, yes!!”

“At the store?”

“Yes, yes! Santa Claus and beard… Yes, and so… Engagement ring. And then I… I… oh…. Hmm… the… couple gay people… sixties, seventies. Hmm… gay people, wedding rings… And then I hmm… professor in… two professors hmm… 60’s… no, 70’s… hmm… white female, black, black… hmm…”

“Male?” I ask.

“Hmm hmm…” Larry confirms.

With a mischievous look on her face, Susan suggest,

“Tell her about the Budweiser…”
Larry chortles as they exchange knowing glances.

“Ok... The mall store, the hmm... where hmm... two stores... College kid... working... the mall hmm... the hmm... robot... was... is... moving up and down the hall...”

“It was supposed to be Halloween...” Susan explains “So the kid was dressed as a robot”

“Oh!” I laugh, as I get the missing link.

“So... robot...” Larry continues, “Hmmm... Entered my store! And I was... hmm... hmm cameras... service desk... and I... was hmm... hmm... and I had a beer belly! So, he said... hmm... Robot, pointing...”

“The robot? Pointing to your belly!” I ask.

“Belly, yeah! He said ‘You have a Budweiser bubble!’ ”

We all explode into roaring laughter. After we catch our breath again, Susan comments,

“He lost weight after that! Never gained an ounce back!”

***

And then after we closed the three stores

what did you do?

Became a jeweler consultant for first

the … Gordon Brothers in Boston, and

seven years… Six years, seven years,

I was... Six years... And I be...
hmm… Boston… Was quitting jewelry business and then I affiliated with KWHS consultant. KWHS incorporated, then… Eight years, seven to eight years… And hmm, fourteen years anyway, working consultant.

Then what happened?

Then… I have… with the stroke, thirty-three months ago.

From ABCs to Journaling

“Do you remember anything from your stay at the hospital?” I ask Larry

“Yes,” he replies. “Asleep… woke up… mouth… didn’t function!”

“Hmm hmm…” Susan agrees. “I remember I was on my way to get you. All you could say was ‘I don’t know,’ ‘yes’ and ‘no.’”

“Hmm hmm…” Larry recollects, “Glasses… in… photograph… glasses… I… would… see… photograph… glasses… fork… in therapies… hmm… hmm… tape… re… Recorder… Cup… Relearn everything…”

“Everything…” says Susan, picking up the remainder of the sentence, “We had to start with ABC… the… 1, 2, 3, 4, 5… we had to start from the very beginning… how to write it, how to print it…”
“Everything!” continues Larry “Yeah… So anyway… I hmm… progressively… progressively… reading really, of course… but not totally. And hmm… So, I… hmm… hmm … hmm… well… study… grammar… the hmm… phonetically… and… hmm… spelling is… hmm… is… proving, improving… so… hmm… so I guess… hmm… spelling wise and hmm… or… communication… hmm… 75% of normal… so… slowly is… Proving…”

***

As my first visit draws to an end, we transition to the kitchen table, where Larry shows me his collection of notebooks and folders from his two years of speech therapy. I marvel at the neatness of his notes and at the volume of his materials.

“They made him work!!” Susan exclaims as she carries a number of folders. “Which is good, I mean, that’s what it’s all about! I went with him to therapy every time because they said he did better when I was there! So I stayed with him through every session, three times a week.

I browse through the notes and accompany the progression, organized chronologically, from monosyllabic words, to compound words, phrases, sentences, and paragraphs. One green notebook, however, catches my eye. It was Larry’s journal.

As I browse through it, I find this entry,

“10/25/02:
From the tenth floor to the third floor of the Sarsota Memorial Hospital

Dr. S’s domain! He would start his routine with a daily conversation to each of his patients, “What month is it? “What date is it?, and “how do
you feel today?” Every ten days their was an evaluation. Then the nurses and the therapists would sit down stare at you. Fortunately, the stroke did not leave me impaired permanently. The weakening of the right side of the body has responded. Matt, Danae, and Lucy, as well as others, helped me to commit to self improvement. Speaking was a matter of concern, one or two words were all I could say. Joyce, Sophia, and a student from USF, Lori. Speech therapy at least 14 times a week, for 45 minutes each session. In 22 days I could indentify an object with titles, and sentences. How good it was to get home after 28 days and sleep in my own bed? A week later, Leslie Smith came in to my life. She started were the 10 foor left off and had me 3 day a week, 45 minutes a day. Leslie had me about six weeks when see requested I have a notebook for a record. April 24, 2002 was the first entry and last entry was October 25, 2002. Thanks to Leslie, who motivated me toward self-betterment and perfection.” Noticing my interest, Larry explains, “My journal. I would like to… give it to you… read… I… treasure that!!” Honored with his trust, I ask him, “Are you sure? Can I borrow it until the next time I come back?” “Sure.” Larry replies. “Hmm… that’s… eternal… you know? And… hmm… see these… you have… knowledge of therapy…”
“He is so proud of his notebooks, because he’s worked so hard!!” Susan adds.

“I promise I will take care of it!” I reply, gently sliding the notebook into my book bag.

I thank them greatly and as I gather all my materials, ready to leave, Larry stands up and says,

“Wait a minute… wait a minute.”

Not sure exactly what he meant, I look at him between confused and worried. Had I taken more materials than I should?

“He doesn’t want you to leave in this rain” Susan comments, disentangling the question mark on my face.

I try to reassure Larry that I would be fine on the road, but his grey hair and firm smile offer me a gentle and protective resistance. He only allows me to leave their home after the storm was assuaged. I hug them both warmly, and wish Larry good luck on his interview. Only then I notice Larry had a large umbrella in hand.

Gentlemanly, Larry opens his large golf umbrella and escorts me to my car. Thanking him and Susan once more, I drive back home, dry and safe.

***

Fall semester, 2004. Due to fast pace of the semester, I am not able to see Larry and Susan again for several months. Later in November, as things started to calm down, we schedule our second interview.

Speaking with Susan on the phone, I notice her voice is tense and concerned. She mentions briefly that Larry had undergone surgery for cataracts, and I cross my fingers and toes, hoping everything went well.
Thankful for a bright sunny day, I find Larry’s and Susan’s house easily this time.

As we greet each other at the door, I notice something different about Larry

“See me with glasses before?” He asks, noticing my frown.

“Yes! That’s what’s different!” I exclaim. Looking a little closer, I notice that the left lens was missing.

“Hmm hmm… not missing” Larry clarifies.

“He’s had his cataracts removed!” says Susan

“Wow! And now you have 20/20 vision on that eye?” I ask.

“Hmm hmm!” Larry exclaims with a large smile. “20/20!”

Larry and Susan lead me to the living room. As we find our seats, Susan explains what had happened,

“We’ve been through an awful lot with his eyes for the past 30 some weeks… When they removed his cataract they found a film on his eye, under the cataract…”

“No… no…” Larry interjects.

“A scar…” Susan corrects, “So we had to go to the retinologist…. We had to wait 11 weeks, and go every week, and have his eye tested, and his vision came back, and then… we had to go to the retinologist because… hmm… he had a stroke in his eye, but we didn’t know that… so when he had his initial stroke… is when they think he may have had the stroke in his eye, but they couldn’t tell because of the cataract. So the eye can go either way with the vision, but his vision, the doctor this morning was really encouraging, his vision is just doing great, so…”

“20/20!!” Larry exclaims happily.
“Hmm hmm!!” Susan sighs, relieved. “This is one of the first times he’s ever worn glasses in 35 years!” she exclaims. “By the way, did we ever mention how Larry got fitted with his contacts?”

“No…” I answer.

“Oh, let me tell her that one, honey! It needs to go in her paper!”

***

Ok, this is his eye doctor from West Virginia, who flew down here to fit him with contacts... it’s a long story, but... he came down here to help Larry with his contacts after the stroke. That was emotional... and one of the doctors in Bradenton that the ophthalmologist told us to go to, let us use his office... We used the office for four hours to work on his contact lenses! He’s always worn a hard lens, bifocal, with the bifocal correction lens there, and nobody in Sarasota will touch it. So his doctor up North came down here and said, we’re gonna do this! And they did it! I mean... That’s how blessed we’ve been... with people and with friends! The ophthalmologist couldn’t believe the doctor from the North came down here to fix him with contacts, in an office in Bradenton!!

Blessings and the Telephone

“We have heard so many heartbreaking stories about disrupted friendships after a stroke, especially during our aphasia group meetings...” Susan comments. “Most friends leave because they don’t know how to handle the situation. That has not happened to us…”

I notice Larry’s eyes, surrounding Susan in a warm and loving gaze.
“Why do you think that is?” I ask Susan

“You know… I’m not sure… Maybe it’s because Larry is older, and his friends knew how to handle it because they’ve seen more of life. I don’t know… But since his stroke, in the 30 months, we’ve not missed a party, we’ve not missed a dinner, we’ve not missed any function. Our friends who are here and our friends who are away, far away, have remained very supportive. They call and check on him, and so many have come to see us! We, Larry and I have really been blessed with that aspect of it. We have constantly had this support system around us, young and old… So that’s been very healthy, wouldn’t you say?

“Yes,” says Larry

“See,” Susan continues, “In the very beginning he had twenty-eight men who left something on an answering machine asking, ‘What could they do?’ So our daughters and I organized the names, and instead of saying ‘Well, you can’t do anything…’ we had each of them call Larry! We had it set up so that everybody called him at different times, for about 30 seconds because he really could not speak. They called him in the hospital to tell a joke… They’d say ‘You’re OK, we’re thinking about you,’ and hang up. They programmed by when to call. So it made them feel like they were doing something to help him, even though he couldn’t, he could hear them but he couldn’t respond to them…”

Larry exclaims, visibly moved, “See… I, I, I … don’t… appreciative of the fact… I didn’t know what you do!”

“I know you didn’t know…” Susan acknowledges and reaches for Larry’s hand.

“But see, I told Leslie, our speech therapist, to tell other people that, because… the phone
kept ringing! There were so many, so many people called in the night, they told him a joke, and the neighbors brought him a Playboy magazine…”

Larry explodes in roaring laughter, and Susan and I join in.

“So, you know…” Susan continues, “That kept him on the phone from the beginning, so that the phone was not an intimidation as we moved on in time. One friend in South Carolina called every night, and one friend in Denver called every morning…”

“Bill is our best man” Larry adds.

“He’s the friend from South Carolina” says Susan.

“And then, suddenly, mother’s day, he’s had a stroke. So… now… our turn to play… We call him.” Larry completes.

“Yes, every other night now we call him” nods Susan.

“Does he have aphasia as well?” I ask.

“Hm hmm…” replies Susan, “He has Wernicke’s aphasia.”

“But hmm… he… he is… constant babble!” smiles Larry.

***

That's a blessing... it's just a blessing... one of the nurses for the ophthalmologist said, hmm, “He has an angel on his shoulder. He’s got angels all around him!” So, we’ve got a lot of blessings, and a lot of friends that have helped us get through this. Without the friends, I don’t know what we’d do... I really don’t...

A lot of things have happened that have been wonderful through the process of this nightmare... and it is sort of a nightmare, it’s a blur, when you’re going through it, you know? I look at the calendar and it is sort of a blur, of... doctor’s appointments, and, and... going here and doing this, but it is OK, we’ve gotten through it...
Several months later, while reading Boazman’s account of her life inside aphasia (Boazman, 1999), I cannot help but admire Susan’s insight into the turmoil experienced by most individuals with aphasia when confronted with the task of using the telephone. As Boazman describes it,

“Before I pick up the receiver, I try to anticipate the conversation. Then I write it all down, making contingency plans in case the conversation does not run according to my expectations. The tone of voice of the person on the other end of the telephone affects my response as well. If the person replies in a friendly and relaxed manner, then I feel relaxed as well. In turn my speech is more fluent. If, on the other hand, the response is offhand and brusque, this affects my speech adversely. I begin to have word-finding difficulties and my mind goes blank. The more irritated the person on the other end of the telephone becomes, the more I begin to fantasize about how he or she perceives me.” (p. 16)

As I reminisce about my own experience as a foreigner and speaker of English as a second language, I empathize deeply with Boazman’s story. To this day, whenever confronted with the task of placing an important phone call (especially to strangers), I still go through the nerve-wrecking task of planning and anticipating questions and answers in an attempt to calm my own fears of failure to communicate.

*Golfing and the Four Musketeers*

7-06-02, Saturday
The battle of golf at Village Green.

I met Curt at the Village Green Golf Course at 3:45 pm on July 5. The one armed swinger against the two handed slinger. Two hours later the contest was over, much to the satisfaction of both golfers.

I know the help I was giving Curt was unprofessional, but he eagerly learned. I enjoyed being able to swing the club at a target.

Curt did not keep score, but in my head I kept my score.

Curt and I have scheduled golf next week. We had fun!

Larry’s journal entry

“We have made new friends, too, after the stroke,” says Susan

“Yeah! Tom, Curt, Bob, and Larry The Four Musketeers!” Larry agrees and laughs. “Is is wonderful because… we have… so much in common!”

“Yeah, that’s true!” Susan replies, “They check each other out all the time!! ‘My leg, my arm’…”

Larry laughs in amusement and continues,

“Well… hmm… competition is fine… The physical and… golf… See, I have hmm… I have… limitations… and I… so… anyway… happy… when Curt could meet me…”

“Yeah, they scored the same on the last golf match…”

“Is… is… fun!” Larry

“You were one of the Musketeers that started teaching golf to the others, weren’t you?” I ask Larry
“Yeah!” Larry replies.

“He has always loved to golf” Susan adds.

“I was a golfer at fifteen years old…” Larry reminisces. “I… I was privileged to become the… friends… My friend, eleven months younger than I… His father to me, hmm hmm hmm father image… My friend… I… well… I guess he was behind me in school, but the hmm… the hmm… so, I was always buddying up with him, and then his father… father image became Mr. Garrison. So I hmm…the… After stroke, small course yes. No more large course. Doctor’s orders.”

**Progress, Limitations, and a Little Grammar**

Mulling over the comment about the transition from the large to the smaller golf courses, I ask,

“Larry, with the compromises you have had to make after the stroke, do you feel you continue to have personal freedom?”

Larry pauses for a moment, as if organizing his thoughts, and then replies,

“Well, sure, hmm… I… have… 90% hmm right hand… 80% right hand… See…” he says, gesturing with his right hand, “The function is 90%. And… I… dragging the feet the right side… So… freedom, yes, because Tom and Bob, and Curt, is… paralyzed.”

“Are paralyzed…” Susan intervenes.

“Are paralyzed… thank you…” Larry says, with an amused grin, “She’s the educator…”

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“Well, Leslie said if you don’t learn it right the first time he’ll say it wrong the second time…” Susan justifies it.

“She is constantly reminding me… She is grammatically correct!” Larry jokes and smiles.

“Well, I’m supposed to constantly remind you” Susan explains. “Leslie told me that, a long time ago. See,” she says, turning to me “When Leslie gave him speech therapy at the hospital I sat in every session… She tried… not having me be there, but it didn’t work as well, because he wanted me to know what to do, so… I sat in on every session that he had for the seven months, and now I’m really glad that I did, because I learned… Leslie would say, ‘Now Susan remember this, remember that…,’ so it helped me a lot in trying to teach him! Poor Leslie, put up with us for seven months!”

I smile, feeling mixed feelings about the therapist’s advice. I reminisce back to the years when I used to teach English as a second language in my home country. One day in particular stands out in my memory. Noticing the unsatisfied look in one of my students’ face, I approached him and asked for his honest opinion about the course. The response was straightforward: “I don’t like it. I don’t know what I am doing wrong and what I am doing right.” From that day on, I started giving him prompt and constant feedback on the grammaticality of his mistakes. He was very content after that.

Why do I feel so different about aphasia therapy, however? Could it be because I am a foreign clinician? Or could it be because I am usually younger than most of my clients? What right do I have to correct their grammar? Maybe a lot of it depends on how therapy is seen: what is the conceptual framework that underlies it? How much, in aphasia therapy, is restitution to an old self, to things as they were, and how much of it is
compensation, transition, learning new and idiosyncratic ways of doing the same things differently? Should one strategy be valued as more or as a better standard than the other?

“Anyway” continues Larry and my attention drifts back to our conversation, “I feel fortunate that I… overcame… 50%… 20 months ago I… have… no right… left hand… so… oh… it’s funny” he smirks, “But… 2 months no… 2 months from… stroke… I was able to right hand… asshole!” he says, indicating how he cleaned himself in the restroom. “Yes!! Two months ago, is… left hand only… is awful!!”

The living room is filled with laughter. Larry continues,

“So… I guess therapy… occupational therapy… two months of the… occupational therapy… was able to… hmm… fulfill hmm… three months… anyway… Strengthening myself… so I feel fortunate… It’s hmm… where I am… so… I’m proud of that…”

***

Yeah… We have personal freedom, except… right now we cannot travel, and that’s been really hard because his Coumadin count is constantly… off kilter… and… hmm… His blood, his blood… He’s on Coumadin, blood thinner, and it’s constantly off… anything that he eats that is green… because of the vitamin K… for some reason… his… his Coumadin is always off track, so we don’t, we can’t go anywhere… we have to stay very close to home base, because we go practically every week, you know, for a blood check… Well, now it’s two weeks… but… so that would be our biggest restriction… Not being able to travel… because we, we’re marketing consultants and we traveled everywhere! So that’s… I would say that’s one of the major things, but I’m so thankful we live in Sarasota where it’s lovely… And people come here, so it’s really not that bad! So
we feel very blessed that we live in such a beautiful place, and... the... hmm... we've had so much company... hmm... but that's been wonderful, that's been a very positive thing.

**Miracle Cure?**

With questions about restitution and adaptation rolling in my mind, I ask,

“Larry, what frustrates you the most at this point? Is it when the words don’t come as quickly?”

“Yes!” he replies. “and Aricept... is hmm... rewarding because I... anyway... is rewarding half way... but it is hmm... I guess hm... it’s... mentally alert, but... still searching words... searching words...”

“So you feel that the Aricept is really helping you in some aspects?” I inquire.

“Hmm...” Larry answers, “Dr. Hudson, hmm hmm... Dr. Hudson is... USF... Dr. Hudson, neurologist... says the nerve endings will be... able to... hmm... regenerate... So... sometimes... it’s perfect... and sometimes... isn’t perfect... But, anyway... I... Dr. Petrovsky hmm... and Dr. Hudson... is... life savers!”

“No now you’re on Sinamet also...” Susan adds.

“Yes, Sinamet... three times a day... is going... good because... is... Aricept and Sinamet... I... so... slowly... yeah... but hmm... I have... much recall...”

“Sinamet is a medication used for Parkinson’s...” Susan explains, “And hmm... it’s really helping him! He thought 30% improvement... the doctor thought, 30% since he’s been on it! And he’s been on it since you were here... I mean... I think we started that since hmm... you were here the last time...”
“Yes…” Larry agrees, “but the… dopamine… effect dopamine effect is… sin… is assimilating dopamine…”

“He feels like it is healing the brain…” Susan says.

“Yes! Dr. Hudson…” Larry confirms.

“He’s unbelievable…” Susan continues, “And all the nurses have told us he’s the most dedicated doctor that… they’ve ever worked with… so… I…. you know, I praise these doctors because…”

“Hmm… Curt… Tom… and hmm… Is on…”

“The other Musketeers?” I ask.

“Yes!” Larry nods. “Curt and Tom on… anyway… hmm… something I was allergic to…”

“Oh, they’re on bromokryptine…” Susan clarifies.

“Bromokryptine!” Larry confirms.

“Larry was violently allergic to bromokryptine…” Susan explains, “So, see, we had to wait a long time before he started… But the other men are all on bromokryptine…Curt is on seven a day, I think…”

“No, five a day…” corrects Larry

“Five a day?”

“Five milligrams…” Larry confirms.

“Curt thinks it’s a miracle!” Susan mentions. “He told Dr. Hudson he improved 85%... Dr. Hudson said, I don’t think it works that way, Curt!”
Who Am I?

I… think… myself… is… human beings, and… Rotary, I… belong to Rotary… And I… hmm… guess I feel… embarrassed… because… shameful, no… so, embarrassed because I… readily cannot talk… but… hmm… but… is … good because… I was… was supposed to… every… lifestyle… and so I… I changed… but I embarrassed because I didn’t… words slow… Yes…. But see the hmm… but hmm… dysarthria… Is slow… and so… I… pronounce slow… slowly… Twenty-nine months ago, I speechless… and I… I… I… guess I would… will able to become useful and hmm… fulfilling, and… earn waging again, so… I definitely have a purpose in life, but whatever it is, is going to be good!

The doctors say to me, always say, always ask me, well, how has Larry changed since the stroke, and since… but he really hasn’t changed… there is nothing about him… and I’m so thankful for that because… he’s not changed since the stroke, and… this is not what I hear in the aphasia group from the other women… or men… or whomever, you know, is in the co-survivor group… hmm… I don’t hear that at all… I hear other things… but… every doctor wants to know, first question, how have you changed since you’ve had the stroke? And… there is really no… no change!!
The Twinkle In The Eye Of The Jeweler

Larry excuses himself for a restroom break, and Susan and I continue talking in the living room. Celebrating his achievements, Susan confides,

“I’m really proud of him! I think he has just… He has fought this, every day, just like Curt, just like all of them! But he has really… He has talked to the industry. That is very difficult. He’s had to order things for people, not simple things. It’s one thing to order a diamond for a customer, but it’s another thing for a customer to say, ‘I want this complicated piece…’ and… he’s had to go from point A to point B and it’s taken… Sometimes two, three days, but we’ve done it, you know? I’m really proud of what he’s sold, of what he’s done. Larry is very respected in the industry, and these men take time out of a business day to call him, to make sure he’s OK. That has been extremely emotional. I’m so proud of him! Someone called him yesterday, they lost their diamond, and they want to make sure that what they get to replace it is what they had, you know… I mean, and that’s it… go the appraisals, get the work… it’s been a challenge, but it’s been wonderful!! You know? Because… He’s… back in his world. He’s the happiest back in his world of the jewelry, that’s when he’s the happiest!

As Larry returns, Susan asks him,

“There’s a story that I want you to tell her, that she doesn’t know…”

“All right! Sure…” he replies.

“I want you to tell her the story of Melissa and Daniel, and the earrings, and what you had to do…” Susan explains.

Taking his seat back again, Larry tells us the story,
“Four months ago…. Well… a year ago… I had knowledge of somebody who was going to buy a… hmm… an earring, two pierced ears, from a friend of mine, so… and hmm… he unsuccessful approach that he had with a… fellow jeweler. So said, ‘You have knowledge of… hmm… diamonds…’ I said, ‘Yes’… so… two months later I forgot about it… Then later, friend said, ‘I… was surprised when wife saw the advertising, and we went and we bought… we bought a mistake…’

“They couldn’t return them because it was on sale and they signed a contract. Remember?” Susan interjects.

“Hmm hmm…” Larry continues, “So… You have… jewelry has to have a pleasant look… so I said… 800 hundred dollars 900 dollars is what… I would… cost… cost… hmm… is… all right… but I said, double, double, hmm… hmm… 900 dollars, the gemologist appraising, appraising, were 1800 dollars. So, no way! But I guess they had already been… two times the refusal… and so I said… I will… I was representative of the American Gem Society. So, all four of us appeared, and I said, ‘I don’t think that carat 38 is right. I guess hmm… falsely represented for caract 38.’ So the hmm… manager hmm… parted the prongs and weighed, carat 32.”

“It was a fraud!” Susan says, “So people got their money back.”

“But I guess, I guess I had… assumed the carat 25, but… OK, 32.” Larry laughs.

“Yeah!” smiles Susan “Well, but the amazing part was, they were here for a long time and he didn’t write anything down, and I said, ‘Why aren’t you writing anything down?’ See, because the earrings belonged to the people, Larry couldn’t take the diamonds out of the mounting to weigh them, so he guessed, with all his knowledge, he
estimated the carat of the diamond! The interesting part was, when we left home to go up
there, hmm… he packed all his diplomas…”

“One…” Larry corrects.

“Well, one… two… you had two, in your briefcase…”

“Yeah…” confirms Larry

“In case he couldn’t speak. I didn’t understand it at first and asked ‘Why are you
packing your briefcase?’, but… he was smarter than I was!!” We all laugh. “So… they
got their money back! They were thrilled to death!”

“Wow!!” I reply, surprised. “How did you know that it was a fraud?”

“It’s a strength he’s got” Susan replies.

“No, no…” Larry gestures, humbly. “Measurements… Micrometer: I show you.”

Getting up from his chair, Larry invites me to see his den.

Smiling, Susan says “He’s taking you to his world!”

I enter the mid-sized room with great respect. Larry shows me his scales and
micrometer, and I admire the precision and delicacy of the instruments.

As I turn around, I see a beautiful picture of a ballroom dance on one of the walls.

“What a gorgeous picture!” I exclaim. “Who are they, Larry?”

Laughing, he replies,

“My daughter and myself.”

“No! Seriously?”

“Hmm hmm!” he nods, confirming.

Surprised, I come closer to the photograph and look at the details. Suddenly, I
realize the similarities in the profile, the smile… That was Larry all right!
As he laughs, my mind wanders back to the last day of group in the clinic. “So that was the twinkle in the jeweler’s eye” I think to myself. I recognize in the picture the eye of the jeweler who has had so many strong and supportive women throughout his life (his mother, his sister, his first wife Liz, his daughters, and most definitely Susan) and has learned to read them, as a man and as a skillful jeweler, just like the palm of his hand.

Coming full circle, I turn to Larry and say,

“Thanks for everything, Larry!”

Giving me a big hug, he replies, “Sure! Anytime.”
Chapter 6. While My Guitar Gently Weeps

Hello Goodbye

Group therapy session at USF, spring of 2003.

Standing at one end of the narrow and crowded computer room on the fourth floor of the Communication Disorders building, a student clinician flicks the light switch twice in an attempt to gather the attention of the chatty and lively members of the aphasia group for the next activity. As their voices gradually fade into a faint and bubbly murmur, she explains,

“Last session we agreed on what foods to bring to our picnic at Lettuce Lake Park. Today we are here in the computer lab to look up some recipes for the folks who could not decide what they wanted to bring. So pair up, find a computer station, and let’s look up some recipes! We’ll vote on the best ones at the end of the session.”

As the room gets busy and the student clinicians start circulating to provide individual assistance, Miz Paul, the clinical supervisor, notices that one of the clients had not yet found a partner. Approaching me as I take my notes in one of the corners, she suggests,

“Hey, Linie, why don’t you buddy up with Bob over there? He may need a hand.”

“Sure!” I say as I put my pen and paper down. “Will do!”

***

“Hi there!” Bob says cheerfully.
“Hi!” I reply. “Is this seat here taken?”

“No, not at all!” he says courteously.

As we introduce ourselves and exchange our first hellos, my accent dances a discrete samba through my vowels. Looking at me inquisitively, Bob asks,

“Where you from?”

“Brazil.” I say smiling, as my heritage shows. “How about you? Are you a Floridian?”

“No,” he laughs. “I from Sashashusetz.”

Unable to understand him at first, I get a bit closer and ask again, “What was that?”

“Sa-sha-shu-setz,” Bob repeats politely, giving me one syllable at a time. Feeling slightly embarrassed for my untrained ears, Bob and I play twenty questions as we narrow down the multitude of possible answers.

“Is it in the USA?” I ask.

“Yes, yes!”

“South?”

“No, North,” Bob corrects me.

“East coast?”

“Hmm hmm…”

Thinking about the number of syllables and the geographical location I put two and two together and ask, “Is it Massachusetts?”

“Yes!!” he replies. “Sashashusetz!”

As we both laugh, Bob turns to me and says,
“Ok now! What…da… what recipe?”

“Oh, I don’t know,” I answer. “Are you a good cook?”

“Yes!! Oh yes,” he responds proudly. “Spaghetti, my specialty!”

“Really?” I comment, amused.

“Oh yes, yes! Really good spaghetti!” he reassures me.

“All right,” I respond. “So how about we find a good pasta recipe for the cookout?”

“Oh!” he agrees, and we both start searching for cooking and gourmet websites.

After a few mouse clicks, we find a good spaghetti recipe, but unfortunately it doesn’t win the first place in our group pole. “Oh well” we both say, “It seems like a good recipe anyway!” At the end of the session, we part our ways in hallway, saying our first goodbyes.

***

PCD 3017. Gently opening the door to Dr. Hinckley’s research lab, I hear an enthusiastic “Eureka” coming from the inside.

“Yes! That’s it! That’s what I was looking for!”

Stretching my neck down the short corridor leading into the room, I see Lori, Dr. Hinckley’s Ph.D. student and clinical fellow, working at the computer. Lori is at least two years ahead of me in the program. I have looked up to her from the very start, with a mixture of admiration and a hint of competitiveness, hoping some day to be half as good and knowledgeable as she is. Turning around as she hears my footsteps, she says, “Oh hi Erline, I didn’t notice you coming in!”
“Hi Lori” I say as I lay my backpack on one of the tables. “What did you find there?”

“Oh,” she says, looking back at the screen, “I found this really cool website for phonetic placements that I think may really help one of my clients. Take a look!”

As I come closer, I see a large sketch outlining the cross-section of a head on the left side of the screen and a list of all the phonemes in the English language, organized neatly in categories on the right side. As Lori clicks on each of the listed phonemes, the tongue, lips, and jaw in the sketch move to the appropriate articulatory position in the mouth, giving me the funny impression that the computer screen itself is talking through the loudspeakers.

“Isn’t this something?” She shows me. “I want to try this with Bob, see if it works for him.”

“You’re working with Bob?” I ask her.

“Yeah!” she says, surprised. “Do you know him?

“I just met him the other day when I was observing group!” I tell her. “How’s he doing in therapy?”

“Well…” Lori says, “The problem with Bob is that he hasn’t been practicing the things I give him consistently… So… We’ll see… Hopefully this will help him.”

***

As time passes, these snippets of conversation slip into the back of my mind, where they remain dormant and undisturbed for at least one year. Meanwhile, I see very little of Bob in the ensuing weeks and months, as he stops participating in group activities
to take part in a research study conducted by one of the faculty members. It would not be until much later, in the summer of 2004, that I would meet Bob once again.

*All Together Now*

Opening reception of the Speaking Out! convention, 2004. Walking through professors, presenters, and an inspiring multitude of stroke survivors, I spot a group of familiar faces from the USF aphasia group and make my way towards them. As I come closer, I see Bob, helping himself to a glass of lemonade, close to the bright yellow and green balloons from USF. Tapping him on the shoulder, I say,

“Hey, Bob! So how was that spaghetti?”

Laughing, he replies, “Oh, delicious!!”

“How have you been?” I ask him.

“Oh, good, good!” he replies, “And you?”

“Good as well! Have you decided what sessions you would like to attend here at the convention?”

“Not yet…” he answers. “But I see Larry, Curt, and Tom, of course!”

“I know! I will be there also.” I tell him. “Have a good time at the conference!

“You too!” he says, as we part our ways.

***

At the time, the fact that Bob decided not to deliver a speech at the convention did not call my attention. “He’s probably more reserved and introverted than the other Musketeers,” I think to myself, “and that’s why he opted for making the introductions instead of a speech.”

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Figure 9.  Bob at the Speaking Out! convention, 2004.

Sitting at the end of the very first row, I watch the presentations mostly through the lens of a video camera, as I try to capture every word and every gesture from all the participants in film. The audience is replete with family, friends, and other fellow survivors and caregivers who laugh, cheer, and become emotional with the presenters as each speech is delivered. As I move the camera lens from the presenters to the audience, I see the pride and enthusiasm blossom in Bob’s face, as he celebrates the great achievement of his fellow Musketeers in this formal meeting.

The end of the session is crowned with a large wave of applause and a warm gathering of families and friends to congratulate the presenters. I join them, hug them, and gently slide outside the room, as I try to split myself in two in order to attend other sessions.

***

One month later, IRB approval in hand, I dial Bob’s number, without knowing exactly what to expect. From the Four Musketeers, Bob was the one I knew the least. “Would he would be interested in participating in the project?” I think to myself. “How
should I word my invitation?” After a few dial tones, I hear Bob’s voice on the other end of the line.

“Hello?”

“Hi, Bob?” I reply, snapping back into reality.

“Yes?” he confirms.

“Hi! This is Linie, from USF, one of the clinicians. Remember me? We saw each other at Speaking Out! not too long ago.”

“Oh, yes! Da… I remember! How are you?” he says, after a brief silence.

“Pretty good! And yourself?”

“Not bad!” he replies.

“Bob, I am beginning to work on my thesis project now and I was wondering if you and Diane would be interested in participating.”

“Oh yes?” Bob exclaims, between hesitant and curious.

“Yes,” I confirm as I briefly explain the purpose of the project. “So, what do you say?”

“All right!” Bob replies. “When da meet?”

**Tell Me What You See**

One week later, I find Bob and Diane’s home in a quiet neighborhood in Venice, surrounded by golf courses, palm trees, and neatly trimmed lawns. Getting my gadgets out of the car, I slowly make my way towards their house and hear the soft “ding-dong” of their doorbell, punctuated by the firm barking of the family pet.

“Hi Bob,” I greet him as he opens the door, “Thank you for seeing me today.”
“Oh, no sweat!” he replies with a smile, “C’mon in!”

As I enter, I notice the beautiful Collie standing tall by Bob’s side, looking at me suspiciously as if trying to decide how to react.

“What a beautiful dog!” I comment. “Can I pet him?”

Bob chuckles and says,

“Try… but… he… skittish…!”

As I stretch my hand towards its nicely combed fur, the Collie looks away politely and starts walking around in rhythmic circles, as if circumscribing his own personal space.

With a knowing smiling, Bob says,

“Diane inside, da… I go get her,” and directs me to a quiet sitting area.

Diane, Bob’s wife, is a tall and charming lady, with wavy blond hair and long delicate hands. I first had the chance to meet her at Speaking Out!, as we frequently ran into each other in between presentations.

“Hello!” she says as she enters the room. “I hope you had a nice drive!”

“Oh yes,” I comment. “No bad traffic, amazingly!”

I find myself a seat in the cozy couch by the wall, as Diane and Bob sit opposite me in their armchairs. After working out the details of the informed consent, Diane says,

“The only limitation I have as far as meeting is in two weeks I go back to work.”

“Diane teacher,” Bob explains.

“Oh, no problem,” I assure them, “I can work around your schedule!”

“All right!” Diane agrees.

“What do you teach?” I ask her, not knowing she worked with education.
“Seventh and eighth grade.”

“Really?” I reply, surprised. “How do you like it?”

“Oh,” she sighs, “I’m getting on the down side of that…” Her tone was between tired and humorous. “You know, the kids aren’t getting any easier! Are we ready to start?” she asks, noticing the questionnaire with the “Psychosocial Wellbeing Index” (Lyon et al, 1997) in my hands.

“Sure,” I reply and we move on.

***

Do you feel you have a purpose, a direction in life?

I think so, yeah. [Deep sigh and silence.] Well, first… thing…

hmm… One at a time. This day, and next day, and next day… hmm… [sigh] but… Good, better, better, better, better!! And hmm… the arm, too… [says somewhat sad and disappointed] Not good… the leg, yes! But arm, no… And I… really miss… guitar…

Do you feel you have personal freedom, to do what you want to do?

Oh yes, yes… Yes! Because the car, go with anywhere! ... Silence…

Do you feel that you start activities on your own?

I think so! Yeah! Yes! ... Silence…

How busy do you stay during the day?

Hmm…. Well…. Sometimes yes, and sometimes no. Da… depends, you know?
How do you currently think of yourself, how do you see yourself?

[Silence – sigh – deep sigh] Yeah, right [laughs] Better, but… not, you know… not… really… guitar, no… [Silence]
The arm is da… the mind… you know? And guitar, of course… and hmm… oh… what else?

Is there something you miss deeply from before?

Oh… [sigh]… Work!! The… engineer… Bioenvironment… Bioenvironment…
I think so… [thinking – long silence] I don’t know… I think … the whole thing… better today. Yeah, really! The… because… the… more out. You know? I hmm… I … hmm… …Silence…
I speak [thinking] I don’t know… but changed, oh yes… yes!!
Right? [Bob concludes, turning to Diane]

***

Looking at Bob and then at me, slightly puzzled, Diane replies,

“I’m taking he’s supposed to be answering…”

“Oh, no,” I answer, relieved to find an explanation to her silence and an outlet from the mechanical format I had unfortunately transformed the interview into. “I was amazed you were so quiet!” I comment.

“I was purposely not answering…” she explains.

“Oh, no, please! You can participate at any time!” I remark.

“Even if I have a different view?”

“Absolutely,” I confirm.

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“Because I have some very different views than he does!”

“Oh really?” says Bob, and initially I cannot pinpoint if his voice was ironic or indeed surprised.

“Yes… I do,” Diane continues. “So, let’s see… what was that last one you asked?

***

I would say… Bob… he’s much more… empathetic and compassionate towards anybody who has any kind of disability. Before, when Bob was in the work world, working 18 to 20 hours a day, he just didn’t have time… he was so busy… it is not that he didn’t care: he was just too busy… But now he’s extremely compassionate towards anybody, and goes out of his way to help anybody… I think he knew what he wanted to say when he said “better now…” But I think you couldn’t put it into words [looking at Bob] So… I would agree with you on that question… [Bob nods gently].

I don’t know that I would agree with some of the other ones before, though…

When you were talking about your purpose… I don’t think you have a real clear purpose… Bob is not a goal-setter now, and… it drives me crazy… Because I don’t ever know where he’s going, or what he wants to accomplish, and I… I think that it comes from a fear of failure… so he won’t set a goal, and say what he wants to do, so I don’t think that he has a clear purpose, and I don’t think that he has enough to do during the day… He isn’t busy enough… he isn’t busy I don’t think that he’s busy enough at all…

He wasn’t like that before… Oh no

[Not AT ALL! Oh no!]

He was busy every… Every single minute...

[Every single day]
That’s why there’s been such a... the hardest thing for me is that... he’s such a different person... A very different person... Just the idea that he... he... always had something in front of him that he was... trying to achieve, or do, whether it be at work, or whether it would be at home. Always had things going on, you know? At home, whether they were projects around the house, or doing things here, and... he doesn’t now. And I always ask him, “What is it you would like to do?” because there isn’t anything really he can’t do now, that he could... that he did before, I mean, when he puts his mind to it, he can do it. It’s not like he can’t do things... including... hobbies and all... But he...It’s like he doesn’t have... The motivation, I guess... He feels frustrated...

[Oh, God, yes…]

VERY frustrated, all the time... So... I would disagree with that purpose thing. I don’t think he has enough to do, I don’t think he has a clear purpose...

No Reply

“You talk about the stroke as a major divisor of waters,” I comment, looking at Diane. “What do you both remember from immediately before and after you had your stroke, Bob?”

Looking at each other, trying to decide who would speak first, Bob begins.

***

In society’s view of disease, when the body goes out of control, the patient is treated as if he has lost control. Being sick thus carries more than a hint of moral failure; I felt that in being ill I was being vaguely irresponsible.

Of course, the problem is not that I or any other ill person has ‘lost’
control; the problem is that society’s ideal of controlling the body is wrong in the first place.”

Arthur W. Frank.

One day… the… the stroke.

Vice president and then slump…

[makes a “down hill” gesture with his arm].

The night… the morning, really

And the bed…

I sit… [silence] the bed… sit…

And then… stand.

And then… [silence]

Fall… the floor…

And then… nothing.

Nothing…

One week, nothing…

Wake up, frustration [Laughs…]

A LOT.

Angry…

The whole thing, really bad…
[What were you angry at?]
Me…

[You? Why? Of all people?]
Well, yeah… me…

[Did you blame yourself?]
I think so… yeah…
Not you! ME!! I mean…
Because me the stroke has hurt…
Me… My brain, not you!! ME!

[But you don’t have control over that!]
Well… You know…
This morning… The stroke…
Night before… I wonder…
Not stroke because I don’t know what stroke means… but
Some… Thing wrong…

The plane the afternoon…
And then… stop… the restaurant…
Then… going home… and sleep.
The next day, the stroke.

I don’t know…
Stress, you know, the stress…
Always there… So what?
I don’t know…
I don’t know… I don’t know…

But something wrong…
I don’t know what…
I don’t know…

Stroke?
No way!
I mean… no… not cross my mind
Not at all!
Not at all!

***

When he came in the hospital, the neurologist was, he was hmm… very proud of himself, actually, because he said, “Oh, I just knew when I took a look at him, that this was a really bad stroke, I’ve just seen a thousand of them, and I just knew by looking at him that this was…”

You know? He was really patting himself on the back… [Diane comments, indignant] My brother was there, and what we had done was, our older daughter, Jennifer and her husband, who were living in South Carolina at the time, started up to Philadelphia for Kathlyn’s
(our younger daughter’s) graduation, so they were in route, and...

What we had decided to do... was... have Jennifer stay up there for Kathlyn’s graduation, so she’d have somebody there, and my brother flew down to be with me here... in Atlanta... and actually, Bob, you were on the phone with Kathlyn, you were talking then... Because you made that decision... you said, “No Kathlyn, you stay there, I’m fine…”

And... my brother was there when the neurologist came in, and my brother just... Couldn’t believe... because he just was... so patting himself on the back and went through this solemn speech about how bad it was, and... that in 30% of the times people don’t... when their brain swells like this they don’t survive... rather saying than in 70% of the times people don’t have any problems!!

Uhhh!!

Yeah...

And I... I’m sorry because he was from Emory, and... the rest of the time we were in Atlanta, we managed after we got out of the original medical center, and we... hooked up with Emory rehab and all, our experience with Emory was just wonderful, and he was not an asset to Emory at all, this neurologist! At all!! He just was...

What everybody said was, was, you know...

I don’t know…

Right!!
them, and Jennifer said, what about, what is that, now what would they have said... I don’t know, they just... that whole group of neurologists, just were... ugh!! [laughs] Just really awful!!

Yes! [Laughs!]

***

Saddened as I listen to Diane’s turmoil as a caregiver during Bob’s first days at the hospital, I think back to my externship experiences in hospitals and the different ways of relating that I had observed in patient-physician interactions. Some doctors seemed to have a greater sense of empathy than others, and were able to approach patients and families successfully, having immediate (or at least gradual) access to their trust. Others, however, seemed very uncomfortable in a counseling position, and wrapped themselves around the disturbed anatomy and physiology of their patients, as if attempting to make the unpredictable realm of emotions dissolve peacefully into a world of science and logical predictions.

Facing Bob and Diane, I wonder about their long life together and how their life stories had evolved from when they first met until that fateful morning in Atlanta.

And I Love Her

“How we met?” Diane asks.

“Oh… Gosh!!” Bob exclaims. “Well… the… summer… Cape Cod… Diane waitress…”

“… in a resort,” Diane comments.

“… and me, the band. -tar.” Bob continues.
“Gui-tar. Two syllables,” Diane says, sounding the word out.

“Gui-tar!” Bob obliges. “Band, well, college…Band is all college students! So… I play guitar, and the… different things… the trumpet, the drums… a little bit of everything. We play rock and roll! Really good, you know? Nice… money, too! Really good! And… the… Diane and I… meet hmm… in the hotel.”

“Well, it was the summer,” Diane clarifies, “and we were in college, so we went back to college, but…”

“Me Boston, and Diane… from Ohio. We meet middle! I go to Tuf… Tufs…”

“Tufts,” Diane assists, exaggerating the final “ts.”

“Yes…” Bob nods, “and you…the… hmm…”

“I went to Florida Southern College, down here.”

“Yeah,” Bob nods and continues, “Then dating and… college… and then military.”

“The military?” I ask surprised.

“Yes, oh yes!” Bob says with pride. “I Air Force.”

“Really? I didn’t know that.” I comment, eyes wide open. “Were you ever in combat?”

“Of course…” Bob answers. “I was in Nam…”

*Helter Skelter*

I twenty-one...

No sweat… I mean…

Really good… you know… under circumstances…
But... the people, good! Really nice!
Always playing, guitar! Oh, God, yes!!
Really, the whole thing...

Beautiful people!
Beautiful... the hmm... trees, and... the air... the sea... the sea good!
God, beautiful!
And water, and sand... oh, God!!

But war, and war... you know?
Decimated...
God... You know?

I Air Force... the hmm... the base, the big base...
Me, the hmm... en... engineer...
Not... the... sho... shooting...
But hmm... still, you know?
War, the war!

Me, hospital, all around base
Go into shops, inspect
The air, the light, the pollution, and safety
Safety things
So not so bad... But not good...
War, you know?

Scared, of course…
And the bombs… I see it!
Because… right there!
I mean, right THERE!

One time, the… bomb spell
Into the… hospital…
Me inside hospital!
Different wing, but yeah…

Vietnam, one year
Then come back… but, hmm…

Two or three people there, my friends…
Pilots… killed in combat…
Tough…
Breaks your heart and soul…

But…
Get over, move on…
What the hell!
I mean...

Then after war
Me and Diane

Many, many letters!! Oh!!
Diane... one year... college
Me, Vietnam... then my wife
So... OK really, you know?

_Here, There, And Everywhere_

“How long were you in the military, Bob?”

“How long were you in the military, Bob?”

“Two... hmm... two... two... three...” he responds in frustration and finally exclaims, “God damn it! **Twenty** years.”

“That’s a really long time!” I comment. “How did you like it? What was life like in the base?”

“Oh!” Bob exclaims with a sigh, “Beautiful!! The people... the really good... and hmm... Good memories! And good for you, too,” he says with a sweet voice, turning to Diane, “and two childs! Because... all there, the commerce, the barracks, the medics...”

“Yeah,” Diane agrees, “We wouldn’t change that! That was great!”

“Really!” Bob confirms. “Travel a lot, many, many times!”

“Tell her were we lived” Diane suggests.
“Let’s see…” Bob says searching his memory. “San Antonio, Austin…”

“M…” Diane intones as she nods in agreement.

“Maine… And England… Three… no, four years in England. Beautiful! But rain everyday!”

“Just about!” Diane nods, smiling.

“And D.C.… And… hmm… Tampa… No hmm…”

“Not Tampa, not then…” Diane comments. “We tried, but… never got it!”

“But your favorite…” Bob suggests as Diane looks at him, slightly confused.

“You said Maine… Unless you’re being funny…” she continues as the lines in her frown relax.

“Yes!” Bob continues. “What’s the name … the town? Really close to this… the… the…” he struggles.

“Oh!” Diane exclaims, “You mean Jacksonville?”

“No, the, north! A…”

“Atlanta?” Diane guesses.

“Yes!” Bob sighs, relieved.

“Oh, Atlanta!” Diane states, disappointed. “But that wasn’t in the military… We lived there when you were working as a civilian… Yeah, we did live in Atlanta,” Diane acknowledges, “But that’s where you had your stroke…”

“But you, like Atlanta, no?” confirms Bob.

“Well…Yeah…” Diane concludes. “I did. Until then.”

***
Eight Days A Week

“Bob, you mentioned you are an engineer…” I comment.

“Yes! Bioenvironment…” he confirms.

“Did you always know that’s what you wanted to do?”

With a chuckle he answers,

“Well… One year Tufts… The… the teeth… hmm…”

“The teeth?” I muse to myself as it suddenly dawns on me, “A dentist? You wanted to be a dentist?”

“Yes!” he nods, laughing, “But then… hmm… No, not right… nah…! So, engineer! But what engineer? Two people in hmm… in fraternity house… hmm… in bioengineering… So I think… ‘Oh, really? What’s this?’ So, there you go!”

***

I would say that Bob is the kind of person who defines himself by his jobs… He used to always LOVE every day of his work. He would come home at night, honestly, and never complain about his job. [Oh yes!! Not at all!] He would talk about how much he loved it! I would come home, on the other hand… [Laughs!] With those kids! But him? As stress-filled and competitive as it was in the business world, somehow, he dealt with it, and I… I think that he dealt with it because… He was always so involved in the process that he was doing… Always… Always… The goal, you know, the goal was… The goal always was to win, but… He was always so… He was always so involved in the process that he was doing… He just loved it, he just loved it! And he always did such a good job! Such a good job with it, and was so successful at it, he… He… And I think that it snowballs: you love what you’re doing, so you’re good at it, you’re good at it, so you love it, and it just
kind of all snowballs, so he just, he always loved every minute of what he was doing. He always came home and talked about, even in the air force, he loved every minute of what he was doing.

***

Me, before stroke…
The work…
Business…
The first one, the work…

Long hours… Many times!
And… not the same work!
Travel, a lot of travel, too…
Oh, a lot! Oh, God, yes!

The whole thing! I miss it…
My job…
I miss it…

Not the pay…
No, not the pay…
Just…
The whole thing…
I miss it…
The stroke? Of course, really bad… Oh yeah…

I miss it! The friends… good friends the hmm…

But, you know?

Forward! Yes! Forward, forward, forward… really!

I like the job… and the military and…

Bio…. Environmental… yes… I like it!

Really good job!

And I like the people, the military and the civilian, too!

The boss… good… I mean,

The… the whole thing is… really good!!

So… the whole day…

The work

And the night, too!!

I love job… I think so…

Conflict at home?

Not me, but the wife yes… [laughs]

Because, you know…

Me, the work the…
Forty hours a week, no way!
A lot… more!
Not the military, but the… civilian… yes.

Me gone… Traveling…
Not be here… In the house…
Two, three days… the week…
Hard job!

And more! The weekend, too!

But I liked it…

***

As the afternoon turns into evening, we conclude our first interview and make arrangements for a second meeting before classes start in the fall.

“I have these two sets of questions,” I explain as I gather my materials, ready to leave, “and I was wondering if I could interview you separately on our next meeting.”

“Sure,” they both reply. “We’ll see you then!”

***

As I drive home that night, I revisit the aspects of the interview that I wish could have gone differently.
“Why did I insist on sticking to a questionnaire when I knew that would not be the best approach?” I mumble to myself, disappointed in my own judgment. “Why did I feel safer hanging onto the questions on paper? Why didn’t I just follow their lead?”

As I shift lanes, I ponder, “Maybe there were no leads… Maybe I was just puzzled by Diane’s silence in the beginning… And Bob’s answers were so short at first that I felt uneasy, almost uncomfortable to probe further…”

Keeping a squinting eye on the road as the night becomes pitch black, I sigh in resignation, “No wonder so many people shy away from the so-called ‘psychosocial issues…’ It is a messy business.”

_A Beginning_

August 2nd, 2004. As I ring Bob and Diane’s doorbell again, I hear the familiar barking from the gorgeous Collie coming from the inside. As Bob welcomes me at the door, I ask him,

“So, do you think he’ll let me come an inch closer this time?”

“I don’t know,” he says softly, as he watches his pet walking around in circles.

“Maybe!”

I stretch my hand out into the air, taking my chances, but no response.

“It’s a lost cause,” I joke as we get settled for the interview.

“Nah, someday,” Bob replies, sitting comfortably in his armchair. “So, what today?” he inquires, smiling.

“Well, since we’re doing the interviews separately today,” I mention, “I was wondering if we could start by talking a bit about you.”
“Me?” he asks, with a puzzled smile.

“You” I confirm and suggest. “Your family, your childhood, growing up… You decide”

“All right, then,” he nods. “Here we go!”

***

Massachusetts… Winthrop…

Boston Harbor…

The island! I love the island!

Not big, but… two or three… small …

Boating, of course, because island!

Then sail… sail…

But not anymore…

Years later, England,

Beautiful!

I love England!

Also island.

My father and mother…

Two generations…

Three generations… [Your grandparents?]

No, one more… [Great-grandparents?]
Right! Right! Right!  
Yes!  
[European?]  
No, the south!  
[North of Europe?]  
Yes! Yes! Both sides…  
[The south… Were they Italian?]  
[Laughs!] Yes! So…  
[That explains the spaghetti!]  
My friends’ father, yes…  
[Did they keep a lot of the traditions?]  
But mother and father…  
Not at all really, no…  
[Brothers and sisters?]  
Two brothers and one sister  
And mother, and father…  
I’m the oldest.

The sister… Massachusetts and Venice…  
Come back and forth.

My brother, one brother… Down here…  
And the other one… North…  
[All engineers?]  
No, no…  
Me, only one.  
The family, one engineer.  
University degree, just me and father…
Me role model, I think…

Siblings…

Because me, college
Brothers and sister no college.
I don't know…

Sister… hairdresser…
Going to… hair dressing school…
The two brothers, not really… the…
College, no…
One brother, not good [disappointed sigh]
Other brother, very nice!
He working in old home… Nursing home.
Sister now retired…

Father hmm… the… law. Lawyer.
Many years!
Enjoy? Hmmm… I think so, but…
I don't know…
But I enjoyed… my job!
Oh, God, yes! Beautiful!
In school, bands!
The trumpet… Started with trumpet…
Then guitar…
And the piano…
And the banjo…

Guitar…
Three, four, five… three… four… five…
Six… Yeah!
Six years old! Or seven…
Knack for music… good ear!

My mother, guitar… and… the piano!
My brothers not musical…
Me and my sister… only…
My father, no way!
Just me, mom, and sister.
Play three together sometimes.

I teenager… Parents separate.
No problem!
Beautiful!
The father is an…. attorney!
No sweat! Really!
Beautiful! Beautiful!

The… divorced… the… the first day…
“C’mon over, Bob!” the father and mother,
“C’mon over and sit down,”
No sweat… No surprise…
I knew, of course…
I could tell, many years ago…
Grew distant…
But really good talking!
Good friends!

Then step dad…
The second floor
We first floor…
The second floor… the stepfather…
Neighbors!
Two floors, one, two…
Not a… Building, just two floors…
[Was he an important person in your life?]

Yes, of course! Yes!

My father and mother and stepfather

The father… the engineer, no…

But the… in the yard…

Always the yard…

The bushes… all the same, you know?

My father and me…

Go and… shrubs, bushes…

And not the sister and other brothers,

But me, and father, and friends…

Go… out… to dinner, you know?

Really buddies!

[Could you talk to him about anything?]

Oh, yes! Father and mother too!!

Oh, God, yes!!

Because me…

My personality…

Father, no. The mother, me.

My personality, the mother!
Not the father…

The dad… is… hmm… engineer, no.
The… hmm… the office…
Big shots…

So, you know, the… the mother…

Very close!
But with father, too, you know?
Father too…
But the personality, really…
More like mother…

Father…
The job… the job…
But me, the job too… you know?
[Laughs…] I know…

The mother, once a week,
Tuesday…
No, Thursday!
My mother the…. The pot…
The… in the pot…

Yes, the pot! [In the kitchen?]

The spaghetti…

And… I mean, not a lot… a BIG lot!!! [Like a good Italian family!!]

Oh, oh good, oh yeah!

And my friends…come, once a week…

“C’mon!! C’mon!!” [So it was a very warm family!]

Yes! And the military, same thing…

The friends… Yes…

Do You Want To Know A Secret?

A few minutes later we hear the garage door slowly lifting.

“Diane” Bob mentions, “coming home.”

As he hears her steps entering the house, he sings,

“Hellooo!”

“Hellooo!” she sings back as she leaves her purse and keys on the kitchen counter. “How is the interview going over there?”

“Pretty good!” Bob mentions. “You come?”

“Yes,” Diane replies. “Just give me a couple of minutes.”

***
As Bob finishes up his interview, Diane disappears into the house and gets herself ready. When she returns, she motions to Bob,

“Ok, it’s my turn now. You’re not supposed to listen to it.”

Getting up from his armchair, Bob walks into the kitchen, where he lingers for a couple of minutes. Diane then takes a seat in her armchair and says,

“Okay, I looked over the questions: they were easy! Should we start?”

“Sure,” I reply, “Whenever you’re ready.”

**Don’t Ever Change**

*The first one is about personality before stroke... I would describe him as very outgoing, very outgoing, on the go, all the time... Always wanted to be... Around people...*

*Controlling... Certainly “in-charge” person... Whether at work, at home, any place, absolutely... You know, an” in-charge” person... I would describe him as controlling...*

[We can hear Bob laughing in the background]

*Bob!!! This is not funny!! It needs to be private!!! You need to go some place else!*

[Hey! Cool it!]

*No!!*

*Hmm... Let’s see... hmm... [thinking] If possible, you know, Bob was very, you know, flexible with, with most... Plans and things... hmm... Sometimes not very flexible [says it more in a whisper] but usually flexible with things.*

[We continue to hear Bob in the kitchen, now washing dishes]
Let’s say that, in a group situation, people decided to do one thing, and it wasn’t what he decided, what he wanted... In those cases he wasn’t flexible. I mean, he definitely... if it was a group decision to be made, you know, like “where are we going to go out for dinner?” and 2 people suggested something, Bob would want it to be what he suggested.

In a big group of people... Bob would be the kind of person who would take charge. If you had a group, you know, sitting around, and somebody had to make a decision for something, he would be the kind of person who would stand up and take charge. If you were at an amusement park, in a group, or you were traveling with a group, and everybody was standing there, waiting for somebody else to do it, Bob would make the decision to take charge. So... he was a quick decision maker. I say this because Jennifer is so much like him, my oldest daughter. A quick decision maker rather than think things through, rather than think and plan things through.

What else... Bob was very outgoing, always around people... He always had lots of friends over all the time... and he was always very loyal to friends. Bottom line, always, always, always, loyal. What he said you know he meant. He was always very upfront with people. True to his word – if he said he was going to do it he did it. Always very, very, very true to his word and in business also. Bob had in the hospital as many competitors visit him as he did people he worked with. That was the one thing that kept coming through, all the time: how honest and fair he was. He always was, even with... with... competitors. A good business person, a man who really worked for the contracts. He was never sneaky... you know? He was always honest and fair, and full of integrity. Always, always, always...
[And the water keeps running.]

**Crying Waiting Hoping**

*What do I remember from his first days in the hospital? Probably... a lot of chaos and probably shock because, as a... as a survivor you... kind of walk around in disbelief...*

*[Water running…]*

*Everything... it’s like the unbelievable... thing... happened...*

*I remember the neurologist... coming in... after they saw the MRI, and they gave me all this bad news, and then they started doing all these ultrasounds and MRI of the neck and another MRI and ultrasounds of the brain ultrasounds... and... I kept asking myself, “Why are they doing all this stuff?” And they said... They wanted to find out what caused it because they had no earthly idea what had happened. But it just didn’t make any sense to me because all I wanted them to do was... Make him... Do something to help him... Make him better... And it just... seemed so ridiculous to me that they were doing these things...*

*Come to find out that there was nothing they could do to make him better... Even in the medical narrative it was page after page, and then finally the last paragraph says that it must have been a dissection because it was not... this, this and this...*

*So I think kind of... Really chaos and shock.*

*During the first days at the hospital I really assumed that Bob could get better, as did everybody from his job. As soon as that word was out that he was in the hospital, gobs and gobs of people started showing up... Bob doesn’t remember any of that... But*
they all assumed he would be fine, too... Because they’re all... his age or younger! Bob was... he had just turned 51, so... some of them were in their 40’s and, you know...
“There by the grace of God go I!” They knew about as much about stroke as I... as we did...

I think the whole situation only dawned on me over a long, long period of time... I would say over a couple of years... I had a long period of... of... anger, and rage...Several years ...

At first maybe I accepted “Well...this might not be perfect, but... I can handle being able to do this and this, and maybe a little bit more...” So I think... I kind of took it in by... little spurts, by steps... hmm... rather than one whole... I think that’s what I did...

Bob’s company carried him for a long time, you know...Even after what their document says... So... I kept thinking, “Ok, if he has 6 more months we can get this speech thing under control.” So, I kept thinking, “Ok... maybe he’ll be able to work...”

I just did not take it in...

It was a long time before I did... I think getting that letter... One of the hardest moments for me was getting that letter of involuntary termination... That was a hard letter to get... I don’t know if it was that hard for Bob, but it was a really hard letter for me to get...I guess because I really and truly hadn’t... 1000% accepted... I just had not come to that point yet...That would have been a year and a half after the stroke....

The Long and Winding Road

His response to therapy...

I think, right from the beginning... therapy... was frustrating...
At the very beginning Bob went through the whole emotional thing, with a lot of crying... Not so much anger, at first... but crying... And that was hard because it didn't seem he was making progress.

Then he went through the anger, or the meanness, which was directed towards me... Even though I was warned by nurses in the hospital and the private doctors to expect it... It is still really hard...

In therapy the biggest change was... the lack of motivation, from the very beginning... Everything Bob ever did before he was so motivated to do, whether it was... painting the garage, or... doing anything... And he was just never motivated in therapy. He just never had a goal, even though... I know they have to set goals for insurance, so there were always goals there, but he personally never had a goal. He never, ever, would set a goal... Therefore... he never... moved... I never thought... Just never moved...

The neurologist at first said something about that to me... I asked him the very first day,

“Will he be able to work?”

And he said... I can’t remember the exact words, but he said it in a very... very bad way to me... something about how high level his job was, and... The way he said it to me made me want to respond,

“Well, of course, it’s high level!”

But my response was that he was an engineer and he was a go-getter, and he said... he did say that he might not be... quite so... hmm... so... much of a go-getter anymore...He did say that. He didn’t say “would not be motivated anymore” but... he did bring that up...
I think Bob could do so much more in therapy if he were willing to work because he’s had, I think, what a lot of the other guys haven’t had… And the fact that I would be willing to work with him eight hours a day… I would be willing to start in the morning and work with him 8 hours a day… and get any of the software that is out there, or… any of the other things… And our kids look for all the software in the internet, so… I think that he has resources that a lot of other people don’t have… And yet, he’s not willing to do the work to do it.

I gather it’s part of the damage to the brain… I think that every little part of the brain has a… function, and I think that’s… I don’t know…

They always say recovery depends on your age and the severity and all of this… but the one thing that has surprised me, absolutely, positively the most, is that Bob has not been more motivated. To me, his biggest deficit is not speech, or reading, or any of that. It’s the lack of motivation… It’s never the kid in school who is the brightest who achieves the most… it’s the kid who is the most motivated. I will take a motivated kid at school any day, to the smartest one…

So… that’s what I would like to see happen… Because really and truly, over the years, the amount of work that he has done, really, is very little… very little in time…

*Lonesome Tears in My Eyes*

Our social interactions… Well, our whole social situation has changed.

At first, when we were in Atlanta, everybody that Bob knew managed to get to Atlanta to see and visit him. All his friends were real faithful about calling as well. So we knew the people, they knew us prior to the stroke, and things were basically the same.
Now, when we moved here, of course, nobody knew us before the stroke, so it’s meeting all new people... and... That really has been... very difficult... because of Bob’s problem with speech... It’s difficult because people will want to interact, and ask him what he likes to do, typical kind of conversation, and since he won’t respond, or, won’t be able to add much to the conversation, it is very difficult...

I don’t mean people aren’t nice: they are. People are very nice and... they’re more than surface nice, they are genuinely nice, but as far as making new, good friends, as far as Bob making new good friends, it’s difficult for him... very difficult...to get together and go out and do things during the day, which is what he needs to do... He does it, but by himself... I wish to God he had places to go, volunteer work that he could do because he desperately needs to be around people.

Xeroxing is not his kind of thing... He really is better, even though his speech is not good, he would do a lot better by doing something to be around people. That’s why visiting his friend at the assisted living place down here was so good... It was good to both of them...

So ideally Bob would do just fine doing something like visiting people who had strokes at some place like that. Even going and playing games with them, or playing... if he could... if he could ever get back into playing music.

She’s Leaving Home

The last question has to do with our family dynamics...

I think that the stroke has certainly changed all of our family, forever... Nobody will ever look at things the same again... For one, our youngest daughter is becoming a
neurologist... The one whose graduation we were going to... Now, in all honesty... She started out in biomedical engineering, and everything she ever did in college had to do with the brain... She’s a resident now, she’s a second year resident neurology... Who would never go into somebody and say those kinds of things, by the way... Now, you know, we don’t know... if Bob had not had the stroke, would she be in neuro? It’s impossible to say... You don’t know... you don’t know...

Jennifer is an engineer... she is a true engineer. And she’s also in business. She’s in with other people in a company...

It’s... it’s certainly... It’s changed the way everybody looks at everything.

That summer... is almost like a... silence... it’s almost like a... blackout to me...

I know Kathlyn came home from school, the one who graduated from college was there that summer. She came home, and... had a part time job at an engineering firm and really led me through the summer. Honestly, she led me through the summer... I really leaned on her then... And our older daughter was kind of close by because she was about two hours away, in South Carolina. So, you know, it really changed everybody...

Before the stroke, Bob had always been the person truly in charge, even when our kids were young adults... and he’s not now. The kids are on their own, they really are in charge of their own lives. And... I’ve had to... kind of... step out and also be in charge... So, instead of Bob being in charge of things, he’s not... so... family dynamics have completely, and entirely changed.

Jennifer is like him in personality.

[All of a sudden, Bob voices something from the adjacent room… he had probably been listening to the whole conversation up until now!]
Bob!!

[What?]

As they got older, of course, they didn’t like to be told what to do, so... Now... if Bob tries to tell them what to do they get angry, and they tell him,

“You can’t tell me what to do now...”

And Kathlyn too... But Bob still tries to tell them what to do...

[Bob starts laughing]

Like let’s see, hmm...

“Oh, let’s all go to the mall...”

“I don’t want to go to the mall, dad...”

“No! I decided let’s all go... let’s all go to the mall...”

Maybe that’s an overblown thing... But rather than him making this decision...He can’t make decisions for everybody anymore... that sort of thing... and he... he... he...

When Bob gets frustrated, he will tend to scream and holler... He thinks the louder he hollers... the better...

[The more... AHHHH The better it will be...Of course! Right?]

[Bob gradually enters the room]

No... it’s not funny...Bob...

[Yes...]

No, it’s not...

[Bob sits by her side and slaps her legs]

No, it’s not... when you get frustrated and then... be careful, Bob!

[What?]
While My Guitar Gently Weeps

As the interview comes to an end, questions start floating in my mind about the dynamics of the separate interviews. “Why did Bob insist on ‘eavesdropping on’ Diane’s interview?” I pondered. Diane had mentioned that Bob knew exactly what her perspective was on everything, but I still wondered how he felt. I was especially moved by his strong response to Diane’s comments about his relationship with their daughters. Even though I felt intrigued and wanted to ask more questions, I felt unprepared for the task. How can you probe on a sensitive wound without hurting?

As the three of us make conversation, waiting for the right time to leave for the aphasia group meeting in Sarasota (which I would attend with them later in the afternoon for the first time), I gather the courage to ask Bob something that had been in my mind for a while.

“Bob,” I start, “I was wondering… Would you be interested in giving me guitar lessons?”

Shaking his head sadly, Bob replies in a whisper, “No…”

“You’re not going to teach her? You can’t teach her?” Diane intervenes, resolutely. “I know you can’t teach me, but that’s a different story… I was a lost cause…” she says smiling.

“Yeah! Right! Really!” Bob laughs, shyly.

“Why was I a lost? Tell her why I was a lost cause…”

“No… rhythm…” Bob replies.
“No rhythm, there you go!” Diane comments, smiling. “But not everybody is like that Bob… No, not everybody has… has that sense… has that poor sense of music…” Diane says in a joking manner.

Feeling pressured as Diane and I gently gang up on him, Bob looks at me and caves in, “All right…”

I was ecstatic! I had learned how to play the guitar several years past when I was a teenager, and I definitely wanted to take it up again after so many years. Inspired by an autoethnographic piece written by my advisor, Dr. Hinckley (Hinckley, unpublished), where she worked with a client who was a piano teacher, I was hoping that by asking Bob to be my guitar teacher he would gradually return to his guitar.

“All right! Can I bring my guitar the next time I come?” I ask.

Looking at me between surprised and amused, Bob replies,

“I… I… lots guitars…”

“Oh, Bob’s got plenty of guitars!” Diane interjects.

“You have more than one?!” I ask, obviously showing I was never even close to being a really good guitar player.

“Oh, are you kidding!” Diane asks, laughing. “We have guitars…”

“Oh, God, many, many, many! Many, many, many!!” Bob confirms.

“My first guitar was from my… my grandma. She was the one that started to play guitar, and she composed her own little songs in the guitar, and all that… and then when I was… maybe 14, she gave me my first guitar” I comment.

“Me too!” Bob replies, a bit more enthusiastic.

“Really? From your grandma?”
“Yeah,” he nods.

“You used to play with your Mom and your sister, right Bob?” I recollect from the previous interview.”

“Yeah…” he says, “My mother… not a guitar, the pi…Pi-a-no…”

“Your mom played the piano?”

“Yes! And me… the… I the… trumpet… Many years!” Bob says with a deep sigh. “But better the guitar!” he concludes, laughing.

“And do you like to sing?” I ask.

“Yes… hmm… I have chorus…” Bob mentions.

“Bob does sing in a chorus at church!” Diane explains. Looking at her watch and ensuring we had enough time to drive to Sarasota, Diane suggests,

“Bob, why don’t you show her your guitars? We still have about a half hour until we need to leave for group…”

“All right.” Bob agrees.

As we enter the room, I am amazed by the number of guitars Bob has lined up in his closet, stored in hard cases. He did indeed have several guitars, and he looked at them all so lovingly, as if each specific guitar had a great story to tell. As he takes his favorite guitar out of the case, I ask him,

“Is it tuned up?”

“I don’t think so,” he replies and starts tuning it up. It was only then that I realized how hard it was for him to use his right arm to stroke the cords while playing. He hugged the guitar with passion and longing, and I could not help but think about what a great and inspired guitar player he was before his stroke…
Moved by his struggle and intense frustration, I realize we would probably not start having lessons together. I blame myself silently for asking too much and for being so forceful, and I hope with all my heart that I had not hurt his feelings.

Watching the sad beauty of his gestures, I ask him,

“Bob, can I take some pictures of you and your guitars?”

Smiling, he says, “Sure… go ahead.”

Figure 10. Bob in his element.
Figure 11. Dialogue of left and right hands over the cords.

Figure 12. Soulful strumming.
Figure 13. A glimpse into the past.

Figure 14. Twin guitars.
Figure 15. The Master and his Instrument.
Ask Me Why

It is only several months later that I contact Bob again and we schedule our last meeting. As we get settled to start the interview I notice Diane is not around. “She’s probably still at school” I think to myself. Reading my thoughts, Bob comments,

“Diane, you know… school I think… I don’t know, we’ll see.”

“No problem,” I reassure him. “In fact, I came today hoping to talk with you, so that’s OK with me!”

“All right!” Bob smiles.

As I lay my recorder on the table, I ask him,

“Bob, I listened to the recordings from the last two interviews and I was wondering… Your perspective on things and Diane’s perspective are really different.”

“Oh yes, oh God yes!” comments Bob.

“Why do you think that is?” I ask him.

Get Back vs. All Things Must Pass

I think… me… change, yes…

But… not really the… opposite

Some, yes, of course.

But Diane…

This way the first one and this one

[referring to before and after the stroke]

180! Really!
Me… No… No…
This many, you know?
90 degrees… Or… or more…
But… not… the opposite.

The stroke…
Of course, not good… but… you know?
So what? So what?
The another day, you know?
Move on, what the hell…
So… I do it.

Me the stroke…
Diane looking the stroke
Different…
Different… Perspective.

Diane three… four… five…
Really bad…
The first… the second…

Not day… Weeks!!
I don’t know…
I out!
And… Diane, “Ohhhhh!!”

So, you know, different…
Different… than me…
I don’t enjoy it!
But Diane…

I think… Me…
The rest of the time
Slowly slowly slowly
I… Getting there…

I like life!
Way back, yes… and… still!

[Diane mentioned that for you it was really important to have control
of things in your life…]

Oh, yeah! Ohhhhh, God, yes…

[When you had your stroke, I imagine it was like losing control]

Definitely…

Oh, God, yes!!!!
The beginning… Hard!
Bummm… [makes sound as if collapsing]
Rough...
Bad… really bad...
Big crash…
Oh, God yes!!

But… still… now… better…

Of course!
Not the same…
But… different…
But still… better… and better, and better, and better…

Me… Hard
But… I cope…
Diane… Wow… Really bad!
Really bad!

I think… Diane… Really…
The other way…
Me… [shrugs shoulders]
So what… you know?
Not work, yeah, I know…
Big deal…
But... I cope...

But Diane....

God!

Not cope…

Not at all…

Nothing!

[It must hurt you…]

Of course! Of course! Of course!

[Do you talk about it?]

[Sighs…] Well, yeah…

But not… You know?

Two or three… not… often…

Way back, yes… But not now…

Now… Good… you know?

But… ssessometimes… one or two years…

Way back… wow!!

Diane, angry!

Oh, God… yes… yes… yes…

Because… the… me!

Only me the… you know?
Way back…
Diane sit home…
And me, work.
Now… The other way!
For Diane, not easy…
Not at all!
Different… You know?

Way back, more… more… REALLY more…
More fun… more hmm… wake…
More… outwardbound
“Oh Hi!! Hi!!!! Yeah!!”
Yes… yes… oh, God, yes…

So, you know…
Diane knows that…
The other people no…
Not at all…
But Diane, of course…

So, different…
I cope...
Not lonely, not really
Because of friends, you know?
But I think Diane…
Knows me, and knows the way back
Really a lot of friends!
Before, many many!
And now… not… not at all…
Not at all…!
So different…

[Do you miss that Bob, from before?]

You know, me, no…
But Diane yeah!
Oh, God, yes, yes, yes!

[How did you move on?]

I don’t know…
I don’t know…
But I did… you know?
But Diane… No… Not at all…

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I’m Looking Through You

“Bob,” I comment, as I recollect events from the separate interviews, “How have your daughters reacted, in your view, to everything that happened after the stroke? I remember you mentioned that one of them is really similar to you, right?”

“Oh yes, yes…” Bob says with a sigh.

“How have you noticed changes in how you relate since your stroke?”

***

Daughters… Different…
Because now… not me…
The wife, the kids, you know?
And way back, me.
It’s… the hmm… me.
And no more…

Because… what?
The… little girls… and now…
[indicates they are grown up now]
So… Not me, you know…
So what?

Talk more Diane… yes!

[Because they’re grown up women, or because you
have your aphasia?]

Oh, no, the aphasia…

[Do you feel that they don’t know how to communicate with you, or… that they’re reluctant to… talk to you?]

Oh yeah, of course…
But… but I… I know…
So what? You know?

[Did you ever talk to them about it?]

[Silence]… Hmmmmm…
No… no…
Because three or four times… here…
Not very often… No… not at all…
So, you know
And me to go there… kids house, too
And I enjoy it!
But hmm… I mean… I… do it…
but hmm… kids, you know…
I know… something wrong, you know?
I can tell…
Yeah! Of course!
My girls, what the hell!
You know? I can tell…

Me the stroke, of course!
So… yeah… The two engineers!

[So you were a huge role model for them!]

The second, doctor and engineer…
And the first one the engineer!

You know? Yes!!

[Would you feel awkward sitting down with them and talking about it? Bringing up the subject that now things are different that you feel that things are different…]

No, not at all… I mean…
Somewhat…
But… this… different days, you know…

So what? Move on!!! You know?

Move on…

[You’ve really made your peace…]

Yeah! I mean… What the hell!!

What option, really!

“Ohhhhhhh…” Bullshit… you know?

***

As I listen to Bob I feel torn between my professional and personal history. When I started my first semester of school in the United States, I went through the experience of
losing my father, miles away, in my home country. I felt fortunate enough I had the opportunity to fly in and see him, hours after he had passed. As I stood beside him, hands cold and crossed on his chest, I felt a wave of repentance and pain, a desire, stronger than any emotion I had ever felt to tell him so much… So much that I wished he knew… I loved him more than life itself, and he was the first person I had ever lost. As my life flashed in front of my eyes, from my first bike ride to the moment he took me to the altar, the pain just ripped me through my insides, and tears rolled down my cheeks, uncontrollably.

Sitting in Bob’s company that afternoon, I wished he could reach out to his daughters, beyond the surface, beyond the routine. I just wished those two strong and determined engineers would never, ever feel the same pain I had felt two summers past…

**Free as a Bird – Drive My Car**

Trying to compose myself again, I ask,

“Bob, have you ever felt as if you were caged in?”

“Way back, yeah…” he replies. “But… the door opened… many years ago… I wanted go out!!” he says with a chuckle.

“How did you find the key?” I ask.

With a wide and somewhat bittersweet smile, he answers,

“The first year or so… cage in the house, in a room, in bed. And then… the… drive… no drive… You know? And rehab… Oh, boy… In the hospital… rehab feel like cage…” he comments with a sigh. “I wanted… out… Really out…”

“Did you feel that way because of the therapists?”
“Oh, no… Therapists beautiful, beautiful!” he explains, “But… Same meals you know? And… the bed… ugh… Oh… On, and on the bed… you know?” He sighs, “Tough… you know? Big cage, rehab.”

“How was it when you got back home?” I inquire.

“Well, in beginning, caged in at home as well… downstairs… because… not upstairs… And slowly… I remember the first one… upstairs…”

“You remember the first time you went upstairs?” I confirm.

“Yes!! Yes!!” Bob says, “Right! And the car… really, the car… good, because… FREEDOM!! FINALLY!!! You know? One month later! The car, hope…”

“Really?” I ask him.

“Oh yes!” he says, nodding, “Car, hope!”

**We Can Work It Out**

Diane and me now?

Well… Good and bad, really…

Good is… three or four years ago…

More speak… talk each other more…

And the kids, too, really…

Way back, not at all… right after stroke

The bad…

Because… [Starts laughing, a bit shy]
No sex! Well, some… finally!

[Who was it that would avoid it?]

[Silence…]
Me… I think…
Why? I don’t know… I don’t know…
Now, yes! Yeah, you know?”

Diane… Beautiful, of course!!
And I speak… really! [says with great tenderness]
And I mean it!! I mean it!!
Oh, God, yes!! Oh, God, yes!!
Beautiful! Beautiful!! [Sighs…]

So… the only bad, I guess so…

Now, life… in between, you know?

What Goes On In My Life

As we come closer to concluding our interview, I ask,

“Bob, what do you see in your future?”

***

Now… In my life
Once a week, I go to… Old home…
Nursing home
And just work…
And… I speak… and…
One… [Silent… eyes swell up with tears]
The… die…
A lot older… a lot older me…
But still… I…
I don’t know why…
But I… get attached…
Tough…
Because the… stroke…
I know… what it’s like

I think next year I hmm… the wheels
Meals Wheels…

And golf…
Friends… Good friends!
“Slow down! Slow down!”
Oh, hard!! [says, laughing]
But group, rewarding
Mrs. Paul
Curt, Tom, Larry,
Beautiful!

***

Noticing I had completely lost track of time, I jump to my feet and exclaim,

“Oh, goodness! I was just so engrossed in our conversation I forgot I have an interview scheduled today with Tom and Erika!”

“Call!” Bob suggests, and I reach for my cell phone to warn Tom and Erika I would be a few minutes late.”

As I gather my gadgets together, I turn to Bob and thank him profusely, once more.

“No sweat,” he smiles.

Getting ready to leave, I notice Bob and Diane’s pet walking quietly in circles in the dining room. Taking my chances, I come a tad closer to him and stretch my hand. For the first time, the beautiful animal comes closer, sniffs my palm and allows me to pet its soft and profuse fur.

“Skittish,” Bob comments, “but slowly, slowly…”

Ecstatic with the honor, I give Bob a grateful hug and embark on my next journey.
Chapter 7. Light Bulb!

Larry and Sue’s home, on a warm and torrential morning in Sarasota. Waiting for the storm to let out, we sit at their cozy kitchen table, casually talking about the next meeting of the Sarasota Memorial Aphasia Group.

“There are about eighteen of us in the group,” Sue says, “and one of our survivors is an artist. She started painting about 8 years ago, not long after she had her stroke.”

“She never painted before?” I ask.

“No, never. She’s incredible! She does watercolors, she does flowers. I’ll show you a picture she painted of the Ringling Museum. Hold on!” Sue disappears briefly, and returns with a small watercolor, with bold and soft colors blending harmoniously. It reminds me of Monet’s *Cathrédale de Rouen*.

“She did this from a small photograph…” Sue says. “I think it’s incredible!” I look at the painting. It is quiet, peaceful, but resolute. The brush strokes are firm, but not rigid, allowing the colors to dance with ease. I lose myself in the small scene, trying to imagine the hand who painted it, and wondering what allowed that hidden talent to blossom.

Noticing my interest, Sue continues. “Edie lost movement on her right side after her stroke, so she paints with her left hand. When Leslie got married, she painted her a beautiful scene of Siesta Key, with the sand and the beach… It was unbelievable! We all think that Edie is going to be a very famous artist someday! Wouldn’t she be a wonderful
person to incorporate in your paper?” Sue asks. “If you come to the next aphasia group, she’s always there with her daughter, Cathy.”

***

Venice, August 2nd, 2004. Given my infamous luck with directions, I gladly accept to follow Bob and Diane’s lead to Sarasota Memorial Hospital for the monthly aphasia group meeting. I tailgate them faithfully through a succession of bends and turns which I could never retrace from memory. Despite the traffic, it does not take us long to get to the hospital. We park in the garage and look for the elevators. As the three of us walk down the wide hospital halls to the aphasia group room, we run into a tall lady, head held high, walking with a four-point cane and a large artist’s bag, overflowing with paintings.

“Hi Edie!” Bob and Diane hug her. “Where’s Cathy?”

“Parking car!” says Edie, pointing to the garage.

When we finally get to the meeting room, therapists and the other members of the group greet us warmly and get caught up on the latest news. Noticing Edie’s bag, they all gather to see her most recent paintings. With eyes wide open, we collectively travel from tropical lush greens and glowing crab claws, to peaceful beach scenes, and meadows of flowers which would make Monet proud!

A couple of minutes later we hear footsteps approaching in the hallway. “Hi everybody!” says Cathy as she enters the room. “Today’s Mom’s birthday, so help yourself to cupcakes and something to drink!” With cupcakes in hand and drinks served, everyone finds a seat around the large room. Edie and Cathy sit side by side. Two
generations of a quiet and tempered strength. That night, I leave the room as if walking in clouds: Mother and daughter had both agreed to participate in the interviews.

***

I pull into the parking lot of Ms. Edie’s retirement community and give my name at the front desk. “She’s expecting you” the lady says courteously. “Third floor - hallway on your left.”

As I ascend to the third floor inside the roomy panoramic elevator, I notice a large painting hanging on one of the walls. It is a montage with four scenes portraying the same street during the different seasons of the year. I wonder silently if that is Ms. Edie’s… It does have her style!

I find Ms. Edie standing by her doorway. She welcomes me into a quiet apartment, full of light. A large window lies above a drawing table, covered with brushes, watercolors, and papers. I take a seat close to Ms. Edie, and without knowing exactly how, we start talking about her husband. To my amazement, I find out she divorced him not long after her stroke, after being married for forty-one years.

“Poor me… Poor me!” Baloney! Baloney!

The doctors say my husband…

“You know, your wife is very sick… be careful… because maybe have a…
Your wife is…. hmmm… dead… Or… is a coma… and hm… vegetable.”

“Vegetable!!? AHHHHH!!

My world!!! My world!!!
You did it! You did it!"
Ruined! Ruined everything!"

Me, confused…
I did that?
Months, me, depressed…
Have happy pills…

Wait a minute,
Wait a minute!
Something goofy here!

My brain… Well, have a stroke!
Big deal!
That’s all!
Ok!

What to do, what to do?

One day
(I remember clearly, clearly!)
Light bulb!! Big light bulb!
You know what? I have a divorce!

Good! Is amazing!

He was crazy

He was drunk

Kitchen

Lots of times!

Fall down, and hm…

Wacking…

Hearing… and …

Blows… and…

“Ohhhh…” with telephone,

“Cathy, Cathy! He’s coming!

He’s… he was very… drunk, and… have a blood here…

I can’t do it…”

He’s drunk…

Worried…

Nervous about husband…

He was… in problem!

Alcohol…

And every day, what to do… what to do…
Cathy, help me!

Chris is drunk again!

What to do?

Two years…

Three years…

And more…

More…

And then,

Light bulb!

***

[Several days later, sitting with Cathy in a quiet room at the retirement home]

Things didn’t get really terrible at their house until about 5 years after Mom’s stroke. I thought, “Where should Mom live”? Because… Dad was just… Crazy!! I mean, drinking to falling down, and Mom would call me screaming bloody murder… “What, what oh…. Cathy!!! Oh!!!” Just crazy!! [Her eyes swell up with tears, but she contains herself. I sit across from her, eyes open wide so my tears will not fall]. And… and Mom … left, you know, at one point, “Come get me, come get me,” as best she could communicate… and… I brought her to my house, and… trying to formulate a plan, you know, what’s gonna happen here… and… and she insisted that he had to go to… rehab… you know… which he… went to eventually, and stayed for 2 weeks and left. Got tired of it and left, “This is stupid, I don’t need this.” And… So… Then we take her… back… and
show up at the house, and there he is on the sofa, with a jug of wine sitting there... So she’s just... [deep sigh] shattered... and... [tears swell up in her eyes, and I can barely contain my own] So it was an... ongoing mess... but... it turns out... I didn’t know it as a kid, but... he did just... stupid things... [silence]

**Gruas y Cucarachas**

“My history?...” Edie thinks for a while and then continues “Hmm... My hmm... birth... hmm... Chicago, and... then... my Dad have a... after the war, hmm... WWII, and... a had job for liquor store business... liquor hmm... distillery. And all the family go Mexico city, and m.... also grandma coming, all Mexico City, and no Spanish! Everybody, ‘Ok! Venture,’ you know? Venture!’ But I have 10 years in Mexico City!”

“So you lived for 10 years in Mexico City?”

“Yes!”

“How old were you?”

“Ocho, ocho!”

“You were eight years old? So you speak Spanish?”

“Yeah, but, you know... I understand Spanish, but is... vrrmm... the stroke... blup!”

“Really? The stroke took most of your Spanish?”

“Yeah... was... once in while have the wrong numbers, numbers especially, because what have as child for the... counting... and the money... is strange... maybe have a... the word for strange people... Cucaracha! Grua! Hmm... It’s different... It’s my brain, poopoo, poopoo, and that’s all.”
When my mom was a kid, she knew... she was very close with a family, and the husband... Well, he had a totally separate life from his married family. I guess he had a mistress some place, and the guy would never show up. But, when he did come back to the home, with the children and all, the wife would... do his dirty laundry that had accumulated while he was off with the mistresses...I guess mom... saw this girl who was so... traumatized by this... crazy, obviously crazy situation, and I think mom thought, well, let’s... kind of keep things... keep the peace.

To the best nurse, with love

“And after Mexico City, Ms. Edie? What happened?”

“And nursing school in… hmm… Baltimore, John Hopkins. Scholarship. Three years scholarship.”

My job

Years go by...

Have a nurse

Nursing!

Operam nursing.

35 years.

Ever different, every day something new!

Oh! That’s good! Oh, good!
It was everyday!

Different patients,
Different doctors,
Different hospitals
Very comfortable.
Very calm

Operam room
Have a hand cut off, and then… oh…
[Re-attach?] Yeah, yeah!

I'll tell you everything you do and…
It's calm…
And doctors, good doctors, very good doctors
It’s hmm…
My sense that calm is very important
Calm people

Nervous
What’s the uh, uh!!! Hmmm!!!
Patient
Operation
Very scared everything!
Everything!

I'll tell you everything here
Don’t worry
That’s just here… and the… pressure… [gestures going down]
And then 5 minutes
And the pressure - It’s amazing! [gestures getting stable]
Very calm!

“Oh, how are you, and… you children?”
“How many children?”
And then talking, talking… [gestures pressure going down]

Is amazing!
But my sense… talking one to one…

“Oh, I have a… doggy or something?”
That’s something good…
Then [sound effect of pressure going down]
That's good…

That's good…

***

Edie points to a plaque on her wall.

“Oh, is that your award?” I ask her.

“Yes, yes!!”

“Can I see it?”

“Yeah!”

Carefully holding it in my hands, I read the inscription “The caring award, chosen by the nursing staff as the RN who practices the art of nursing with exceptional skill and genuine concern for others!”

***

I got a B.A. degree in health planning and administration. I worked as a nursing home administrator and… it was horribly frustrating to me… to have inspectors come in… and… find fault with all sorts of… issues… related to nursing… and not have any… idea what they were talking about, or why that was significant. It was a mess, the whole business part of the healthcare was just… a mess… and… so I went to nursing school… because I was always interested in health, but found that the business side of it was just… Crazy!

So that’s… how I think that I got into nursing… But then also…

When I was a kid, a few times at least, mom took me to work with her, and she worked in the operating room. In Kentucky, at the trauma hospital, she took me in at
least a couple of times, and I saw fingers being re-attached, and all sorts of things, so…

I’m not sure how, exactly… but that’s part of it…

Cupid’s Broken Arrow

“How old were you when you got married, Ms. Edie?”

“How…” She searches for the piece of paper where we were keeping record of the dates and writes 20 in neat handwriting.

“You were 20 years old?”

She nods.

“My goodness! You were really young! How did the two of you meet?”

“And the hmm… high school.”

“Were the two of you high school sweethearts?”

“No, no, no, no…” She responds emphatically, “Hmm… date, eh… Blind date!”

“Blind date? Really?! How did it happen?”

“Emm… you have the… the… nursing school, and have a… lots of… girls and… hmm… one the girl ‘I want to have a… artist… no…hmm army man…’ ‘oh come on, more men is, three men is… hmm…” ‘That guy like… dying…no… sigh…” Date. Blind date. Then… three girls and three girls [guys]… armies… that’s all. Uhm… after… hm… February… March… and… something…” searching for the paper once more, Edie writes 5 weeks “This one here… all the way… marriage.”

“Oh wow!! Really?”
“Yea!! Yeah!! Yes, my… friends hm… hmm… nursing home [school], ‘No, be careful! No, no!! Oh!! Slowly, slowly!!’ No more… I don’t think so, I don’t think so… Yes!… marriage, good, marriage!”

“You wanted to get married right away?”

“Young! The man is perfect! But the… the… nursing school … the… very… young people… adult people, they say… the… nursing staff they say, ‘Yeah… oh oh… be careful… something happened here, be careful! Maybe your dad, the telephone contact, because what’s the matter? Your your daughter is is getting marriage… you understand??’ And they have a… my dad have a… hm… telephone…me…”

“Your dad called you?”

“Hmm… Mexico city no telephone in house… but my hu… my Dad have a… job… and then have a … ‘Well, I don’t know… I I couldn’t do it… I say is bad or good. I can’t do it! You decide!! You decide!!’ And then have a… ha… telephone… hum…”

“Telegram?”

“Telegram… hospital, the… John Hopkins, the nursing school… ‘Ok, my husband… my… daughter is all right, all right…” Because everybody, ‘Wait a minute!! Something goofy!!’ But anyway… that’s good.”

“So you fell in love with him at first sight?”

“Yeah… 5 weeks! But now… divorce. Problem… he wasn’t good… But that’s all right.”

Moving Saga

The husband… hmm… ah… he
was army... 2 years army. And then go to hmmm NY city. He was a pof... accountant... school... 1 year... NY city. Then my husband said, “You know, I think so professor, good idea... it’s no money, but is good…”

I was born in Alabama. We were there for about 2 weeks. Dad... I think maybe he got his Master’s there...

So, Alabama, one and a half years... Paper... [Writes June 1961 - August 1962]. Here, and then all the way, then August... Cathy... One year a half... [You were there for a year and a half before Cathy was born?] My husband he have a job in the summertime, all the year, to summertime, that’s all... [So he started in June of 61 and he got his Master’s in 62 before Cathy was born? And he got his Master’s at the same time? In one year?] Very close because hmm... Final test,
very important, the… here…

[Friday] and here, Cathy [Sunday]
My husband have a final exam…

[writes Friday] [On a Monday? I
ask] No… [On a Friday!] Then test,
and the baby is coming! I did that!
You have your test, calm down,
baby is coming, but… [So you were
calming him down with a big belly?]
Hot! Hot! Hot! Summer, Alabama!
But, calm, calm, calm…

Then we moved to… Tennessee, I
think... We lived there for... a year...
year and a half. I think he taught at
Vanderbuilt...

Then we lived in Ohio for a short time...

Then moved to Indiana...

Then moved to Kentucky. West
Virginia we just lived there for a short
period, like for the summer, because he
had a job starting at U of L ... in the
fall... And then he was at U of L for a

Louisville, KY, the University of
Louisville. The children almost…
ten, thirteen… fifteen years going
to school in Louisville, was good.
Then, my husband decided ‘How
long time, teaching... and he got his JUD at U of L. about lawyers, lawyers?’ He was the professor in the night time lawyer, lawyer.

Then moved to Illinois, U of I, Champaign-Urbana. Dad was getting his Ph.D. there... and... In Illinois I did my junior and senior year of high school and college, And then... 3 years, 2, 3 years... you know... we go to... Champaign-Urbana University hmmm Illinois and more studying for doctors for... [Ph.D.?] Yes! The accountants... Oh... My God!

And while I was in college my parents moved back to Kentucky and then to Florida.

Mom was a nurse, so she could get work anywhere. My husband had a job... University of Tampa... [writes down 1983]

So, hmm... lived lots of places... Me? My job nursing, everything is good! Have a good hmm... money. Ocho... Ocho states...

Figure 16. Edie with newly born Cathy in her arms, and her husband.
“That’s you and Cathy, right?” I ask Ms. Edie, pointing to the picture on the wall, above her nursing award.

“Yes, yes!”

“Is she a model?”

Ms. Edie laughs. “No, no, no!!! The… glamorous shop… pictures, pictures. [It’s an organization that has set up places, usually in the mall… And you go in, and you… hmm… You have your hair done, and your makeup done, and you pick through their wardrobe selection.] We laughing, and joking around!! Makeup and fancy outfits!! [It’s like… a photo shoot, or something… and hmm… they put you in all… you get to pick out your outfits, and they recommend backdrops, and then they recommend poses, and they say, OK, now, turn your head, lift your chin… It was fun, you know, to get to dress up, and get your hair done, and get your pictures taken. The picture is… It’s since the
stroke, so… hmm… probably, let’s see… it’s been almost 10 years now… so probably 6 years ago… or something like that…].”

“You two seem to have lots of fun together!”

“Yes! Cathy is… is… I can’t believe it! Is… eh… my daughter is… friendship… you can’t believe… good friendship… more… loving, but is… one to one… is everyday! How are you?’, and… I tell you… Is amazing!! Is good mind, and heart, and… is… My angel because otherwise I can’t, I can’t talk!! More doctor’s appointments, and… the… husband… Cathy… husband John, he is an accountant, and where was the money, and… the… bills, and… is everything…”

“So they helped you take care of care of everything!”

“Everything!! Oh, thank you, thank you!!!” Ms. Edie gestures, thanking Cathy and John. “Amazing!!”

“Is she your only child?”

“No. My son, two year difference. But… is different… My son is… my husband is saying… ‘No telephone contact… birthday & Christmas, that’s all.’ But Cathy…” Ms. Edie sighs and smiles. “Every bit… Child, how do it… help me, how to do it, help me, what to do… help me, help me… help me… Amazing!”

“So she helped a lot around the house, even as a child?”

“Yes! My son… good friends, outside, we don’t know! But Cathy, yes, help me for grocery store, ‘I’ll do it!!’ Be… be careful, be careful!! ‘I’ll do it, I’ll do it!!’ Is amazing!! Is good!! Is amazing! I don’t know why! You never know?”

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If I was close to my parents? Oh, close to Mom! Dad was sort of a “non-player.” Too busy doing other things... Apparently he felt like he didn’t have any responsibility to do anything at the house. So mom had to clean the gutters, and mow the lawn, and strip the wallpaper, and paint the house, and put up wallpaper... [It was my team! We have a good time... Laundry done... mowing lawn... but I was worried that the... mowing the lawn because I was nurse for operate room, the child is very scary because of mowing the lawn is ...It's something... I'll do it myself... yep...]

It’s not until later that you look back and think... hmm... he was never there... Stuff that... I didn’t know about as a kid...

A lot of stuff has come out. Since the stroke, I have come to understand that... Motherhood and married life was kind of hard on Mom. I think I... perhaps... was her buddy... because [lowering her voice to a whisper] Dad was a son of a bitch, which is terrible to learn now.

I suspect that... because he was so terrible to deal with, and because I was always around, I was sort of her helper. He wouldn’t do anything. Painting, or wallpapering... he just wouldn’t have anything to do with any of it. So Mom and I did things like that. So that’s probably part of the picture that she paints.

Can’t talk!

My voice

Talk not very well

I have a stroke and very sudden
I couldn’t talk nothing!

I understand **everything!** But…

I can’t talk very well…

But anyway

Big deal… you know…

Oh well, Make speech therapy

It was worried about

The have aphasia… hmm… therapies and…

“Your nose…” Where was nose? I don’t know…

Nothing…

Is bad!

In Michigan, speech therapy

Very intensive!

Summer time, here… 3 weeks.

Weeks? No… no… weeks… this one…

This one… Two, two…

6 weeks! A lot of work!

Ohhh! My brain!!
Oh my god!!

Anyway…

***

Normally you only get rehab for 6 weeks or something, so we looked for other centers where they work with people longer after the stroke, to do home programs… We went to that a couple of times… and each time for a week, six months apart or something… My Dad went with Mom to the University of Michigan Aphasia Program up there… [sighs]… He went with her for the majority of time.

The summary version… His summary view was… that… they’re taking advantage of people they’re not really gonna help… and… he resented… I think… he… felt maybe I was pushing… to go and… “Try this, and do this,” and… I’m told he had a… confrontation with… somebody there, I don’t know who… and said, “This is a crock, you’re charging people thousands of dollars and… you don’t have any proof that they get any better! It’s not right to… feed on people’s hopes, and have nothing to show for!”

[Cathy stops briefly and continues]

I… I don’t see it that way… I think… it was of great value to be in a place where other people are like you…

[Almost starts crying… I wish I could reach out somehow, but I don’t know what to do. We both sit in silence.]

And… hmm… that… if… even if she didn’t… even if she wasn’t… Why is this upsetting me!!…

[She exclaims, surprised that her emotions are still so strong]
Even if... she wasn’t speaking in complete sentences... I think she was with a lot of people who were also struggling to communicate, and saw lots of different ways to communicate... So, I thought it was good, but then... I thought it was beneficial, but then... I didn’t have to spend... you know, four weeks, or five weeks, living in a dorm, with Mom... and Mom being... hmm... Let’s see... Mom was a really good student in high school and college, so it’s very important to her to do well with teachers and tests, and stuff like that... so... it was really frustrating to her... to take the tests... and Dad saw that.

***

Mom... Hmm hmm...

What was the name of that speech therapist at Blake Hospital? Was it Karen Jones?

How was she different than the others? I remember you really liked her!

Yes! Karen... All the... hmmm therapists, walking there... [indicating rush] but the lady is calm... Okay... slowly... slowly, calm... Don’t worry... my voice... bla voice [harsh] slowly, calm... don’t move... too much talking... Tension... because of what the... she said... it’s all right... calm calm... is a... is very important...
because is… have a… the stroke and suddenly what happened? I can't talk!! What is… is very important the lady… that's good… amazing…

*I thought so... She was... in the midst of all the turmoil that she was calm, and that she had more of a sense of what you were going through. And that you were better able to communicate with her...*

Yes... Is very important!

One hand, one hand... What to do?

“How did you discover painting, Ms. Edie?”

“No... nothing special... but... One hand... what to do? One hand... Maybe painting because otherwise is... is gone! We’ll see... I don’t know... maybe have a... teacher, or... High school age... We’ll... we’ll see... we’ll see. The... the... first time the teacher is... let’s see... I can’t talk very well, but I want to know... maybe... with hmm... waters... Try. Anyway... and everydays simple tricks, and what to do... and... colors... and... more and more, and more, more!!! Is... amazing!!”

“So you took classes!”

“Yes, yes!!”

“In the beginning you took classes?”

Ms. Edie shakes her head. “Right now have hmm teacher, Sarasota, too!”

“Oh!! So you continue taking classes!”

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“Yes!! The… I like so much lady is very gentle… and… is… tips what to do, and… hm … I understand everything, but… maybe have to repeat… the… is … colors, different, or dark, more dark here, and… the other is all right… but we have a good class, good class! Wonderful… the… lots of people understand I have a stroke, and they… oh, it’s all right, I understand! We have a good time! You, you… colors different, colors… we are all… we have good time!”

“How long have you been painting since you had your stroke?”

Looking for our paper and pencil, Ms. Edie writes down. “This one here... this one... January 1st...”

“So it was a new year’s resolution?”

“I think... well…” She laughs “The time... the class’s time…” indicating that was when the classes started.

“What materials do you like to use? What’s your favorite medium?”

“Hmm... Watercolors! Very...”

“Soft?”

“Soft yes, but… Bold, and colorful! Or... very softly... But... anyway... is fine… but… my… very important… hmm… calm… everybody calm… water… Very calm, no… telephone, no nothing... very calm! Very calm here…”

**Seasoned Sailor**

“Sailing?” I repeat surprised, ensuring I understood Ms. Edie correctly.

“Yes! Yes!! I try anything!” She replies, smiling.

***
My sailing… my sailing… Very small…very small boat…

All people is nervous…

‘Ohhh ohh, scary!!’

But I…

Because my husband knew,

We had a boat, years go by,

10 years

Understand the waves, and… winds, and… what to do…

Is fun!!

Windy! More, more!!!

Hmmm… Sprinkling, and…

Fast!! The wind is coming!! [gestures with her hand]

The keel, all the way, keel!

My brain is no worry

No problem now!

Quiet… quiet…

No motor boat…

Myself…

Myself…
Myself...

I'll do it myself...

I don't know what...

I have a... I have a stroke,

But painting, sailing... I could do it!

But that's all!

***

I watch Ms. Edie silently, as she gradually brings a flower to life with her watercolors. Her left hand is steady and calm, as she gently allows the flower to bloom on the rugged paper. She seems centered, at peace, completely in her element. I imagine this is what she looks like when she is sailing, or when she was talking, firmly but serenely, to a worried patient in the operating room.

Figure 18. Edie painting in her apartment.
Figure 19. A glimpse at Edie’s palette.

Figure 20. The artist at work.

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Feel Changes?

Oh well... very different... but same.
Hmm hmm...
My job, and...
my hmm... car...
the grocer, I did that and... everything!
Everything! Is different...
But... That’s fine!

You know... I have the stroke...
Now my colors... more colorful!!!
My... my... colorful... more colorful!

[Well... your color perception is sharper.]

Yes! Yes!
Notices colors, things...

We have a driving for doctor's appointment...
“Cathy, Cathy! Look at the flower!”
“It’s driving, Mom!”
“But Is good!!! Look!!! Is amazing!!!”

Is colorful!!!

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Oh my God! Everything is colorful!
The sky, wonderful!
All, all the... the... flowers...
Hmmm clouds,
Colorful no, but...
Almost very cloudy day,
All the cloudy day,
And then, almost hmm...
Snowing coming... snowing...
Sky and... the... danger...

I don't know...
Everything...
I try anything.
My brain is... wonderful colors.

***

I suddenly remember the painting on the wall of Ms. Edie’s retirement home.
Four pictures of the same street, during different seasons of the year. Same... but different.
### Figure 21.

Edie’s “The Four Seasons.”

***

*I get the sense that she is... now... [silence]... more likely to... say... how it is... you know, rather than...saying things... that seem right... or that... people would want you to say. It’s not that she is unkind or anything, but... She’s maybe... Well, she’s definitely less willing to put up with crap, from dad... and... and she... and it’s so...

[Silence. With a quivering voice, Cathy continues]

... helpful to me... that she’s... sort of matter of fact about it... because of the two of us, I am more... I guess emotional about it...
Yeah... the mess it’s turned into... and she is more... sort of... matter of fact about it... and... when he sends crazy letters... they seem to affect me more... because they remind me... what a mess things are... and how crazy... but she is... she just says, “He’s crazy!” And she doesn’t... regret... which I don’t understand, but she doesn’t regret her life with him...

I don’t understand how... [almost crying]... well... it’s hard for me to think... that her life was crappy before... I think it’s crappy now... it’s hard to know... that it was crappy... for all those years when she was normal! But she... [silence]... you know, she can look at old pictures... and she doesn’t... have bad things to say...

Dad... I don’t know... I don’t know... When he got so crazy before she left, he was dreading to do... I mean... just crazy stuff... crazy... and... I have... I suspect... that... [silence]... We talked to the counselor person... that... why would she stay, and... the counselor said... well... it was her choice... and... she may have had... things... in her... in her past... or... growing up, that... caused her to make certain choices... and...[silence]... I suspect... that one of the big reasons people are supposed to stay married is because of kids... and so... [silence]... I hate to think that [almost crying] she stayed in that crappy situation because of me... [silence]... But... Dad has implied that it wasn’t always terrible... and... I guess... certain parts were not... terrible... so... hmm... and I guess it’s... good that she is more matter of fact about things, because if she was emotional about all this it would be really difficult... I mean... hmm... [silence]...

I didn’t recognize, before... well... I didn’t think, before, that she was... very strong... emotionally... I thought that she... and she was... I mean, she was not... probably as strong emotionally... as... she... should have been... if... assuming that the
thing to do would have been to get out of that crazy situation... I mean, it would take a strong... it takes a person to get out of that situation, but it also takes a strong person to stay in it... Do you know what I mean? Hmm... But my sense, before, was that she was... pretty passive... I would think... I can remember thinking that of her... and... maybe... she was like that because she was trying to keep the peace, you know? As a teenager... You’re not aware of it, or, can’t see all the elements... hmm... but now... I appreciate how... hmm... emotionally strong she is... and matter of fact, and... hmm... [silence]... there are lots of times where she’ll say... “Don’t worry about it..., just don’t worry about it!” because I’ll... sometimes I’ll get... hmm... sigh... kind of unfocused on what’s important... because... I want to do things that will help her, but sometimes I have to say, now: what is your priority? Or what... you know? To help me... focus on... what’s important to her.

I appreciate... I appreciate her ability to focus me on what’s important... and on... hmm... and how willing she is to... do new things, or handle things, or... like her art class is starting again tomorrow... the semester starts... and hmm... hmm... she... arranged... that... her art classmates would take her... to get signed up for the class, because it’s something that I had always had to do, and fit into my schedule, and... ideally you get there... at the crack of dawn to sign up, and like... I could never make it... and... so this last time... I’m not part of the class, so I don’t know how it came to that exactly, but it ended up that she went there and signed herself up with some people in the class! So that was nice for me because then I didn’t have to figure out how I am going to get there, and what time, and how am I going to work out my schedule.
Actually that's one of the things that I learned at the aphasia conference in Tampa, was... Speaking Out!, yes, was... The best speech therapy is to have to communicate to get things you want done! It’s not sitting and saying the red truck went up the hill... it’s... hey, sign me up, here’s my credit card, where do I sign, I want that class... you know, all this stuff... so hmm... and so I appreciate that she’s willing to do all that...

***

Sitting in the quiet apartment with mother and daughter together, I ask if I can photograph them close to their Glamour Shot picture. I notice Cathy gets close to her Mom and whispers something to her, quietly. I then realize she was telling Ms. Edie that her hair was sort of bunchy in the back, like it may tend to be when you go to bed with wet hair and your hair is short. Ms. Edie laughs, and leaves for the bathroom to get her hair fixed up for the picture. When she returns, Mother and Daughter give each other the final beauty touches and we have fun with an improvised Glamour Shot.

Figure 22. Cathy and Edie in front of the Glamour Shot picture and Edie’s nursing award.
Figure 23. Mother and daughter posing in our improvised Glamour Shot.
Figure 24. Improvisation number one.

Figure 25. Improvisation number two.
Chapter 8. The Rebirth of a Salesman

Young Diagnosticians in the Field

End of fall semester, 2003. A young blonde man, wearing a cap and comfortable clothes, sits across from a tall and skinny clinician in the speech clinic. A box with a variety of objects and a thick stack of cards lie neatly between the two, while a small tape recorder faithfully spins its tiny cogwheels capturing every sound exchange with methodical accuracy. As the clinician strives to remember all of the details for the proper administration of the standardized language battery, the young man focuses his blue eyes on each card presented and tunes his ears to every word uttered, trying with all his might to respond to all questions to the best of his ability. Quietly, in the semi-darkness of the small observation room, my friend and I watch the testing session, neuroanatomy books in hand, trying to diagnose the type of aphasia the young man possibly had.

“He may have Broca’s” I suggest. “His speech is non-fluent, hesitant, but his auditory comprehension seems to be within normal limits.”

“How about his repetition” she inquires. “I think he can repeat pretty well. Wouldn’t he be transcortical motor?”

Ironically, as we carry out our theoretical discussion, the young man’s struggle to reach the correct articulatory postures for speech production passes largely unnoticed to us. His apraxia of speech, clear to the eyes and ears of an experienced clinician, flies right over our heads without ever triggering our radars.
After we leave the observation booth, I feel shaken. “He’s so young…” I think to myself, “I wonder when he had his stroke and how it happened.”

As the semesters build up on each other and I become more familiar with the environment of the clinic, I hear bits and pieces of Tom’s story. “He was in the golf course when he had his stroke.” One clinician tells me. “I think he was thirty-nine when it happened. He didn’t go to the hospital right away, I think it took hours until one of his friends noticed something was wrong…”

A few days later, while working at one of the computer stations in the student workroom, I inadvertently eavesdrop on a conversation between two student clinicians. Perking my ears, discretely, I hear from behind the lockers,

“He’s gotten married recently!” the first voice says. “Oh, good for them! Did they elope?” the second voice asks. “Yes,” says another clinician, “I think that’s what he said in group! He brought pictures also!”

The more news I heard, the more my curiosity grew. How did the bits and pieces of Tom’s story come together? At home, silently working on my study notes, I wonder about the story behind this man.

Figure 26. Erika and Tom in Las Vegas on their wedding day.
First Client Assignments

Spring semester, 2004. Sitting in room 2036, all first year clinicians wait anxiously for their client assignments. As Miz Paul, the clinical supervisor, hands out the last assignment she says with a huge smile,

“This is my baby! Take good care of him!”

Slightly shaken up and amused, Merete, a fellow clinician, says,

“This is such a great responsibility!”

“Yes, it is!” Miz Paul replies. “He is the youngest member of our group, and he’s improved a lot since he started! So you be good to him!”

As you may have already guessed, the baby was Tom.

***

As with Larry, I never worked with Tom directly in individual therapy, but we interacted frequently during group. All clinicians would frequently tease him because he blushed intensely every time he talked about his wife, Erika.

“I loooooooove Erika!” he would always say, with a huge smile, as we asked for more details about this wonderful woman he so truly adored.

A few weeks into the semester a new person joined our group. She looked very young, almost like a teenager, and at first I remember thinking she was a new clinician observing one of our group sessions. We later found that not to be the case.

“Hello everybody,” Miz Paul said, addressing the group. “I’d like you to meet Mary. She’ll be joining us for group today and maybe for the remainder of the semester.” As it turned out, Mary had had a very recent stroke and was going through a turbulent transition in her life. She could communicate effectively, but reading was difficult at
times. During groups, all clinicians noticed she usually turned to Tom for help and frequently buddied up with him during activities. Tom was always very glad and willing to help.

One day, as we all gathered in front of room 2036 to start our group session, we notice a short and trim brunette standing close to the door. I remember my attention was caught immediately by her eyes, large and green, and her wide and generous smile. A few minutes later, Tom approaches her, and passes his arm lovingly around her waist. “Is this Erika?” I wonder.

As we all enter the room and find our seats, Tom stands up and addresses the whole group. “Hello, everybody. I… I… want you all to… meet my… wife, Erika. We got … married, Las Vegas, and I love her!!” The whole group hoorayed and clapped, and the blushing couple sat down, close to each other. Mary, who was present, never said a word and group activities progressed routinely.

As the clinicians left the room and got together for lunch, we could not help but comment “was he, ever so subtly, letting Mary know exactly where they stood as friends?” We never asked Tom directly if that was his intention, but that, to me, was just the introduction to his and Erika’s story of friendship, love, and hope.

*Girlfriend and Boyfriend First*

No… Well, friends first… then girlfriend and boyfriend… and then, hmm… six… well… three months and I had a stroke… but… hmm… No… three
months… because boyfriend and girlfriend three months ago, three months and then I had a stroke, so…

But we had known each other about… 1 year and a half…

Oh, yeah! Friends… hmm… apartment… I… Erika and I…

We were neighbors…

Neighbors! Yes!! Yeah! And then hmm… always… Ta, ka…

talking to… you and… and me… and…

Because he took me out in the pool when I was in a little bikini, that’s why! [Laughs]

[Laughs] But hmm… you know…

always… ah… always… friends… you know? And then… you know… ask her out… and hmm…

Hmm… well, he kissed me… [Laughs]…

And that did… yeah, we were just really good friends first, and just kinda... evolved from there… yeah, but yeah, he leaned over one day and kissed me… That’s what did
it... Caught me off guard, yeah... it did...

Speaking Out! Convention

Hi, my name is Tom Boyle.

I had a stroke September 15, 2000.

I was thirty-nine at the time.

I have aphasia and apraxia and right side weakness.

Tom’s speech at the Speaking Out! Convention, 2004.

Good afternoon everyone, my name is Erika Boyle, and I’d like to talk to you today for a few minutes about what to do when medical insurance overage runs out and stops paying for speech, physical & occupational therapies. My husband, Tom, had a stroke almost 4 years ago. It was totally devastating and it completely changed our lives. His stroke was something we never thought could happen to us, especially since he was only thirty-nine years old. I didn’t know anything about stroke, and I certainly had never even heard of the words APHASIA or APRAXIA. But I soon learned all about it.


Hyatt Hotel, Tampa, Florida, 2004. On the opening day of the convention, camera in hand, I run into several members of the USF Aphasia Group. Among them are Tom and Erika.

“Can I take a picture of you two?” I ask. They oblige, and I step back, getting ready to hear the quick snap of the digital camera.
As we talk and discuss the sessions we were planning to attend on the following days, I notice how meaningful this convention must be for both of them. They were not only attending Speaking Out! as consumers, but also as presenters, along with Larry and Curt, all active participants in the USF and Sarasota aphasia groups.

Flipping through the convention brochure, I double check the date of their presentation. After following part of their stories as a student clinician, this presentation was something I definitely could not miss.

![Figure 27. Erika and Tom at the Speaking Out! convention, 2004.](image)

***

June 5 2004. Getting the tripod and camera mounted with my crude cinematographic skills, I sit down in the corner of the room and focus my lenses on Miz Paul and Bob as they introduce the members of the panel: Sharon Smith-Campbell,
speech and language pathologist at Sarasota Memorial Hospital; Tom, Larry and Curt, stroke survivors; and Erika, caregiver and co-survivor.

Of the three presenting Musketeers, Tom is the first one to speak. After stating the date of his stroke and its sequelae, Tom says, with strong emphasis and beautiful inflection,

“I have a wife Erika and I love her…” Reassured by her smile, he carries on.

“A… a… a… at the time of my stroke, I was… working at Culligan Water… as a sales manager. After my stroke… I was in rehab for… six weeks. When I left… rehab, I was in a wheelchair and I… couldn’t speak… or write or read… I worked hard with speech therapists and did… speech homework… every day. I… practiced speaking, reading and writing all the time. I will… w… w… no, no…”

Overwhelmed with the flow of his words, Tom stops mid-sentence, raises his hand in self-command and states the mantra of the Four Musketeers with a deep breath,

“Wait a minute! Slow down…” The room fills up with laughter and empathetic nods, and Tom continues,

“It was… very hard to do, and I was scared… and was feeling all a-a- alone. I have been going to the University of South Florida… Speech Therapy… Clinic for 2 years… now… and it has… Slow down…” he says quickly and continues,

“… it… has… helped me very much. Cheryl Paul runs the clinic and she is a wonderful person who is decat…. ded…dedicated to helping us speak again.” As I turn the lens of the camera towards the audience, I notice Miz Paul in the very back of the room, hands held tightly to her mouth, glowing in absolute happiness.
“I… am… glad to be alive.” Tom concludes. “I love my family and friends and I have faith in God. I… will… get… a job someday real soon… and… I… will… get better, slow but sure. I will speak fluently again.”

After a wave of applause from the audience, Larry proceeds to his speech, followed by Curt. As each of the Musketeers finishes their speech, they compliment each other in support.

Finally, after a panel discussion about the benefits of group therapy, Erika stands up and delivers a striking and honest account of her and Tom’s journey since the onset of his stroke. She stands up, microphone in hand, and addresses the audience in a soft but firm Boston accent, which slowly accelerates. Tom, with an amused smirk playing on his lips, nudges Larry who smiles and whispers something to Curt who gently taps Erika on her back. As she turns around to listen to what they were trying to tell her, the three presenting Musketeers, joined in a chorus, recite their mantra in unison, to the absolute delight of all present:

“Slow down!”

Figure 28. Erika and Tom after delivering their speech.
Approximately one month after Speaking Out!, I call Tom and Erika hoping they would be interested in participating in the project.

“Sure!” Tom replies on the other end of the line, “but… Erika not home now…”

“No problem!” I tell him, “how about if I call you both a bit later tonight? That way you can decide together.”

“Ok!” Tom agrees, “c-call… after six, Erika… usually home after six.”

“All right! I’ll call you guys later tonight!”

A little later in the evening, I am able to catch both Tom and Erika at home. After explaining the project briefly over the phone, we schedule our first meeting for the end of the month. Chuckling good heartedly at my profuse gratitude, Erika says,

“Sure, we’d love to participate! We’ll see you on the 22nd a bit after six!”

The Man She Fell in Love with

Before the stroke? Tom was a hard-worker, very very hard-worker… talkative… Totally… talked to anyone… you could never get him to shut up… He was a salesman! Your typical salesman! Very very talkative, hmm… Outgoing, laughing all the time… hmm… a lot of friends, he was very social, hmm… hmm… caring… hmm…. and hmm… romantic… very romantic! Maybe a little less patient than he is now… Yeah, but not… not much… not like me… I was usually impatient, but… yeah…yeah… hmm… less so, since I’m a caregiver…
July 22\textsuperscript{nd}, 2004. I find Tom and Erika’s house in a quiet and cozy neighborhood in Sarasota, on a warm and humid summer day. Greeting me at the door, Tom asks,

“How… how was the drive?”

“Not bad!” I tell him. “When there is no rain on the road I’m usually fine!”

He laughs as I tell him my adventures on the rainy road, trying to locate Larry and Susan’s house. Erika joins us shortly and we exchange our hellos.

“Would you like something to drink?” she asks.

“No, thanks!” I reply.

Sitting around the kitchen table, informed consents in hand, we go over the specific details of the project.

“So this is for your thesis?” Erika asks.

“Yes,” I answer.

“What is it on again?”

I explain briefly the purpose and the methodology of the project and the rationale behind the interviews. Nodding as she follows my explanation, Erika confirms,

“So you’re looking to see what the person will become after they have aphasia?”

“Basically, yes…” I respond. I feel puzzled about how apologetic I sound about the project and its methodology. “Why am I feeling this way?” I think to myself. “Maybe I am afraid they won’t trust me because the methodology seems so much more subjective and introspective than a quantitative project? Would I feel better about this if I could tell them I had a specific hypothesis to test?”

“Part of the challenge of a qualitative project,” I venture, “is not knowing, right from the start, what you will find. I may have some hypotheses, but my main goal is to
listen to what you Tom, as a survivor, and you Erika, as a caregiver and co-survivor, have
to say, without trying to fit your answers into my categories. After what you discussed at
Speaking Out!, and the changes that affected your whole system as a family, I want to
listen to your story, your experience. I’ve never done a project like this before, so this is
new for me also.” I say, being as straightforward as possible.

Nodding in agreement, Erika replies,

“You know, that would be great… because… everyone is so focused on
recovering, which is of course a big thing to focus on… But no one has focused on, now
you need to adjust to this… your life… the way it is now…”

I sigh in relief and contentment as the purpose of the project is validated by them.

With a smile on her face, Erika looks at me and asks, “Ok….So, what would you
like to know?”

***

Almost a year later, when I show Tom and Erika the first draft of this chapter,
Erika asks,

“Go back a little. Where was that part where you talked about the hypothesis
testing? What did you mean by that?”

“Well,” I explain, “when I told some people in the department about this project,
some of them reacted by saying, ‘Well, that’s not really scientific, is it? How can you do
the stats on that?’ I remember feeling very self-conscious about it for a long time, even
though deep down I knew there was a need for this kind of research in our field. There is
some qualitative research being done in speech pathology nowadays, but most of it is
being done abroad, in the U.K. for instance. Here in the U.S. there isn’t much support.”

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After a brief pause I ask them,

“How did you guys perceive it? What was going through your minds when I invited you to participate in the study? Did you feel the same say?” I ask, curious to know what their perception of the process had been.

“When you talk about it,” Tom replies, “I think, ‘Hey, great!!’ I l-love to help people, so… Good opportunity, you know?”

“I think so, too,” says Erika.

“Emotional, you know?” Tom adds. “Stroke, aphasia, very emotional!”

**Hospital Experience**

*What do I remember from* his first days at the hospital? Wake up, in the hospital Sarasota… Down to the food…

*The ICU doctor said:* he could die; Leg and foot… oh man… Hurts, hurts, hurts!!

- he could be a vegetable; or I… couldn’t move it, and
- he could come out of it…”

*His mom came, and his* brother: I couldn’t speak… Ah… ah… ah… ah…

*He knew who they were, but* he couldn’t say anything: Nothing! Speaking is is the worst!!

*Then the ICU nurses said,* “You need a cardio and a neuro consult. Don’t tell the doctors we told you: Just say that’s what you want” They were great!

*I remember everything… He was trying to say that the left side hurt and he wanted some aspirin…*
I didn’t know...

I had a... an... ah...

Aphasia

I remember everything... So... can’t... can’t speak!! I know he doesn’t...

“What? What now? What now?”

Eight days later, when Tom was getting wheeled out of ICU, that same doctor gave him a pat on the back.

Ten days go by... He said, ‘Hey buddy! I knew you were gonna make it; I knew you’d pull through!’ Whatever...

Then... rehab... hmmm...

Six weeks in rehab...

Rehab

“How was rehab?” I ask.

“How long is your videotape, Linie?” Erika replies and we all laugh. “No, seriously,” she comments, “Rehab was the worst experience... On our first day there, the psychologist on staff pulled me out and said, ‘You know, Tom will never be the same again... He’ll never be a salesman again.’”

Reading the lines in my frown, Erika continues, “If you think this is bad, sit tight: that was just the beginning.”

Taking a sip of water, she pauses briefly and continues,
“In OT they taught him how to put a shirt on with one hand and that was about it. I said, ‘Well, can you do something about his shoes? You know, tying his shoes?’ You know what they said? ‘Oh, that’s something you want him to learn?’

“He would be stuck in the bathroom for half an hour sometimes; the light on outside, and nobody would come to get him out. They only showered him twice a week, so I went everyday after work, and I stuck him in the shower myself, and it turns out that we both took a shower” Erika says as they both laugh.

“Saturdays and Sundays their idea of PT was to get everyone in a big huge gym, for 15 minutes. They got 4 people at a time, so it was an hour… but they were only working with each person for 15 minutes… In fact, his roommate… Mr. Jones?”

“Yeah, Mr. Jones!” Tom confirms, nodding.

“A little old man… Every time I saw him, he would be embedded in a wheelchair… One of the Sundays we were at… PT in the gym… I said, ‘Ok, Mr. Jones, it’s time for you to get…’ he jumped up from his chair, and he walked, able-bodied, right around that gym! I pulled the PT aside and said, ‘Why the hell is he in the wheelchair?’ and she said ‘Well, what if he’s gonna fall?’ and I said, ‘Well, then teach him not to!!’”

Getting a breath of air, Erika goes on,

“There was one poor guy in a wheelchair once, and he… he was really out of it, but… his, you know, his butt was hanging all over out of the wheelchair, and he was like this, in front of the nursing station, and the nurses were just walking by him… I mean, he was almost falling, he looked very uncomfortable, and Tom was trying to get somebody…”
“I… I… s… said that… ‘Nurse!!’ You know?” Tom adds and comments, “Well… I didn’t say it, but…”

“Well, you went from room to room, in your wheelchair,” Erika explains, “…trying to get a nurse, and another nurse, who was like, your size, Linie, she was real small, she was trying to pull this guy up and she went, ‘I need another nurse, I need another nurse!!!’” and I was thinking to myself, ‘Yeah, how does it feel to lift a man all on your own?’” Erika sighs, “I think the nurses in rehab were… probably understaffed and overworked… and you know, a lot of the old people there were moaning and crying and… after a while I think they just get aggravated by it… Maybe they just don’t listen anymore…”

***

Can I tell that story about when you were in the nursing station?

Yeah…

Ok… I went in every day after work, all right… I stayed in until about ten, I’d go out, and I was there all day Saturday and all day Sunday…

One day after work I came in, and Tom was sitting in his wheelchair, right in front of the nursing station… They’re kind of like, all parked in there before dinner, so that the nurses can sit down on their butts and and and just… almost like they’re inmates instead of patients, so they would not get unruly and stuff like that… Tom is there, and he’s crying… he had to go to the bathroom, and no one took him to the bathroom… so… he… peed his pants, you know?
Yeah…

And he sat in it, for... like... an hour!! And... I... flipped out, I totally flipped out!!! I, I... I mean... I just... I flipped out!! They bent over backwards to kiss my butt every time after that, I went in there, and I called the CEO, I had, I mean... It was just unbelievable... I said, ‘This is a thirty-nine year old man, sitting in his own urine, there’s absolutely no need for this!’ and they’re all... right in front of the nursing station, and you couldn’t not understand what he needed... I mean, it was impossible to not understand... you know? So... that... (sighs) was really really bad... (I can hear Erika banging on the table with her hand as she retells the story, indignantly) But he’s potty trained now, so... Laughs!

Laughs!!

Thank God!!

Thank God!!

***

“How was the rehabilitation team, though?” I ask, “Couldn’t you guys discuss some of your concerns with the doctors and the other professionals during rounds or staff meetings?”

“Well,” Erika sighs, “We were supposed to have weekly team meetings with all the therapists, and the physiatrist, and me, and Tom… and they had one… and after I was complaining non-stop they didn’t have another one…” Erika sighs in disappointment and concludes,
“They’re all into money, and stuff like that… He was in there for so long, and I just… I just thought there would be more that they would do, and they didn’t, and it was just… a waste… At the time, thank God, he had insurance that paid for all, but, we got the bill and I forget, it was like fifty or one hundred thousand dollars for the six weeks, and I’m just sitting there, going… it’s such… it’s a… waste… I was not gonna make… I felt so strongly about it that I wanted to tell the insurance company ‘Don’t pay them because they didn’t do jack…’ But then I thought, ‘I can’t get stuck with this bill…’ You know? So… it was bad… And when they released him, the social worker threw us into society… she didn’t give us any clues, like ‘Hey, this is what you have to do at home, these are organizations to… contact…’ or any help with insurance, nothing… I mean… it was… just awful…”

**Home Sweet Home**

After Tom’s stroke and his release from rehab, we were both just kind of “thrown out into the world” not knowing what to do or how to handle and adjust to our new life. There was no social worker to point us in the right direction or give us any kind of helpful information. So please learn from our experience. Be creative, look in the yellow pages and on the internet. Talk to people. There are a lot of resources out there and many people who are willing to help. You just have to look for them and be persistent in your search.


“So once you were out of rehab what did you guys do?” I ask.
“A lot of … phone calls!” Tom explains. “A lot of phone calls… Erika… phone call all the time hm… because hmm… I… can’t speak… so… hmm… it’s… all the time… you are… Erika… you… sh-shhh- showed me… to… speak… all… all all… Oh… Wait a minute…” Tom says, slowing down, “all… all over again… you know? Learning it all over, basically…”

“Yeah, that’s pretty much what we did,” Erika confirms. “For instance, he was released from rehab on a Wednesday, and that night he fell out of the bed a few times because he was having some really bad spasms… As we were struggling through the night I was thinking to myself, ‘Why wouldn’t they release patients on a Friday, so we would have the weekend to get more acclimated?’… but… obviously that wasn’t our decision to make.”

“Get them in, get them out” I thought to myself, picturing a hospital ward blending impeccably with the image of a conveyor belt. Time is money…

“But that wasn’t all…” Erika continues. “I think starting the following day Tom was going back to the hospital for an outpatient day program from 9 am to three pm, or something like that. Now, I work, you know… 8 am to five pm, but they just threw me out there… So I needed to find someone, like a babysitter, you know, from 7:30 to 9, and then from three to five! It was like having a child! They didn’t give me any help or anything like that! All they told me was ‘He can’t be left alone, so make arrangements.’

Now, here’s the icing on the cake: at the time, our apartment was on the second floor and the guy from the rehab van, who would come and pick him up, came to me and said ‘Ma’am, we can’t pick him up unless he’s on the first floor.’ So guess what? We had to
move! In 10 days, I packed us up, found another apartment in the same complex on the first floor, and moved us before he got out of rehab!”

Looking at the tiny, delicate woman sitting in front of me, I could hardly believe my ears. “You did what?” I ask her.

“Yeah…” she chuckles. “I think I was still running on adrenaline… you know? Like a friend of mine described, a woman, during a crisis, will stay focused and get through it, and then… fall apart when it’s over … You know? So I guess that’s sort of what happened.”

**Falling Through the Insurance Cracks**

*As a caregiver, I had new duties. None of which I was prepared for.*

*Soon after Tom left rehab, his medical insurance stopped covering his speech, physical & occupational therapies. I was stunned. I thought that whatever kind of treatment you needed, it would always be covered by your medical insurance. I was wrong.*


“So where was I?” Erika asks. “Oh, outpatient therapy. Well, that didn’t last very long. They kicked him out without giving me a warning. They said, ‘OK, today is your last day because your insurance ran out…’ So here I was, basically with no direction, scrambling for resources… I was just shocked. I thought, just like I said in my speech, that as long as you needed therapy your insurance paid for it… so that’s when we started making phone calls and trying to find therapists, and organizations, and stuff like that…”

As I revisit Erika’s speech once more, I find the details of their therapy saga.
“I … had to find a private speech therapist, physical therapist and occupational therapist and pay these expenses by ourselves. Tom was not going to be eligible for Medicare until more than 2 years after the date of his disability. We were not married at the time so I couldn’t add him to my health insurance policy I had through work. After we were married I couldn’t add him to my policy because he was considered to have a pre-existing condition, and again was deemed ineligible for coverage.

I found that the cost for these therapies, if you don’t have health insurance coverage, is very high. As I shopped around for new therapists, I told Tom’s story to each of them, explaining that this was taking a huge financial toll on us and that we simply couldn’t afford these therapies that he needed so desperately; especially since he was still making such good progress. We got very lucky. His physical therapists gave him one-hour sessions but only charged him for a half hour. His occupational therapist charged him a reduced rate and his speech therapist gave him a discount with three sessions a week.

During this time I had appealed the insurance company’s decision to terminate his coverage for speech, physical & occupational therapies. The process took a long time, but we finally won one of the appeals, which paid us for one month’s worth of therapies. We lost the other appeal.”

(Erika’s speech at the Speaking Out! Convention, 2004)

“It’s just wrong… It’s… it’s… it’s… it’s ridiculous!!” She says in contained outrage, fist on the table. “Now we learned that, through all insurances, they’re not going
to start paying for PT, OT, and ST at this stage, you know, these many years post-onset… They say it’s… it’s… too far… you know? He has Medicaid now, which we’re thankful for because it pays for doctors, but it doesn’t cover prescriptions… That’s where having private insurance would benefit us right now.

“The other drawback is that I work for a small company and we couldn’t get conventional health insurance. So they pulled all of these small companies together and got one group rate. The not so good thing for us is that they have more stringent underwriting guidelines, which make it even more difficult for Tom to be eligible… I think maybe if I worked for like, a big company, who knows…

“Did he have any insurance at the time of the stroke?” I ask.

“Hmm hmm… He had insurance back then, but it only covered 60 days, 60 consecutive days! I fought it, fought it… oh, I fought it! We actually got one… I… I… I… filed it twice, one time we were approved, we got some extra money towards therapy, and another time I filed it on a massage therapy benefit, which was great for his arm… but that got denied, so… stupid loophole, you know?

“Insurance, man… I know…” Tom exclaims.

“Yeah…” Erika sighs. “But, I don’t know… It wasn’t easy. You definitely couldn’t speak, remember? It was all ‘yes’ and ‘no.’ There was a lot of guessing games, when he was trying to say something! It was like 20 questions!”

Contacting the Source

“So how was it exactly that you found out about the USF program?” I ask them.
“Well, all of our therapists and treatments that we did actually, we got information through networking…” Erika recollects. “A few months after his stroke I thought maybe we should learn to eat better, stuff like that, and maybe look into nutritional supplements, so we went to a nutritionist, who gave us a the contact information for Barbara Newborn…”

“Wow! So you met Barbara Newborn before Speaking Out!?” I ask them.

“Oh yeah! She was very very nice!” Erika exclaims. “And through Barbara Newborn we got Jackie Hinckley’s name at USF… So probably two years before Tom started in the USF program, or maybe a year and a half before, we saw Jackie. She was incredibly helpful! She gave him the Boston test, evaluated him, and gave us some directions like ‘work on this, work on that…’ until he could start in the clinic. So I kept in touch with her, every few months, e-mailing her, calling her, because I wanted to get him in. I had heard only great things about the Michigan program with Jackie, but that was… I think it’s… about like, 20 thousand, 30 thousand dollars? I don’t know for sure, but it was really expensive… So… I thought, well, this is right up the street, and she says it would hardly cost anything, so we just kind of kept in touch with her!”

“I didn’t know that… hmm… B… B… Barbara Newborn… is… hmm… called… Jackie!” Tom exclaims surprised.

“Yeah, oh yeah!” Erika nods, “Barbara and Jackie are good friends!”

“I… Speaking Out!, I… I, I… I… A… Asked her, Barbara Newborn… I… am getting better… all the time! And hmm… she said… man, perfect speech! I mean… I… I…. you know, I mean… the… you know, one year ago, nothing, not speaking…” Tom says.
“She talked to you three years ago!” Erika recollects.

“Oh, yeah! three years ago…!”

“She’s a counselor, so we had a couple of phone sessions with her, when Tom was still in the very acute stage…” Erika explains. “It was basically me on one phone, and him on the other, and he’s just, you know, ‘yes’ or ‘no,’ and I did all the talking… and she did a lot of the talking… but she remembered him, when we went up to her at Speaking Out!!”

“Yeah, yeah!! Yeah, you know?” Tom confirms. “Then, later, Miz Paul. Oh, man! I love her! I love her very much, I mean… USF, it’s a wonderful hmm… program, you know? I… I… I… USF is… I love it!”

“He talks about the program all the time!” Erika chuckles. “I keep telling Cheryl: you have a walking-talking advertising for USF, that’s for sure! Actually, the other night he called a friend in NY to wish her a happy birthday, and all I heard was ‘USF, wonderful speech therapy, it’s working!!’ You know? USF has just been absolutely incredible… it’s just been amazing!! It’s just been, by far, the best speech therapy he has gotten, and, thank God” Erika says almost in a whisper “… it’s been the cheapest too!! But, I mean, really, it has been the best…”

_from “Yes” and “No” to Community Outreach_

Remember when you couldn’t talk much at all?

Yeah… Toughest time!

Oh… That’s what I missed the most! Just
talking... I didn’t care so much about not
being able to ride on the motorcycle
anymore, which sucked, but... If you had to
lose anything, I would have rather the
physical than the speech...

Yeah… yeah… I know… I love to talk!
Salesman, talking all the time!

Losing the speech was just... devastating...

That’s how we got together... We would
just talk! We always talked!

Aphasia... sometimes... it’s hard to
do... because... thinking about it...
and... saying about it... is... not...
good... But... it’s... Getting better. One
year... I... will... sp-speaking better...
than before... Homework is helping
me...A lot!! And... reading...
newspaper... and hmm... golf...
hmm... golf magazines, and the sports
illustrated! So... it’s... it’s ta... it takes
time... But hey, it’s working! You
know? Hmm... it’s like... baby, really? I
mean...Learning... all... all...

I know! I know! And we're in synch! Now I can finish some of your sentences... But there were so many times before that for the life of me I couldn't understand...

Oh, it... was... frustrating!

And I would go, “OK, turn it around! Give me a hint, a clue, something!” But now we have our own language!

Yeah! Yeah!

***

As the afternoon becomes night in sunny Florida, I begin to understand why Tom’s eyes would always fill up with the utmost love and affection when he spoke of Erika in our aphasia group meetings at USF. This tiny but feisty and strong young woman was his advocate, his lover, his soul mate. Noticing we had been talking for over two hours, we finish our first interview among laughter and jokes and say our goodbyes, scheduling our next meeting for the first week of August.

Later that night, at home, I watch the recording from the Speaking Out! Convention once more, fast forwarding it to Erika’s speech. I am moved, impressed, and inspired by her loving determination and resourcefulness to help Tom communicate again. Trying to imagine what it was like to live through her experience, I close my eyes and listen to her amplified voice as she spoke in that June afternoon at the Hyatt,
“I sat in on most of Tom’s speech therapy sessions. I learned as much as I could, so that we could continue working on our own. We would do his speech homework at night, on weekends and while driving in the car, just about every chance we got. I was working full time and it was getting to the point where Tom was too tired at night to do his speech homework with me because he was so exhausted from all the therapy sessions that he had been doing during the day while I was at work. I knew I had to do something because he wasn’t able to do a lot of his speech homework by himself, and what he learned in speech therapy wasn’t being reinforced. I needed another ME to be there for him. So I thought that maybe I could find a volunteer to help him. I put up some flyers in the apartment complex where we were living and someone in our aphasia support group had suggested we contact our church. I wrote a letter to the president of the Women’s Club at our church and explained the situation. I also called several charitable and volunteer organizations, including United Way, Salvation Army and the Jewish Family and Children’s Services. The response from these resources was overwhelming. We are fortunate to live in an area where there is a large population of retirees and people who just have time on their hands and want to help others. You will find that there are also people in your areas of the country that have time to give and that want to help. We started interviewing several of these volunteers. I explained to each what they would need to do to help Tom. They did not need to have a background in speech pathology or even any teaching
experience. It was as easy as holding up flashcards, doing word repeats and helping Tom practice writing, spelling and simple math problems like, 1+1; 2+2, etc. What made it great for both Tom and myself was that everyone just loved him. They saw his motivation and determination and that made them want to work with him even more. In the beginning, Tom had three or 4 volunteers working with him over five times a week, an hour at each session. It was great because it reinforced what he was learning in speech therapy, enabling him to advance further and improve at a much greater rate. We even got 2 more volunteers through word of mouth because these volunteers just loved working with him so much. It was rewarding for them to be able to see his progress. It has been three years now and he is still working with 2 of the original volunteers, who are just wonderful people and have become good friends of ours.” (Erika’s speech at the Speaking Out! Convention, 2004)

**Discovering Acupuncture… and Wine**

August, 2004. I arrive at Tom and Erika’s house and they are ready for the second interview. “Erika… go first.” Tom volunteers as he sees me. “I’ll… go to the bedroom!” We had agreed that he and Erika would be interviewed separately on this meeting, but I am slightly surprised by Tom’s readiness to leave the room. Some of the other survivors I had interviewed had tended to linger around adjacent rooms during caregiver interviews, following our conversation vicariously as doors were left accidentally open...
Focusing back on the task at hand, Erika and I get settled around the kitchen table, recorder, camera, and all. When we are all set, I ask Erika,

“Since we’re interviewing you two separately today, I was thinking… I would just like to hear a bit more about you and your experience as a caregiver. What were things like to you? What was going through your mind?”

“Well,” Erika smiles, taking a deep breath, “It was hard… I mean… I don’t even know how we did it. I… I… I started getting grey hairs, I didn’t sleep for six months… hmm… I lost weight… You know… stress took a lot of… hmm… effects in my body… I had pains in weird places I never got pain… I’m thirty-five… at the time I was… thirty-two… and… when I saw the grey hairs coming in and I was like AHHHH! No, no!!”

We both explode in laughter and Erika continues,

“Because I couldn’t sleep for like six months, the doctor put me on a sleeping pill… But then I was just so groggy in the morning, I felt like I was… hung over… you know? So… Tom went into acupuncture, all this time… which was part of this non-western medical therapy, so… I started going, too. After a few treatments… I was clean, sober: I got off sleeping pills… And I was able to sleep!! I was able to sleep!” she sighs and chuckles.

“I think I mentioned before that all of us clinicians, during aphasia group, were always amazed by everything he told us about you! We were always saying, ‘Wow! Who is this wonder woman!”

“Oh, God!” Erika exclaims, blushing intensely. “I guess… right after his stroke… he thought that I was gonna leave him… And of course that was never even a thought! But I don’t think that lasted too long, you know? As a couple it’s definitely made us
stronger… It’s given me grey hairs, and… It does funny things to your body, pains here and there, and not sleeping, and…”

“It made you discover acupuncture, I guess…” I comment.

“Yeah…” Erika confirms, “…and wine…” she adds as we both laugh.

Faith – The Family Heirloom

Italian, Catholic family... I went to Catholic school... Actually, I think he did too... I don’t think he went to Catholic high school... I went to two years of Catholic high school and I said, that’s it, I had to get out... I went to a public school... But, I mean, we’re you know... always were... you know?

The other night, after the aphasia group meeting, we went to Boston Market and we were talking to Curt and Bob and Diane, and, you know... Diane was really angry at God after Bob had the stroke... she even told the priest ‘I’m so angry at God’ which is a total natural reaction... But Curt he says he’s a scientist, so he doesn’t... He believes there’s some thing, out there, but he’s not sure... because scientists have to prove, or whatever... But... I... couldn’t imagine... The second we got out of the hospital, and I noticed something was wrong, I said, ‘Oh, God, please,’ and started to pray right away... I just... I couldn’t imagine going through this without...having faith...

I remember the stroke happened on a Friday, and... my mom is a really special person, my grandmother is too... I’m really close with both of them... so it happened on a Friday, and I didn’t call them... I called them only on Saturday night... I just didn’t call, I couldn’t think straight... So I called and I told them what happened... At that point we still thought he was gonna die, or be a vegetable, we just didn’t know... so... my mother
got on the line, and...they... they prayed with me... and she told me how to pray, and what to ask God for... and she says, 'Be strong, have faith,' and all that...

So... that night... over night, into the morning, I just knew he was gonna make it... I just knew he wasn’t gonna die and he wasn’t gonna be a vegetable and that... I was still upset, but... it just... just lifted, something was lifted off me, so... I attribute that to me calling mom, and her saying OK, this is what you need to pray for; this is what you need to say to God...

Equal Rights

Thinking about what I had learned from their story together, I ask Erika,

“I know you mentioned that leaving was not ever a thought in your mind… But how was it for you, in terms of… you were just starting a relationship and this whirlwind catches the both of you, so… What was going through your mind?”

Chuckling, Erika says,

“Well… you know… I was like a mother for quite awhile… and I didn’t really like that…” she smiles. “I don’t know if I told you, but… I was married once before I met Tom… and… my husband worked a lot and he just didn’t… he wasn’t real domesticated, he didn’t… worry about bills and things like that… so when I met Tom, he… balanced his own checkbook, he did his own laundry, all that stuff…” she says as we both laugh.

“So… I was like, thank ‘God, it’s gonna be, equal!’ And then all of this happened. But... Tom is just so great, you know, he wants to do everything… I mean… He wants to do laundry, and I’m trying to teach him how to cook… he didn’t cook before… but… a lot of stuff in the kitchen with one hand is very very hard! Bob has a cutting board that
he’s shown us, and I’ve gone online… and Bob showed Tom how to open a bottle of wine one-handed! But some other things like can openers, are harder…

“What else? He writes all the checks, I get it ready for him, and he writes them out… he hasn’t come close to balancing a checkbook yet, but… it wasn’t good before, so…”

Among giggles and laughter she continues,

“When his Mom was here two weeks ago, I didn’t have time to go buy special foods and go to Publix, so… I was up in Tampa on Friday after work, so I asked him to go to Publix, I gave him a list and… he’s gone to pick up a few things on his own, but it’s… every time it’s been with me, so I gave him this big long list and I’m like, ‘Are you sure?’ and he was like, ‘Yeah, yeah, yeah!’ So… he’s so funny!” she says, with the most endearing tone in her voice,

“He called me, on my cell, probably five times! He’s like, hmm ‘Ok, lettuce, what kind… this or this?’ And I said ‘oh, doesn’t matter get that’… then a few minutes later, ‘OK… hamburger, chuck or ground sirloin…?’ and ‘cheese, cheddar or Colby?’ It was so cute, you know?”

Nodding as I notice the sweetness in her voice, she continues,

“He cuts the grass… he has a friend that comes over that helps him pull the crank, to start the lawn mower… we haven’t figured out how to do that yet… you know, he loves the garage, he has his golf stuff in the garage… He takes care of the plants, and everything… So he is definitely, I mean… Oh, and we were online last night to order his golf club for his birthday, and I’m just… I mean, I’m at the computer 8 hours a day, so I was like, du, du, du, du, du… and he’s like, ‘Ok, I wanna learn…’ and I’m like, ‘Ok!’
mean, everything he wants to learn, everything… And, you know, I tell him, I want you to be, not trained, but I want you to… know the stuff because you should, you know?”

**Old Friends, New Friends**

“How about the friends you had together before the stroke?” I ask Erika. “Do you still keep in touch?”

“Well,” she ponders, “We lost a bunch of friends… They just kind of…”

“Dwindled?” I ask.

“Well, yeah, but not right away…” she says. “In the beginning they were always at the hospital, and then… They just kind of backed off…”

Thinking for a while, Erika continues,

“I think… They’re scared that it’s going to happen to them, you know? Or, now that the acute stage is over, they may think, ‘Well, it’s not really going away,’ so they don’t know how to act around him… But we have some friends that stop by to do a little thing… and we’ve made new friends also.”

“That’s true,” I agree, thinking of the other Three Musketeers.

“It’s gonna be 4 years since his stroke, next month, you know? So… Now we’re starting to make new friends… but that was hard… Not so much for him being afraid, but, as a couple you meet more couples, so she and I start off talking, and how is the other guy gonna talk to Tom? So that was… that was hard, hmm… but we never stopped going out, we’ve always gone out, to restaurants, and hmm… Sea World, and Universal, and shopping, you know, Publix all the time, all around Sarasota, Barnes and Noble, all that stuff… hmm… and he’s close with his family too… So hmm… I don’t think he’s
ever shied away from a… a social situation, you know? I think the group has helped him a lot with that…In terms of getting the self-confidence again to… just go up to people and talk and… that’s one of the constants that all three of them said in their speech at the convention…”

*A True Floridian Ventures Out*

As Erika and I conclude her interview, she says, “Hang on a minute, I’ll go call Tom.” She quickly disappears into the house and I hear her knocking on the bedroom door saying,

“Your turn!”

Laughing, Tom comes out and has a seat around the kitchen table.

“All right, Mr. Tom!” I tell him.

“All r-right!” Tom says. “H-here we go!”

***

I was born in St. Petersburg, Florida…

Three… hmm… three… hmm… brothers…

I, yo- youngest

Growing up in Florida,

I loved it! Oh, yeah!

I… loved it…

No weather… hmmm no… hmm… snow!!
Then, I, 19 years old

No… no… 20! Yeah, 20!

NY

One month

D- Dennis… my brother… and me

Wonderful!!

I… I… I loved it!

NY City – Man! Oh, man!

Buildings and everything…

It’s… nice! You know?

Nice but…

But… dirty, I mean…

Sometimes… Oh man…

Oh, oh… boy… Crazy city!

NY city is a wonderful place,

But… no… didn’t… Didn’t… lik… like it to live! You know?

Too fast!

Then … I… I… go… Chicago

Lots of snow!

Really cold!!
I was, hmm… hmm… ho… H… Hyatt first…

Aunt… lives… in Chicago, so…

I… I… went to Chicago… and… shhhheee…. Worked at Hyatt.

I was… 20… 22 years old.

So… I worked 7 years… at the Hyatt…

Wonderful, you know?

Drivers first… and then… bell boy…

I loved it! Yeah!

But hmm… Six… Seven years… and…

I loved it, money (Hyatt, Chicago? Oh yeah!)

But… you know… Not going anywhere…

So… I decide

Time for change.

The Birth of a Salesman

Sitting at the kitchen table I have a sudden moment of illumination,

“Wait a minute,” I say, looking at the big Culligan water gallon on their tall water fountain, “That’s where you worked after the Hyatt, wasn’t it? Culligan Water? You mentioned it to us in group!”

Laughing, Tom confirms,

“Yes! Culligan water!”
“How did you start there?” I ask him.

***

Main office Chicago

So… I find Culligan in newspaper

I… wro... rea... read the newspaper, and...

Culligan? I will call Culligan!

So hmm... I called Culligan, and... interview... and... And got the job!

But... seven da... seven da... seven dollars!

But! Pretty good, I mean, I... promotion! So.... Yeah!

And then... Sales... hmm... I... was in the sales manager...

Chicago first...

And then... I woke... I said

I... I... I don't know... Florida... I want to... get... a job at... Florida...

Tampa... Culligan water!

So... hmm... two... three, three... months... three months,

And then... I... got a job... I got... Transferred!

Three years... Chicago... hmm... Culligan...

Then... I want... went to the... hmm... Florida, Tampa

Salesman job – Oh, perfect!

Talking all the time!
I love… talking all the time…Perfect!!!

Seven years… ah… Florida…

Culligan water, sales manager

Always talking… Paradise!

Cell phone, and pagers, and all… oh, yeah!

six am… to… si… six pm! twelve hours a day!! You know? But hey!

And then hmm… I h… Hmm… hmm…

Well, three years ago and 8 months I had a stroke, so… no talking…

But… hmm… s… I love to speak… I mean…

It’s my… my… passion!

To speak, fluently!!

Someday… and hmm… I… will…

I will get better

Slowly but surely!!

_Becoming a Father_

“And, you know, baby, too…”

“You’re a father?” I ask him.

“Yes, oh yes!” Tom confirms. “My son, Ryan.”

“But that was before you met Erika, right?”
“Yeah, oh yeah…” Tom nods. “Before Erika… When Ryan born, moved to Florida because hmm… Chicago, cold as hell! Not good for baby! So… I… hmm… hmm… Sunny weather! I… loved it! I mean… and… but… hmm… hmm… ex-wife… is hmm… Problem… so… hmm… not good… You know, drinking… So… always fighting… always fighting… so… divorce.”

“How have things been since the stroke, though?” I ask, reluctantly.

“Well… tough…” Tom replies quietly.

Figure 29. Tom and Ryan a few years before Tom’s stroke.

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Ryan and his mother were living in a house in St. Pete that Tom’s father had left him… So, through their divorce, Tom had to pay for the house, he had a mortgage on it… They had a car, child support, and medical…

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Well, when Tom had his stroke Ryan was about eleven or twelve years old. Tom didn’t have any disability, social security hasn’t kicked in yet, and... Ryan’s mom and Tom were divorced before Tom and I even met, so I was not the cause of it... But... I don’t think she was happy to have me around... She... claimed... “Well, if I can’t have him, no one is gonna have him...”

So... Ryan and I were good and friends, buddies and stuff like that, and the minute he told him we were a couple, before the stroke, she started saying things, and Ryan started to... not like me...

During this time we were trying to find out doctors, and therapists, and insurance... Tom isn’t paying child support because he doesn’t have any income coming in... And then... custody issues came up the line, and all of a sudden she started poisoning Ryan’s mind, and he doesn’t want to spend time here anymore... Instead of sitting down with the kid and saying, “Hey... look... your dad had a stroke, this is what’s happened,” you know, do some research on it and then explain it to him, but no... So...

For about a year and half we had to get a lawyer, we had to fight her... and things were really... rough. He was... his focus should have just been totally on his rehab, but... But it wasn’t, it was very emotional with Ryan, very, very, very emotional. So he was struggling with the two things at the same time... And I was trying to just make him focus on... Getting better... So...

We ended up selling the house in St. Pete, and Ryan and his mom moved to California. You know, she’s... kind of the type of person that... only works enough hours to pay the bills... so she had no place to go and all this stuff... so... they’re living out there with her older son...
Now it’s been… two and a half years and Tom has only seen Ryan once… We have a visitation schedule, but to enforce it we have to go back to lawyers… And that would mean more money… But at least now Tom and Ryan aren’t fighting anymore. So… even though they’re not physically seeing each other, at least there’s less tension… He definitely, his whole relationship with his son has changed… And he was always a wonderful father.

The worst part was… In the middle of all the turmoil, Tom couldn’t verbalize anything back to Ryan… Anything… and it was so… so frustrating…

***

“One week… one… month… ago,” Tom says, “I… I called Ryan… and hmm I… I… read… the… speech….”

“From Speaking Out!?” I ask.

“Yeah, Speaking Out!!” Tom confirms, enthusiastically. “It’s perfect! I mean… Ryan… Blown away!”

“Congratulations!! I’m sure he was very proud!” I say.

“Yeah…”

“Do you feel things have changed a lot between you two?” I ask, tentatively.

Tom is silent for a moment and then answers,

“Well… Ryan says that… No problem, but… It’s a problem… I mean… hmm… stroke is difficult… Mind works… Perfect, but… it’s the hmm… Getting it out! You know? So… I… live for… for… my strength… and… I… God… I… said that… God provides… You know?”

I nod in agreement and Tom continues,
“I don’t know … some days… it’s hard to do because… I… I… sad… I’m sad… I am sad… for… for… me… you know? But… ten minutes, and… Moving right along, you know? So… One week… I said… hey… I… I am not perfect… and… we have… difficult… and… I… think that… I… will get better. I … I… have aphasia… and hmm apraxia… and… right side weakness… you know? So… So… live it up! I mean! You know? What… what… what are you going to do? It’s hmm… life…”

With a smile on his face, Tom concludes his interview,

“You know, Erika said that… sometimes it… is… tough… but… I am tough!! And Erika is tough, so… we… we… are… we are… together. That’s what matters… Sometimes I… this is… not… fair… but… God… provides. Three years ago, I had a wheelchair. Ah… ah… one month ago Erika and I was on the beach… and and then… I will… no cane… no cane? No cane. Ok, so… and then… man… I did it!! Always!! Yeah!! So, takes time, but it’s helping me! Foot is a problem, I mean, but hey… some… som… inverted… But… two years, man! Couple more years!! I know! I am happy, all the time, you know… Yeah!”

“I can see that!” I say as we both laugh!

*From Sales to Golfing*

As we conclude the separate interviews and Erika rejoins us, I ask Tom,

“What would you like to see yourself doing in the future?”

“Well,” he says promptly, “I wan, wan, go… I want to s… be… a teacher… A golf teacher!”

“Really?” I asked.
“Yes, yes! One hand, you know? Well, one month ago, I said that… hey… always like Sarasota or Tampa, or everything… is hmm… one hand is a problem, so… learning… one hand… is… I mean… one hundred and forty yards, one hand, driver, and man, it’s better bef… it’s better than before! So… I… I… said, hmm… you know, learning to… one hand! Like hmm like… now two hands that’s putter, you know? But it’s helping to… learn the… the… ropes! Yeah! I mean hmm… I… I… t… I think… that… I l… I love to play golf… and… I love to… lo… loo… love to… learn, so… and then… one year and I… practice and practice and practice, and… walk… and homework too! No break from homework!”

“Homework first,” Erika interjects.

“But… people… all at home… all over the country, or Sarasota, or… Venice, or Tampa… Yeah, and you know… it’s great! I mean… you know? Like hmm… Sarasota hmmm… Fire… Fire…. No… Foxfire Golfcourse… and hmm…. Learning and… hmm… but hmm, a lot of money! I mean, hmm…

“There is another… there is another man that teaches adapted golf!” Erika mentions.

“Yes! Yes! Adapted golf! And a lot of money! So, you know? Now, hmm, John, is a… a… survivor… at Tam… Tampa… University of South Florida… Five… f… four years or five years, I don’t know, John… but, a long time ago, two hands, not a problem. And then… he… had a stroke… and no golf… so… I st… I sa… I t… I talked to him, and… two times I… I… got a… ah… got… him out… So, you know, some… some day… learn… I will … golf… teacher, or something like that… some day…”
“And how is your golfing with Larry, Curt, and Bob?” I ask. “I heard you guys have your regular time together on Fridays.”

“Yes!” Tom laughs. “The Four Musketeers! Oh, man, wonderful!”

“Who’s winning now?” I ask, knowing they are pretty competitive about their golfing.

“Well, Curt, you know, because Curt is hmm… Sa… Sundays and Saturdays… but… Fr… Fridays, Chuck, hmm hmm… George, playing golf too…”

“Who are they? Are they other golfers you guys have met?” I ask.

“Yes!” says Tom. “George… is hmm hmm hmm… eighty-five years old! Yeah! And Chuck is forty-two… no… forty-three! We’re same age… twenty years ago he had a stroke, though… He was twenty-three. Hmmm… hmm… hmm… ca… carotid artery! Clogged up! He was working out! I… I mean, I… you know? But… hmm… he’s… he’s… hmm… he’s… OK… and… no no… problem speaking… No, no… long time ago yes, but… now… but now… I mean, no… no problem… with Chuck… I mean… He… he’s all right… You know?”

I notice how enthusiastic Tom becomes as he talks and I try to imagine what he was like before, with all his pagers and cell phones in the world of sales. “He will be a great teacher!” I think to myself, watching Erika’s hand resting lovingly on his. “Just give him some time!”
Has Tom changed?

How has he changed? Let’s see... I think he’s compassionate... more... sensitive to... say... if he hears something on the TV or radio, something bad that happened, he’s much more like, "oh...". You know? He was like that before, but it’s magnified now...

What else... Stronger faith in God... now... hmm... very strong faith in God... I saw... strength emerge from him that I didn’t know was there, and I didn’t think he knew that was there...

They say everything happens for a reason... I don’t know if that’s the reason, but... If you had told me this was gonna happen, I don’t know that he would have been able to handle it.... plus, I didn’t really know him... I knew him, but for one year and a half before, but we were only together as a couple for a few months... So... I didn’t know that side of him, but I didn’t think that he would have been this strong... I mean, now he’s just like... super strong! He has his moments, but his determination is just incredible...

Hmm... he’s a little bit more patient... Well, he laughed a lot before, too, but he finds humor in things... I mean, he was always like, “Mr. Life of the Party” before. Now he doesn’t drink as much as he used to... not that drank a lot before, but I mean, like the whole... that whole...You know... he hasn’t cut it out, or anything, but it’s not... you know... not like it was before. He was just a single guy before ...

Priorities have changed, too, you know? Like things that were important before, or that weren’t, you know, are now, and vice-versa...I think for anyone that’s ill, or had something happen to them... priorities change.

I would like to have him get total speech back, but... smiles... I guess I told you the thing that surprised me was... his strength... Everything that happened brought us
closer... I mean, even all the... crap with... his ex-wife, and the custody, and the battling with the son and all that, that’s behind us, and hmm... fighting insurance companies...

That’s... that’s hard...

A lot of these people who have had strokes and have aphasia, they’re in their 50’s, 60’s, and 70’s, they already had a house, they already had grown kids... They’re either established, they were established or they were retired, had pensions, and we’re, OK, we’re just like in the prime of life here!

I don’t know if we would have been as committed and as strong as we are now... see, because we weren’t together that long... I know at the beginning he depended on me, but... you know... he thinks I’m strong, and... I mean, I know he’s appreciative ...

How do I see him now that he has aphasia? Oh... He’s my sweetie!

Figure 30. Erika and Tom during Christmas in 2004.
Chapter 9. Survivor

The Lonesome Cane

I was first introduced to Curt during my second semester of graduate school. I was a student clinician back then and Curt was one of our clients in the aphasia group, along with Tom and Larry. Curt had some right hemiparesis at the time and walked with a cane, especially for longer distances. His relationship with his cane, however, was an interesting one. Instead of holding onto it as a source of security and gait stability at all times, Curt always made a point of leaving it against the wall outside the aphasia room, as if its presence were not allowed in his therapy environment. Later on, as I discovered more about Curt’s life history, I came to understand why his cane was purposefully meant to be left alone.

***

The Four Musketeers have always had a cheerful and friendly disposition about them. Curt was no exception. I remember, when I first met him, he struck me as being a very bright and pleasant person. He was reserved at first, but gradually became more sociable and lively as he familiarized himself with the new clinicians. Later in time, I discovered he had been a weight-lifting champion on several occasions, and had three master’s degrees in different fields including anthropology, exercise physiology, and counseling. However, the biggest surprise (at least from my perspective) came only a few months later.
It was an early afternoon in the clinic, soon after lunch. For reasons I no longer recall, some group participants were discussing major turning points in their lifetimes. Several survivors mentioned their strokes; others mentioned a death in the family; some referred to their experiences in the Vietnam War. Curt, however, remarked,

“I was an alcoholic, many years. Finally, fourteen years ago, I join AA – no more drinking. I start counseling other alcoholics. It was rewarding job!”

I was surprised. Curt had always seemed so centered and focused in group it was difficult for me to picture him with a six-pack of beer in each hand, struggling to keep his balance and mind straight. As the thought crossed my mind, I felt a wave of guilt and embarrassment bring me back to my senses. “So much for not thinking in stereotypes…” I mused to myself, disappointed in my promptness to judge.

It was only later in time that I came to realize, however, that Curt’s attitude toward alcohol was not so different from his attitude toward his stroke.

As the old saying claims, sometimes the wounded make the best healers.

***

I had the opportunity to meet Christie, Curt’s wife, about one year later, during the Speaking Out! Convention in Tampa, Florida. Curt had told us about his soul mate in group on many occasions, and it was endearing to see them at Speaking Out! as they attended several of the presentations together. From what he had mentioned before, I knew Christie was a nurse and they had three children together, but that was the extent of my knowledge at that point.

***

Saturday, June 5, 2004 – Speaking Out! Convention.
After Tom and Larry concluded their presentations, it was Curt’s turn to deliver his speech. He approached the microphone quietly, greeted the audience, and took his first step towards his new firmly set goal: to become a motivational speaker for stroke survivors and individuals with aphasia.

***

“My name is Curt Mathes. On April 14, 1999, I had a stroke. I have … aphasia, which makes communicating difficult. My I.Q. is fine. My words are scrambled. I am going to tell you my experience of aphasia. I am not alone with my struggle. One million people are affected with aphasia in the United States. As group members, you will be interested in my story. In the past I didn’t have any difficulty. Shortly after my stroke, I had difficulty with any language. Currently I am still working with my therapist towards my goal of speaking clearly and fluently. In the future I hope to motivate other stroke victims to improve the way I have, and group members as well.” (Introduction to Curt’s speech at the Speaking Out! Convention, 2004).

***

One month later, I approach the telephone hesitantly, and try calling Curt and Christie to invite them to participate in the project. I had mentioned it to them during the convention, but with all the emotional impact of Curt’s speech on himself and his family I assumed they would not remember. As we speak on the phone, however, they both promptly reply,

“Sure! No problem! We’re in!”
After thanking them profusely, much to their amusement, we schedule our first interview.

_Barking Announcement_

After a rainy and thundering drive from Tampa to Sarasota, I finally arrive at Curt and Christie’s house. As I get to the door, I am welcomed by Rufus, one of the many family pets, as he barks profusely, announcing my arrival. Trying to calm him down and introduce myself, I say,

“Hey there buddy! I’m Lini, how are you?”

To which his continued barking seemed to reply,

“I have not made up my mind just yet. How about a better chance to sniff all those bags of yours and I’ll tell you in a minute?”

A few seconds later, Curt and Christie come out to the door and greet me, much to Rufus’ contentment. They invite me to take a seat at their kitchen table and we chitchat for a few minutes, while I awkwardly set the camera and the recorder up. With all the formalities taken care of and Rufus quietly taking a nap on the sofa, we start the interview.

_Roots_

“I guess a good way to start would be talking about you, Curt? How does that sound?” I ask them.

“Sounds good!” He says with a chuckle.

“Christie, please make comments at any time!” I mention upfront, trying to avoid making the same mistake I had made with Bob and Diane.
“No problem!” she replies, smiling.

Figure 31. Curt draws his family tree.

**Father and Mother**

<table>
<thead>
<tr>
<th>Ralph… My father</th>
<th>Mary… My mother</th>
</tr>
</thead>
<tbody>
<tr>
<td>He is from Arkansas</td>
<td>She passed away…</td>
</tr>
<tr>
<td>Land of the Brave</td>
<td>[Writes the date next to her name]</td>
</tr>
<tr>
<td>Land of opportunity.</td>
<td>October 10\textsuperscript{th}, 1986</td>
</tr>
<tr>
<td>He’s got… nine brothers</td>
<td>Hospital… St. Louis</td>
</tr>
<tr>
<td>And… two daughters…</td>
<td>Liver disease…</td>
</tr>
<tr>
<td>[Meaning sisters]</td>
<td></td>
</tr>
<tr>
<td>Eleven… Siblings…</td>
<td>Drink? No, no, no…</td>
</tr>
<tr>
<td>It’s huge!</td>
<td>But pills… very much, the pills…</td>
</tr>
<tr>
<td>Ralph, Liz, in Arkansas</td>
<td>She has had a back injure…</td>
</tr>
<tr>
<td></td>
<td>In-ju-ry [Says it deliberately]</td>
</tr>
</tbody>
</table>
A long time ago…
Two kids,
Bob and Peggy,
My half brothers…

[Meaning half siblings]
Later, Mary in Illinois
Ralph and Mary, two kids
Me and Greg

Ralph was poor growing up
Father was an alcoholic
Oooooh, man!
This is genes, I guess!!
Ralph was an alcoholic.
He’s got sober…
Twenty-two years ago

He’s a strict… disciplinary
Disciplinary caring…

He… beat me… severely…
Sometimes…

Operations… So…
Abused painkillers…
Badly…
She needed, I guess…

I cried… but, of course…
Life goes on…
Mary died
Ralph…
Straightened up his act
But… he’s an alcoholic…

I was sixteen or seventeen

I beat him, finally!

But now he’s pretty good.

He’s loud, sometime…

Soft sometime…

What made him sober up?

I think Mary, my mother…

**Curt’s Siblings**

<table>
<thead>
<tr>
<th>Peggy</th>
<th>Bob</th>
<th>Greg</th>
</tr>
</thead>
<tbody>
<tr>
<td>Half brother</td>
<td>Greg was living</td>
<td>He is president</td>
</tr>
<tr>
<td>[Meaning half sister]</td>
<td>In Venice, Illinois</td>
<td>Waste manager</td>
</tr>
<tr>
<td>She is… Clean…</td>
<td>He is good guy…</td>
<td>Jacksonville</td>
</tr>
<tr>
<td>[Laughs]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peggy is a nurse.</td>
<td>He’s alcoholic,</td>
<td>Big company!</td>
</tr>
<tr>
<td></td>
<td>Of course…</td>
<td>He’s rich!</td>
</tr>
<tr>
<td>She's in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oklahoma.</td>
<td>He is… 62…</td>
<td>He went to AA</td>
</tr>
<tr>
<td></td>
<td>Still drinking…</td>
<td>A long time ago…</td>
</tr>
<tr>
<td></td>
<td>Stubborn…</td>
<td>Twenty-two years</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Greg been sober!</td>
</tr>
</tbody>
</table>
Curt and Christie

I was born in Illinois… Well, my mom was a nurse and, my grandma was a
I like it… nurse… It kind of runs in the blood… It just kind of
Play baseball… boxing… happened, and since we both lived in the same town,
The golden gloves! neither of us moved away except when I was going to
I sixteen… or seventeen… school for the three years… And it was only over to St.
I was skinny… Louis that I was going to school, so… I was home for
Oh, man… 130 pounds! the weekends… So… we just stuck around Granite
city. Both of us worked there, lived there, and just kind
And tall, six foot! of stayed together after that…
Those were the days!

Music, Band, and Love

The Sweetest Clarinet

As I hear Christie mention how they “stuck around” after college, I ask,
“How did the two of you meet?”
“We meet in school… Junior high… Almost forty years ago…” Curt says.
“Nooo… Forty years?” Christie exclaims surprised.
“Yes!!!” Curt nods.
“I guess so!!” she agrees, smiling. “We were both in band…” she reminisces. “I
played the clarinet…”
“… and I saxophone…” he completes.
“We’re from Illinois, both of us…” Christie explains, “and we were in… grade
school… or… junior… middle school together!”

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With a smile playing around his lips and a spark in his eyes, Curt says,

“I want to show you! Have one picture!”

He stands up and walks toward their bookcases, looking intently at their family pictures. After a few minutes, he returns, holding two tiny photographs in his large hands.

“Remember?” he says, looking at Christie with a loving smile.

As he lays the pictures on the kitchen table, I see two playful and cheerful teenagers, making funny faces and kissing happily inside a photo booth, as the click of the instant camera makes their moment eternal in the tiny snapshots.

“Are these the two of you?” I ask.

“That’s when we were first together!” Christie explains, sweetness in her eyes.

“We were probably about … sixteen…”

“You both look so different,” I say as I take a glimpse into the past and try to imagine them meeting for the first time during rehearsals.

“Yeah…” Curt chuckles. “I ninth grade, Christie eighth grade. She’s a sweetheart! Those were the days!”

***

*We were in junior high... He was a year older than me... We were in the band together, and we went on a field trip to a different school or something to play music. We had to sit together on the bus because we were the last two people, and that’s where it first started... Oh, and I think we went to a dance together, too...*

*When he went to high school I was still left in junior high... We weren’t going out then, we kind of broke up for a couple years, but then came back together when I was back in high school with him... It’s been going on and off ever since then!*
Saxophone

As the afternoon gradually turns into evening, Christie continues,

“Curt was really good with the saxophone… Actually, he also played in a band outside of school.”

“Oh yeah…” he recalls, “Six… hmm… weeks…No…”

“No… six nights a week…” Christie corrects. “When he was in eighth grade, he was going out and playing with bands till one and two in the morning and then getting up and going to school the next day.”

“Not much sleep,” Curt chuckles.

“Well, you didn’t do too well in school because of that…” Christie nods and chuckles back. “But once you got out of high school then you started… I guess that’s when you quit playing music… Except maybe on weekends, and got better at school and took it more seriously…”

***

A long time…

Fourth grade!
I like the saxophone!

I’m a jazz musician

And rock n’ roll of course, in high school!!

I take lessons

And the school band

I’m good!

Six nights a week I’ve been playing!

I’m high school! Junior high!

School… Oh… not so good!

The lower bottom…

But I graduated, finally! [Laughs]

Oh boy!

I’m intelligent… Sometimes

It is fun!

I love the saxophone!

Greg, brother, plays guitar…

Ralph, my father, is a guitar nut!

Bob plays guitar, too…
And I the saxophone.

Saturday and Sunday, Ralph is playing music

Ralph, in the beginning

International shoe store in St. Louis

He played on weekends.

Ralph loves the guitar…

He’s good!

He played with Elvis, Everly brothers, Hank Williams…

He still plays, every day.

Two times a… Two hours a day!

At least!

He’s good! Really good!

_Hawaii to Granite to Florida_

I knew Elvis and some jazz musicians, but to Curt and Christie’s surprise and utmost amusement I was completely unfamiliar with the Everly brothers and Hank Williams. As they laugh and kindly situate me in the musical background, I ask them,

“With all that music tying the two of you together, how did you transition from the school band to getting married?”

“Oh… It took us a _long_ time!” Christie answers.

“Oh yes!” Curt agrees, laughing.
“Everybody was teasing us for being together for so long and not getting married… So, eventually, we did…” Christie explains.

“Were you waiting to graduate college or something like that?” I ask.

“Nah, not really…,” Christie continues. “We just… never… felt the need to, I guess… Then one year we were going to take a vacation over to Hawaii, and his friends lived over there, so we just kind of made arrangements to get married there, since it was a nice place!”

“Don’t forget! Five… thousand… dollars!” Curt reminds her.

“What?” she asks, confused.

“Thelma, and… hmm… hmm…” Curt says.

“My dad?” Christie ventures.

“Yeah!”

“Gave us five thousand dollars? Oh, I don’t remember that!” Christie concludes, laughing.

“Really?” he looks at her amazed. “Oh, I remember!” he says emphatically.

“And that’s why we got married?”

“Yeah! I think so!!” Curt replies as we all roll in laughter.

Recovering from the hearty belly laugh, Christie continues, “That’s probably why we took a trip to Hawaii!! It was just kind of assumed that we would get married, so nothing ever was said about it… At least I don’t remember any…”

“What?” Curt asks, curiosity rising in his brows.

“A proposal…” Christie continues.

“Well… sort of…” he replies.
“Oooooh, I don’t think so!” Christie says and we all fall into laughter once more.

“I proposed!” he says confidently.

“Did you?” she asks, truly searching her memory.

“Yes!” he says resolutely. “Forty years ago!”

“What did you say?” she asks as a challenge, with an amusing tone in her voice.

“I love you!” Curt says, mellowing. “Get… Get married!!”

With some laughter playing in the corner of her eyes, Christie replies,

“I don’t think so… I don’t remember that! But anyhow…!”

As our laughter quietly subsides, Christie continues,

“After we got married, we lived in Illinois until 1996. About twenty years…”

“Where in Illinois?” I ask them.

“Granite City.”

“Grand City?” I ask as my foreign ears betray me.

“No, no…” Curt and Christie giggle, sympathetically, “Granite. You know, like the rock!”

“Oh!! I see!” I respond, a bit embarrassed.

“I don’t like Granite City,” Curt continues.

“Why is that?” I ask.

“It’s a small steel mill town,” Christie explains. “It’s real dirty, stinky… dirty town… We just like the people that are there…”

“I think I can relate,” I mention, thinking of the craziness of my hometown and all the loved ones my husband and I left behind.
“It was especially nice when we were raising our three kids,” Christie mentions. “We had good neighbors and kids across and down the street would always babysit for us, so it was not too bad… I really liked the neighborhood we came from, and our house… We had a good time there, a lot of friends, a lot of family. But now that we are in Florida it’s nice too because we have a lot of visitors! So we have the best of both worlds.”

“What brought you from Granite City to Florida?” I ask.

“My mom had moved here,” Christie explains. “After my dad died, my mom decided to move to Florida, which was funny because she always hated the hot weather. But all of a sudden she decided she wanted to move to Sarasota. After she moved down, we decided to follow her because she was here all by herself. It took us a while, but we finally did it. She was down here about four or five years before we came down.”

***

Noticing the time had advanced faster than I had accounted for, I thank Curt and Christie for the interview and ask them when we could schedule our next meeting. As I’m putting the camera and papers away, I meet Courtney, Curt and Christie’s second daughter, as she was feeding their beautiful blue-eyed white cat. Excited with the possibility of incorporating her voice into the narrative, I explain the project to her and ask if she would be interested in participating in the interviews sometime.

“Sure! We just need to work out the schedule…” she says. “I work nights.”

“Courtney and I are both nurses,” Christie comments. “Shawn, my first daughter, is a nurse, too, but she’s still living in Illinois.”

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Surprised by the number of nurses in the family, but trying not to overstretch my stay, I make a mental note for the following interview and start my way back to Tampa.

**Pass me the Beer and Play me the Blues**


I arrive at Curt and Christie’s house and as soon as my feet touch their doorstep I hear Rufus announcing my arrival from the depths of his canine lungs.

“Shsh!!” I hear Curt saying, “Quiet, Rufus!”

As he opens the door and we exchange our greetings, Rufus performs his regular sniffing check of my camera and bags, accompanied by Charlie, a cute and loving cockerspanial. As I pass the careful inspection, we cheerfully get ourselves situated around the kitchen table and Curt and I start the interview while we wait for Christie and Courtney to arrive.

***

“Curt” I ask him, “last time we talked a bit about your family, especially your dad, and the impact he had on you. I also remember, from clinic, that you mentioned you were in AA before…”

“Hmm hmm…” Curt nods.

“Can you tell me a bit more about that?”

“Ok…” he agrees.

***

**In the beginning**

I’m eleven pretty much…
Well, it started fourteen years ago

[Meaning when he was fourteen years old]

I’m sick… Shy man

Really shy… A long time ago

But… Still… Shy…

In some ways.

Why shy?

Genetic… I feel…

Ralph dominate my life…

Still… does… sometimes…

He’s a strictest disciplinary

And I… Always shy

Even world champions… Boxing… Everything…

I thought still shy…

In the room, I feel scared…

If the friends, one on one, no problem…

My problem is… Always shyness…

Alcohol… Hit a block for me

I’m in trouble all the time…
At high school, drinking all the time …

You don’t think about nothing…
Just drinking… Just drinking…

A long time ago, fifteen years ago
I lose my mind, almost…
The doctor said…
“One day you’re living at the hospital
In a straightjacket!”
I almost catatonic!

Liver disease… Cirrhosis…
I almost died!
Thirty days in the hospital…
Need to dry it out…

I was messed up
I thought AA was a bad thing
But… What are you gonna do?
I know one thing:
I don’t need to drink, ever.
Never, never, never.
Thank God for AA!!

1989… I got sober

Finally

Five years ago I had a stroke

No more AA… Well, rarely…

But I’m gonna go, one year later

I'm gonna go back again!

Christie, she’s happy!

Finally, I sobered up…

She is my sweetheart for life…

Trust me, she’s puts me… With me a lot!

That's the part of my life!

Thirty-seven years… Alcoholic…

What you’re gonna do, but change life?

Get over it!

Greg’s made it.

I made it.

Ralph made it, finally!
And Bob… He’s still an alcoholic…

But we’ll see…

I’m sober, finally!

***

“How is the interview going over there?” Christie asks as she arrives and takes a seat at the kitchen table.

“Talking about me, sober!” Curt remarks, chuckling.

“Oh,” she says with a sigh.

“What was that period like for you, Christie?” I ask her.

With a saddened expression, Christie sits back and ponders for a couple of minutes.

“Well…” she sighs, “It was rough.”

***

In the beginning he was gone all the time because he was drinking, and after he quit drinking he was gone all the time because he was going to school, and trying to work, and different things like that…

We would get along pretty well, except when he would drink, and that was always at night. I worked evenings, so I didn’t have to see him a whole lot, I guess… I was either working or sleeping when he would come in late. He was always at the bars until one or two in the morning. [Silence]

It was a lot better once he quit drinking. He was just like a different person. I mean, everybody liked him; he was always a nice person. He would help everybody and
get along well with, everybody, but... I guess for one he wasn’t very family oriented, because he didn’t grow up in a family like that, and he wasn’t home for his kids or me that much either, which I thought he should be and he thought he should be doing other things I guess...

Despite everything, we’ve been together almost forty years. We just have such a history together! We were always going back to each other, even though we’d fight and break up. We’d always come back, either because of the kids, or... because we had the same friends... or because we love each other, I guess... [Smiles] Even with the drinking, we still loved each other...

What made him quit? I don’t really know... I think he’d been wanting to and it just happened to be the right time. I can’t really remember if anything happened to make him quit... [Silence] All I know is he wasted 40 years of his life, but finally grew up!

Genetics?

As Christie mentions her relationship with Curt and their children, portions of the last interview gradually slip back into my mind.

“Christie,” I comment, “last time, when I was leaving, you mentioned you have two daughters, right?”

“Well, and Zack too!” Curt interjects.

“Yeah,” Christie confirms. “Our two girls, Shawn and Courtney, are both nurses.”

“Really?”
“Hmm hmm… It runs in the family,” she says with a chuckle. “My mother was a nurse, I am a nurse… They never thought about it I guess. They just did it… Like I did… And then we have Zach…”

“Ohhh! Zach is problem child…” Curt says laughing, and then remarks, “No, I’m joking. Zach is Zach, you know? He’s a kind person. He’s gonna make it some day!”

Shaking her head, Christie comments,

“Zach’s not doing anything now. He quit school… I’m so worried about him… He’s talking about getting his GED. I don’t know what’s going to happen with him… He just got lazy, I think. He just got disinterested in school, I’m not sure why…”

“He’s a sh… he is a smart!” Curt comments. “I.Q. is… 130!”

“Who told you that?” Christie asks surprised.

“Shawn taught… told me…” Curt replies. “I.Q. in the classroom…”

“I never heard of that!”

“Oh yeah! I know!” Curt mentions confidently. “He’s going to make it someday!”

“Well, I sure hope so…” Christie adds with a sigh.

**The Art of Parenting**

“What was the experience of becoming a parent like for you?” I ask them.

“We had kids right away,” Christie mentions. Life was good the first few years…” she adds with a sigh.

***
I guess… after Courtney (our second daughter) was born, he had a girlfriend, so we broke up. We actually got divorced for a couple of years I guess… But somehow we got back together again and got married for the second time…

I thought the second marriage would be better because things were going to be different, which they weren’t, really… It was better, in a way, but he was still drinking… When he finally quit drinking is when it really got better, but then he got so busy going to school and everything like that it was almost like when he was still drinking that he was still gone all the time, so… It was better, but it wasn’t as good as what I thought it should be. I always thought it could be better, even though it was good, it could be better…

***

Zachary two years old…

I still drinking

Shawn and Courtney hated my eye

I was drunk! [Laughs!]

Being a father, I didn’t know how to do it!

Always drinking…

Always!!

Two kids and the beer every day

Religiously!

Oh, man!!

Being father, I didn’t know how to do it, but…
I tried…

Now, I'm happy!

I'm proud of Shawn, Courtney, and Zachary…

I'm good… Good dad

Finally.

***

A few minutes into the conversation we hear footsteps from inside, getting closer to the kitchen.

“Hey Courtney!” Curt exclaims as he sees their daughter approaching. “Jump in!”

Somehow I was surprised with how openly the three of them discussed some of the issues they had confronted in the past, issues which for more conservative families would have probably been kept aside as taboos. Courtney joined us, but did not speak freely right away. It was mostly during a separate interview later that day that she expressed some of her concerns and shared memories.

***

A lot of the kids at school, because it was a small town, they knew what was going on in our family… [Courtney remembers] But once we got older and he did stop drinking, he started going to school and everything, everyone still looked back on us like that was… They still judged us according to that, but my dad was going to school and probably doing a lot better than a lot of the other guys were doing. I don’t know… I guess my dad was a perpetual learner.
Perpetual Learner

I’m terrible in high school
My teacher, Peter Frank
Made me change.
He straightened me up!
Finally!

***

“He continuously went to school!” Christie comments.

“And I was bad in high school!” Curt chuckles.

“I guess you changed your mind about school work…” Christie says smiling.

“You went to Bellville Junior college, remember?”

“Yeah… I liked Bellville College…” Curt says, “Is… pretty … easy… but… SIU is hard, very hard… but… I’m getting by…”

“Yeah…” Christie nods, “Once you graduated from junior college you went to Southern Illinois University, and that’s where you started doing…”

“Geo-anthropology…” Curt fills in the blank.

“Yeah… And digging for… bones…” Christie continues.

“Yeah!” Curt reminisces, “I learned… all types of earlier… civilizations… I loved… Paleontology! That’s my passion! Fossils… Monkeys… and… hmm… Dinosaurs… Yeah! Geo-anthropology… First master’s degree. Then, well, 90… no, no, Early… It’s 19…89… I went to… Back to school… hmm… Exercise physiology.”

“He’s always worked out.” Christie clarifies. “He’s always been a weight lifter, since high school!”
“One hundred and thirty… Five years ago, I’ve been… Still working out! I used to be skinny! In high school! Picture! One hundred and forty… hmm… One hundred and forty pounds! Skinny!” Curt says laughing and mentions, “I love school!! Perpetual learner!”

**Anthropology**

“Curt, where did you work as an anthropologist?” I ask him.

“Well… I’m a… assist….assistant of directive… of Mastodon Park… digging up bones… Halsey Miller, he’s my professor. He’s a good guy, my mentor. I always liked him. He died heart attack,” he replies.

“He was also into exercising, wasn’t he?” Christie confirms, checking her memory.

“Yeah,” Curt says, “and beer too…”

“That’s true…” Christie nods casually, “He was a drinking buddy, too.” After a pause, she asks,

“Did he do anything with your teaching in college?”

“Well,” Curt answers, “not really, but… faculty hmm… really helped me… tremendously. Introduce me to faculty,” he clarifies.

“Oh, OK,” nods Christie, “So he introduced you to people there in the college at SIU…”

“Yeah…” Curt nods.
“Well, but you also went from one thing to another… because all through when you were going to school you were still working part-time construction, security… What else?”

“I’m eclectic!” Curt comments good-humoredly.

“Oh, yeah! He sure is!” Christie nods laughing.

**Exercise Physiology**

*I use to be a teacher at Rehab Solutions in Tampa, an exercise physiologist at Southern Illinois University at Edwardsville, and an alcohol counselor in St. Louis and Bradenton, Florida. Formerly, I held the World Record in the Squat, lifting 800 lbs in St. Louis, Missouri in 1980, and a first place in the Master Division at the Raw National Powerlifting Championship in Orlando, Florida. In 1997 Curt’s speech at the Speaking Out! Convention, 2004.*

“So after geo-anthropology came…” I ask, trying to organize the events somewhat chronologically.

“Exercise Physiology,” Curt continues. “I used to teach school… lectures… in… hmmm… Physiology… I love it! And hmm… I taught class, hmm… And archery, working out… hmm…”

“Well, that’s when you were going to school and getting your… What degree?” Christie interjects.

“Well…” Curt says, a bit confused.

“Masters of… Physical education?” Christie asks, confirming.
“Yeah, physical education…” Curt confirms and smiles.

“Yeah, he was going to school for a while,” Christie continues, “And… doing all the student teaching into physical education.”

“I loved to… hmm… Work out… A long time ago…” Curt mentions.

“Yeah,” Christie recollects. “Even before you graduated from high school… Remember? You had been weightlifting for a long time.”

“Oh yeah…” After a brief pause, as if a light bulb had gone off, Curt says,

“Wait a minute – I show you something,” and disappears into their bedroom. When he comes back, his hands are replete with family pictures.

“Look!” he says, “That’s all um… Ten years ago… That’s me!”

Almost in disbelief I exclaim,

“Wow! You’re kidding! These weights are humungous!”

“That’s… Six… Eight… Seven hundred and thirty pounds!” Curt says.

“Holy macaroni!” I say astonished, “That’s a lot.”

“That’s a picture world record – eight hundred pounds!”

“Jesus!” I exclaim, eyes wide open.

Laughing, Curt explains, “Well, the 80’s! In St. Louis.”

“How did you do it?” I ask, truly puzzled. “Doesn’t your back hurt when you lift that much weight?”

“No, never!” Curt replies.

“Really?” I say, still stupefied. “How do you train to lift that much weight?”

“Well… It’s dedication, I think…”

“And lots of practice!!” Christie chips in.
“Many practice! Every single day!” Curt agrees and laughs.

“How did you first decide to, you know, try weightlifting?” I ask Curt.

“Well,” he thinks for a while and then responds. “I saw… hmm… Rick… hmm… Lesco… He benched one… Two hundred and… hmm… Thirty… Three reps! Man, that’s a strong cat! I wanna be just like him!” he concludes, laughing.

Figure 33. Curt receiving the first prize trophy from his mentor, Halsey Miller, in Roxana, Illinois, 1979 after squatting 755 lbs.
Counseling

“Well, after the physical education program,” Christie continues, “Curt decided he didn’t want to stay in physical education, that he wanted to go more into rehab counseling…”

“What prompted you to go into that area?” I ask.

After a brief pause Curt replies, “I just like people, you know?”

“He just hmm… Couldn’t decide what he wanted to do!” Christie smiles.

“Yeah…” Curt chuckles.

***

I counselor in
[Sighs...] 19… 90… 96…

Really recent… hmm… eight years ago…

I’m a counselor!

I’ve got my card! [laughs!]

Still here!

Counseling alcoholic

I like…

The other side now…

Sit down in the class, and discuss…

A lecture, me… of course…

I like the lecture… [laughs!]

It’s fun!!

And hmm… introducing myself, and

Talking about the sober life…

That’s all…

I was good at my work

I like my work!

It’s a rewarding!
Stop drinking, hmm… half and half, approximately.

Half make it, some… No… not make it…

Three steps: death, institutionalization, and hmm…

Death, institutional, and sober.

Two… Two… Three options [Laughs.]

***

As our second interview draws close to an end I ask Curt and Christie,

“Would it be OK with you guys if next time we talked about your experience before, during, and after the stroke?”

“Sure!” they reply. “Just tell us when!”

**Stroke Inside and Out**

After a couple of weeks, I return to Curt and Christie’s house. This time, to my surprise, Rufus sniffs me perfunctorily and allows me passage without further inspection. In fact, he was even open to some petting!

“Wow!” I comment content and surprised, “This is such an honor!! I was recognized by the family guard dog!”

Laughing, Curt and Christie nod in agreement,

“I guess he recognized you this time!” Christie comments.

After a brief moment, Curt redirects us,

“The stroke?”

“Sure,” I nod.

Looking at each other, deciding who would start, Christie volunteers.
April 14th, 1999.

Curt was at USF. He was a teacher’s assistant, or whatever that’s called, and he was also doing these part time jobs, running around. He went to lunch at the Subway, got a really bad headache, and somehow got back to the classroom, but didn’t go in. The teacher that called me later said some students found him in the hallway, really confused, and walked him over to the student clinic, across campus. He was there for a couple of hours until they decided to send him to the hospital. That’s when they called me.

I was at home with my mom when I got the call... It was kind of scary because they knew he had a stroke by then. My mom drove me all the way up there. She was a nurse, too, so she knew about all the problems that stroke people can have. It was scary... Most of the strokes I had seen in the hospital were bad, so it was scary... It took us a whole hour to get there, and then when we couldn’t find him, I thought the worst... It was... it was a scary trip.

He was in the ER until about one o’clock in the morning and we didn’t get there until about two hours after he had gotten there... The whole time, we were just wanting them to do something, waiting around for something to happen, and it just seemed like it took forever to do anything in the ER.... I guess he had gotten there around four in the afternoon. They did some testing, not a whole lot. They couldn’t do his MRI because he was too big for the machine, so I think they did just the carotid ultrasound and decided he had a clot. They took him up to the floor about eight hours later and started running a heparin drip. By the time he got there, his whole left side was paralyzed...

It was a lot of waiting, a lot of worrying, a lot of stress...
The second morning after the first night we called Greg, his brother up in Jacksonville. He came down with his wife, and they stayed for about five days. That was nice to have him around because he would talk to the doctors and he was very concerned. He has been really helpful… He would give him money and pay for this therapy, and he rented a motel room for us so we didn’t have to drive back and forth from Tampa to Sarasota. He was really good! He still is.

Several months later, when I read this portion of the chapter to Curt, he breaks into sincere and heartfelt tears.

“Is everything all right?” I ask him, worried that I may have hurt him as we recollect the events from his stroke.

Smiling, still with tears in his eyes, Curt comments,

“It’s OK! Just… Greg… Oh, he’s a great guy!” he sighs, still emotional. “My brother… I love him! Talk to him, two three times a week. I remember, Greg, everything!”

I didn’t know anything…

In the hospital, very confused…

Greg, he’s crying…

I remember, he’s crying…

I don’t know why!

I thought… I’m getting better!
[Laughs!] Oh, man… I was messed up…

***

On the third day Curt developed low blood pressure and high blood sugar because he is diabetic, so they took him to ICU for about a week. He couldn’t speak, couldn’t move his right side at all… We weren’t sure if he could understand anything because he couldn’t really say anything… He just looked scared all the time…

It was just so hard to understand what he was thinking, what he needed, what he wanted… We’d try to tell him something, and we didn’t know for sure that he understood us, so it was rough…

He was in the hospital for about ten days, so I guess he was in ICU for about five days and then he came out on the floor for a couple of days before he went home.

***

Got out of hospital

I was devastated…

I didn’t know anything

Confused

I know the day time

The night time

But confusing

Memory… no problem…

I know what the… memories a long time ago…
Keen with memory…

At the hospital I slurred my words…
Ba... ba... ba...
I can’t… get the words out!
I cried… but…
Scrambled… really bad…

I don't know…
I did not know anything
For at least ten hours…
Eleven…
Two weeks…
Nothing…

It’s funny… I remember this doctor…
He was a limp… limping…
I saw him one…
Two or three times ago…

But other than that
Nothing…
I was like a puppy dog…
It’s horrible…
Horrible…

Half of the body is good…
Half is not working…

In time… So what?
Is life, you know…
But in the beginning, horrible…

***

The first year wasn’t too bad because everybody felt sorry for me. Talked to me, asked me questions, so it was kind of exciting to get all that attention [chuckles]. Then after that it got to be a little hectic…

During the first six months, I was running back and forth between here and Jacksonville. I was working three days straight and then driving to Jacksonville after a twelve-hour shift to pick him up at his brother’s house. Curt was receiving hyperbaric oxygen treatments back then. We did that for a couple of months. That was rough… A lot of working three twelve-hour shifts in a row, driving back and forth… I guess Courtney pretty much stayed at home then. Well, my mom was here, too. She was a really big help.
Joining us after a brief interval, Courtney reminisces about her grandmother.

***

We’ve always lived like a block away from my grandma, so she was always there. She actually used to live here [in Florida] and we would come over for dinner all the time. We were very close with her. It’s always been that way… It’s nice, because it’s like having your best friend and your family, someone that knows you very well and you know you can always trust and tell them anything…

She passed away about five years ago… I guess it was after my dad’s stroke…

***

Years ago I had anger, frustration, anxiety, but no more… I mean, alcoholic is bad… Fifteen years ago,
I’m through…

You had that when you were drinking, but since you quit you’re much calmer…

Oh yeah, much calmer…

But has your stroke been affected with those?

Not really… [sighs]

You didn’t have any anger?

Not really…

Anger is no place for me.

I happy be alive!

Frustrating perhaps!

I think you had some anxiety, especially around other people…

Yeah… [considering it]

You were afraid to talk…

That’s true…

Didn’t want to go places, or talk to people you didn’t know…

A long time ago, yeah. But no anger.

***

Three years ago

I still confused
Now my goal is helping people
I’m back!

The Couch-Potato Syndrome

“What were things like after the discharge from the hospital?” I ask them.

Matter-of-factly, Christie replies.

***

After Curt was discharged from the hospital in Tampa, he was sent to a local hospital for inpatient rehab for about six weeks. He also had outpatient therapy for a couple months. He was steadily getting better. At least he could get up and then eventually start walking. The speech was one of the last things to start... It took him a lot of time for him to do that... But little by little he got better and better.

The first two years after the stroke he really didn’t practice, he really didn’t try to do anything. I think he was expecting it would all come back... So he didn’t do anything to try. He had a physical therapist coming to the house to do exercises with him, but he wouldn’t do any practicing on his own. He’d sit home, watch TV, and... that was about it. That was all he did all day... It was not until the first couple of years that he started. It took him a long time to get started, but once he did he was really motivated and started doing more to try and help himself.

***

Curious about Curt’s perception of his rehabilitation process, I ask him,
“Curt, what was it like for you when you came home from the hospital? What was going through your mind?”

“Well,” he responds, “Getting better! I want to try, but… What do you think?” He asks Christie.

“I think at first you just kind of sat around and didn’t try too hard…” Christie replies. “Probably more depression, even though you’ve always said you weren’t depressed… All you did was sit there and watch TV, and you thought all the stuff was going to come back without even working at it… I think it took two years before you finally started doing something…” Christie concludes. “For the first two years you were just doing nothing…”

Quietly, Curt concedes, “That’s true… I think possibly I’m getting better, you know? But then I take my bull by the horns, I think so…”

“Yeah…” Christie agrees, “But you waited for two years…”

Nodding shyly, Curt concludes, “Yeah, that’s true… I don’t know…”

**Butting Heads**

“How did your family dynamics change after the stroke?” I ask them.

After thinking for a while, Courtney replies,

“Before the stroke my dad was always busy, going to school and all… But after the stroke we had to spend more time with him, on a day-to-day basis. When he first came out of the hospital, someone had to be home with him, and that would be me if my mom was at work. So, it was frustrating because I wasn’t used to dealing with him, and in
the beginning he wasn’t as good as he is now… Certain things I would expect him to do for himself, but…”

“He’s always been lazy, though,” Christie adds. “He doesn’t do a whole lot to help around the house and he never did. He’s just been lazy. You were brought up this way, and we let you stay this way.”

“It’s hereditary…” Curt responds with a funny smile, waiting for the comeback.

“That’s right…” Christie replies with irony. “You never had responsibilities, really. You went from your mom and dad to us, so I pretty much took care of everything, the house, the kids. You never had to do anything, you just did what you wanted to… And I let you get away with that for all those years… You just lived in your own little shell… But you’re trying to be good…”

Picking up where she had left off, Courtney continues,

“Another thing he is that bothers me…”

“Let’s hear it!” Curt says, and I wonder if under the cheerfulness he was just bracing himself for impact.

“He always talks about what he’s doing” Courtney starts, “How much better he’s doing, and what he did today, and… He doesn’t ask what we did… He’s more concerned with himself…” After a brief pause, she amends it,

“Again that goes back to whenever he used to go to school all the time, he didn’t have time to spend at home, or wonder what we were doing. The funny thing is, if me and my mom are in the middle of a conversation, he’ll just butt in, ‘Hey, look at me, look at me, and what I did’…” she says, imitating Curt. “And it’s rude, but… I don’t think it has anything to do with the stroke, that’s just the way he is!”
“I’m a sociopath!” Curt says tragicomically. As I sit in the middle of the quiet cross-fire, I am impressed with Curt’s sense of humor. I suppose it was a pretty strong shield.

“He’s got an excuse for everything!” Christie says with a look of routine and adds,

“Self-centered is a good word… I’m proud of everything he’s done, I think it’s great… but… sometimes…”

“That’s enough, huh?” Curt suddenly says, between joking and serious.

“A little uncomfortable?” Christie says, turning to him.

“He knows all this… He just doesn’t want to hear it…” Courtney concludes.

“Oh yeah… That’s true…” Curt concedes.

_Father and Children_

As all voices gently subside, I ask,

“Curt, do you feel your relationship with your children has changed after your stroke?”

After a brief pause, he replies.

_Zach is Zach_

_I feel closer to my children_

_Zachary… Not really, but…_

_Zachary is Zachary!_

_He’s sixteen or seventeen…_

_He’s a young… Person…_
But… other than that…

What do you think, Christie?

***

Before the stroke, Curt used to do things with Zachary on his days off, but then after his stroke he really couldn’t do anything, he couldn’t talk to Zachary, so they grew apart. Still now he doesn’t talk to him much. It hasn’t been good for either one of them…

I think Courtney has done better with him because she understands where he’s been and what he’s going through. Zachary is too young. Like I said, he wasn’t here a whole lot, but when he was he would talk and do things with them. But he wasn’t here a whole lot for ballgames, or school activities, things like that… I think they were kind of resentful he wasn’t. And they still are. They’ll tell him about it now, “Oh, you didn’t do this with me, or you didn’t do that,” and I think he feels bad because of that now.

Figure 37. Curt and Zach in Panama City, Florida, when Zach was about four years old
There was a time when my dad tried to do more with Zach, but my dad was never a go-out-and-throw-the-baseball-in-the-front-yard kind of guy… He would do different things like take Zachary to a spring, or to the movies.

I guess after my dad had the stroke my brother could never be attached to him because he didn’t understand… Especially whenever my dad first came home, I think, he probably saw too much of everything. So he probably had too much of a shock. He must have been about twelve.

Sometimes I think Zach walks all over my dad because he thinks he’s not going to be able to do anything. Before he had his car, he’d take dad’s car and dad would try to hide his car keys and my brother would come in looking for them and still take the car. He would have done it to me and to my mom, too, so… I don’t think it was a matter of “who.” But my dad wanted to say something to him and couldn’t really tell him…
Nursing in the veins

Shawn, and Courtney… My two sweethearts!
Shawn and Courtney! Both… Nurses
Christie is a nurse…
And Grandma Thelma is a nurse!
Two generations
Three generations!

***

Shawn and my dad have always talked a lot. They moved my grandma Thelma down here together, and she always calls and talks to him. She talks to a lot of his old friends in Granite City and tells him how they are doing… She is the one who talks more to him about the whole stroke thing. When she comes down, they go play golf together. I don’t like to play golf, so I don’t go, but I’m more involved on the day-to-day basis type deal.

I have been to like his stroke support groups. It was good because he was real proud of what he’s doing there. Very early on, when he first started going, he was kind of shy when we went in… It was interesting to see him really trying hard. I guess he was probably a little embarrassed, he didn’t really know anybody there yet or anything… But it was good to see him out, and see that there was a group for people! It’s just a shame that in everyday life they can’t really have much respect because people just don’t understand… That’s the way it is…
My dad and I… We butt heads a lot… I’m looking out for my mom. I try to be sensitive to her and everything that she’s going through. And my dad is kind of… self-centered… I know he holds her very highly and everything, but it’s one thing to say it, and another to actually do it.

I guess my mom has been a big influence on me, as far as going into nursing. Working with her now, I’m able to ask her questions, and she helps me. We get along really well and I think Zach and Shawn are jealous sometimes that we do get along so well.

From my dad… I guess… When I started college he would help me, even in high school… He always could use these different words I didn’t even know and he would help me write a lot of the papers. My mom helped me through nursing, and now that I’m going back to school… I’m taking a philosophy class, and dad said he wants to read the book and stuff, but I’m just not sure that he’s going to be able to… I think now it’s more me helping him on his homework… I don’t know that he’s going to be able to help me this time around…

He always went to school and he’s very smart. He was able to go very far on in college, and so I’m hoping that maybe some of the brains got passed down and I can go too… I have my RN associate now, and I’m going to get my bachelor’s and maybe a Master’s degree in nurse practitioner, or physician’s assistant, or something in nursing.

I work in the ICU now and I like it. It’s more thinking skills than physical skills. You are thinking about what you are going to do. When you call the doctor, you need to know everything, even more than the doctor does, especially if
you’re calling at two o’clock in the morning! It’s more critical and more rewarding because the patients are so much sicker… It’s a matter of life and death, so the patients are more respectful of you as a nurse. Out on the floor you’re more like a waitress… So it is different.

***

With father and daughter sitting around the kitchen table, Curt exclaims,

“Courtney is stubborn, and Shawn is stubborn, and they’re all nurses!!” to which Courtney replies,

“What? Are we stubborn!”

“C’mon…” Curt answers, indicating that question had to be rhetorical.

“Yes, we’re stubborn!” Courtney gives in with a sigh.

“Finally! You admitted it!” Curt says victoriously.

“I don’t know why he says we’re stubborn!” she comments.

“Nurses…” Curt explains, “‘Gabby, gabby, gabby…’” and elaborates, “Strict, you know… ‘I know what the problem is.’ You know?”

“Oh…” Courtney smiles. “I guess we’re… What is he trying to say, probably, is that we’re just strong, independent women…”

“Yeah, that’s true…” Curt nods.

“And yes, probably stubborn if, you know, someone wants to tell us something…” We probably have our own views on it, and we go with what we think…”

“Formalistic…” Curt comments.

“Were you always like that?” I ask her.
“I guess I’ve been that way just… growing up…” she mentions. “Because my mom is that way, my grandma is that way, my sister…”

“Yeah… hmm… Grandma… Thelma… same way…” Curt agrees.

“I think I’m a little bit more laid back than they are, but…” Courtney adds quietly, waiting for Curt’s reaction.

“Hmm…” he replies in disagreement.

“I like to think that, but probably not…” Courtney says smiling.

“I don’t think so!” Curt says with laughter.

A few minutes later, Christie, who had left the kitchen for a few minutes, returns and joins us.

“He said that we’re stubborn…” Courtney tells her.

“He’s always telling us that, yeah!” Christie agrees.

“And I said that I was only like that because I had to grow up with you guys!” Courtney adds and concludes, “I told him I think that I am more laidback then you guys are, but he said I’m not…”

“No…” Christie remarks, “There’s nobody more laidback than I am!”

As the whole table starts laughing, Courtney says,

“Next question!”

“What is it like being a Dad with so many women around?” I ask Curt.

“Is hard!” he says smiling. “Hmm… I like it, though…”

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Late Blooming and the Social Butterfly

“So after those first two years of being a couch potato, what made you decide to change, Curt?”

“I don’t know… It’s funny… But I’m here though! That’s all that matters!” he says, laughing.

“Well,” Christie interjects, “You started going to the aphasia group at Sarasota Memorial, and then USF…”

“Yeah… I’m a social butterfly!” he agrees, laughing. “Working at USF, speech department, three days a week! That’s a full time job! But I love it!”

“Yeah…” Christie nods, “I think the most improvement he’s had has been here, walking in the neighborhood, and going to speech therapy up in Tampa… It’s made a big difference… We were going to the aphasia group up in Sarasota Memorial, and he met Tom and Erika, who had found out about this aphasia group at USF… Erika was the one that mentioned it to us, so that’s how we got started there! It has made a big difference!

“And Ms. Paul…” Curt says with a smile, “She’s a sharp cookie! She’s a wonderful lady, consummate teacher! Give hope!”

***

It took a couple years for him to get really motivated… I think things started to improve once he started driving… He started getting more motivated and that’s when he got in the aphasia group at the hospital and at USF, and they all started going there. By that time he did have a driver’s license, so he could drive… I guess that’s when he got motivated, by going up there, starting to speak better, feeling better about himself… That really helped a lot!!
You know, it’s funny… I always thought that after the first six months that was it, you’re not going to get any better. I was a nurse and I always thought that! I mean, that’s what you read, but… When I first started going up there for the group meetings they kept saying, ‘Oh, don’t believe that’! And it’s true! They do get better! Everything is a lot better now…

I’m just happy that it’s working now, he’s happy with his life, he can golf as much as he wants to, he can work a couple days, which is enough… and he still has time to do other things, go to his group therapies, go up to USF… He has time to do all that stuff… and as long as he is happy with his life, I think that’s great! As long as he is content.

No Cane

“Do you think that people who don’t have a paresis after the stroke recover better, or adjust better?”

“Oh yeah!” Curt replies promptly, “I think so. I envy them…”

“Really?” I ask, surprised to hear that from Curt.

“Yeah…” he says, and with his great optimism he adds, “But so what? You know? It’s life! And I’m going to speak… fluently and walk better, much better!!”

“I don’t doubt that!” I say as I smile.

“I don’t like canes, anymore…” Curt continues. “I hate it… Inside, no problem, but long distance I still have to… Cane… But… Six months, one year… Watch out!” he says laughing.

“I notice you always set goals for yourself.” I comment. “Have you always done that?” I ask, curious.
“Oh yeah!” he exclaims. “All here!” he says, pointing to his head.

***

My goals is…
Walking better… and
Talking fluently…
That’s my goal.

I set my goals
Small, but I like it!

Every six months, re-set my goals.
I know… my goals…
Just here [pointing to his head]
I’m stubborn… [laughs!]

The Four Musketeers and the “Sissy Game”

Physically, I feel good. I work out at the YMCA three times a week, religiously, and like the treadmill. It’s my passion. I also golf in Sarasota five times a week. I love to birdie. I used to think it was a sissies game.

I mellowed …

In the future, who knows... I would like to teach golf to all stroke survivors because it has helped me with rehabilitation. Also, I am a certified
“Strength and Conditioning” specialist. Maybe I could be a personal trainer for stroke victims.

My communication is coming, as well as you. The doctor says I am going to be fluent some day. It may take two years, three years, five years. Whatever it takes.

Curt’s speech at the Speaking Out! Convention, 2004.

Who started the whole golfing thing?

Wasn’t it you, Curt? I think you saw something in the newspaper about golf and handicap and then... So he started first...

and then you got Tom to go...

Oh yeah, three years ago, no golfing! I think sissy game! But it’s fun! Membership now… and I beat Larry and Tom and Bob!

You play a lot more than they do!

That’s true...

They don’t play every day!

Pretty good, though!

You’ve gotten good in three years!

I hit a five wood, 130 yards! And I chip with two hands! Getting pretty good!
Is it?

Oh, trust me! Good!

Old Friends

“Have you kept in touch with many of your friends, Curt?” I ask.

“Friends?” he sighs. “Of course at the... aphasia... Tom, Bob, Larry... and... I get... friendly person... at the... at the golf course... Mike... Jack... Eric... all friends.”

“But those are all friends that you’ve met since your stroke...” Christie remarks.

“Yeah...” Curt acknowledges.

“You don’t see your friends that were friends before your stroke here in Florida. Those friends from the university have stopped coming by, stopped talking to you.”

“In Florida... Greg is my friend...” Curt says.

“But that’s your brother, Curt...” Christie remarks. “You have friends from Granite City that still call you and talk to you, but they’re old friends. You’ve been friends with them for many years! Your friends that you had here for just a few years before your stroke you don’t see anymore... They were workout buddies, basically...”

“Well... That’s true...” Curt concedes. “But some call...”

***

The guys that my dad grew up with back in Granite City if you ever go back there, they just tell stories about my dad like my dad was the greatest guy ever... He was so smart and he always helped people, like his buddies and stuff. They'll just go on and on for hours, some of them will start crying, he's very well-known... Then whenever he came down here, it was kind of... No one really
knew him except for the people at the school, and they were all very supporting in the beginning and then after that people look down on people who’ve had a stroke because they don’t understand, or… You don’t know how really he is, so… Up there, they don’t care… Whenever my dad comes up, they think the world of him.

On the Road Again

As I think about Curt’s transition from his independent and hectic university schedule to the convalescence after his stroke, I ask,

“Curt, how do you feel about returning to work?”

“I’m getting my job, two days a week…” he replies with visible contentment.

“ABC auto auction! I interview with a vocational rehab course.”

“Yes, disability, vocational rehab…” Christie confirms. “He went there a couple of years ago. She wanted him to get a volunteer job before he got an actual job, which he never did, so finally she called up one day and she said she had a job for him. He started out one day a week and now he’s doing it two days a week! He’s driving one day and he is doing the security job one day. He likes the driving part…”

“Fantastic!” Curt comments, a smile glowing in his face. “Venice, and Palmetto, and Brandenton… Full days…! Thirteen hours a day! Long hour! I love to drive! I’m shy… I prefer driving… Much easier… The university is… hard… talking… I prefer driving… Good change!” he concludes with a relieved sigh.
**Speaking Out!**

“And how about Speaking Out?!” I ask him. “What was it like, giving your first step towards becoming a motivational speaker?

“Oh, man,” he exclaims. “Shawn and Tony… From Illinois just for me! Man, I’m scared…” he says laughing.

“Shawn and her boyfriend drove down just to see him present… Just for those fifty minutes!” Christie explains.

“I can’t believe it!!!” Curt says, moved and exhilarated.

“Shawn hadn’t seen him for quite a while!” Christie mentions. “She’d talked to him on the phone a few times, but actually seeing him up there, giving the whole speech like that, she was really impressed! And proud!!! Both!! So… it was nice, it was real nice!!”

**Motivational Speaker**

* I want to be a motivational speaker some day!!

* Herb Silverman, he’s my idol…

* He was… Speaking… No problem!

* I liked Herb Silverman…

* My goal is… Motivational speaker.

* I wanna… Set my goal as a motivational speaker…

* Shortly!
Personality

“Curt,” I ask him. “In the first interview, when you talked about your parents, you mentioned you were shy.”

“Oh yeah!” he says, emphatically.

“Do you still feel that way?”

“Oh, I’m shy!! Of course!” he replies with confidence.

“Well, not that much…” Christie comments.

“It’s a small group… Ten people… that’s perfect…” he says, laughing.

“But he would have to go to the doctor and get medication for when he would talk to large groups, like in college… At least the first few times, when he first started…”

“Very nervous! I’m still…”

“I don’t think you’re half as bad as you used to be…” Christie disagrees diplomatically.
“Shyness is always a problem… But… now I take Inderal… Wonderful medicine! Speaking Out!… one tablet, that’s all! Twenty minutes ago! Is terrific!”

“It’s mostly a heart medication…” Christie explains, “I’m not sure how it works. Probably lowers your blood pressure…”

“It’s calming you down… It’s a miracle cure!” Curt says with relief and laughs.

***

_Before the stroke… I would say that he was a busy, active person. He was working three jobs part time, always running around, going somewhere, doing something… He is very friendly; he gets along easily with other people._

***

_Recently we have gotten in a fight, where he’ll say that I’m hateful and that I don’t do anything for him. I feel like I do a lot, and so that makes me mad whenever he says that… Later on he never apologized for anything, and he was just talking again about how much better he’s doing, and I was wondering how much does he really understand of what is going on?_

_I was kinda telling him he needs to apologize, and I was sort of holding this grudge, but… He just didn’t seem that he understood it all… It’s hard to tell what he understands and what he doesn’t… So I didn’t want to push the issue anymore. The next day he was talking about again about how much better he’s doing with walking, and talking, so to me it looked like he was just trying to keep on what he was doing, in order to stay focused, and happy…_
He’s never had a bad day, he’s always happy, so… I thought that I’d better not push the issue because I didn’t want him to get upset. And I think about how hard he’s got it… It was just hard for me sometimes…

Before the stroke he would have apologized. He would have made a big point of apologizing, and trying to talk it out… Because he was in counseling that was his big thing, you know? So, that day really stuck with me.

Is this just his way of… dealing with it and thinking out what’s going on here kinda thing? I don't know… Then I felt bad for pushing so much…

As far as being a father I don’t think anything’s changed a whole lot… except for, like I said, it’s hard to communicate with him sometimes, just because… hmm… I guess you couldn’t really hold really the same kind of conversation that… But we still go out on vacation together, and go out to lunch… I guess I try to look at it as not really a whole lot has changed, except for the kinds of things that we talk about.

***

He’s nosy…

Yeah, he is!

He’s afraid he’s gonna miss out on something… every time I’m in here, cooking, talking on the telephone… or if I’m reading something… he has to… find out what’s going on…
I’m inquisitive!

If I’m on the computer he’s looking over my shoulder, and I could still be on the same page and he’ll still be looking, like, “What’s gonna happen next?”

But instead of asking you just kind of sneak around and... stare... You could be walking by from here to here: If I’m talking on the phone you’ll just stand there, quit walking, just waiting to see what I’m going to say...

Just nosy!

That’s true…

***

Sometimes he’ll say, “Well, I have aphasia, so I can’t say that…” or “I can’t explain that…” and kind of use that as a smoke screen. I think that’s his way of dealing with things, to stay on track with being a strong person, staying busy… That’s always been his thing: If he stays busy, then he doesn’t have time for anything else. I think that’s how he deals with a lot of stuff, to kind of block it out and keep going… I think it’s just been the way he was probably raised, knowing my grandpa… I don’t think he’s really ever been asked, or forced to, deal with… everything.
It Happened – Get Over It!

I’m content!
I’m learning everything!

Me now, me before
No difference!!

I had a stroke
Left hand is weak, but slowly getting better!
Life is good!

Look in the mirror
What do I see?
I’m happy all the time!

I’m up early
Bright eye and bushy tail!
I will beat aphasia!
I’m confident!

In the mirror
Survivor
I survivor now…
Five years ago, watch out!
But now… I’m back!

Five years ago
I too rushed
Graduate students
Teachers,
All types of different problems…
But I smell the roses now!
Helping people, that’s my goal, in life…

Miss anything?
Not really…
I’m golfing, working out… what to miss?

Soul Mates

Christie’s my soul mate for life
She stuck by my side
Everyday in the hospital
Wheelchair bound …

Oh… I love her!
But… She’s stubborn!
As we gradually approach the end of the interview, I ask them,

“So what do you see in the road ahead, for the next couple of years?”

“Well,” Christie sighs and smiles. “Everybody is happy with their lives… They got worse for a while, but they are getting better… So much easier to live now!”

With the deepest sincerity in his voice, Curt looks at his life-long partner and says,

“Christie! I love you!”

“I know… I love you too!” she replies, smiling.

Thinking about how to ask the question tactfully I say,

“Do you think the way you express love to each other has changed?”

With a shy smile, Christie replies,

“I think actually we do express love a lot better or easier now than we used to, basically because we’re just together more… Because Curt slowed down so much it’s better, in a way… It’s just different… and it’s hard to adjust to it because it is so different… I mean, I always wanted him not to work so much, not to be gone so much, but now that he is here all the time, that’s not good either…” she says and laughs. “Just can’t be happy, I guess! But it is, it’s a lot better now… It’s somewhere in the middle… Finally…”

“I wanna make you proud, someday!” Curt says, chest high.

“I always have been proud! Always have something or another!” she says.

“That’s good… to know!” he sighs in contentment. “You are my soul mate for life!”
Before I turn my recorder off, I ask my last question.

“Christie, what do you think of Curt’s improvement so far?”

“Amazing?” he asks, with a hopeful look in his eyes.

“No…” she says chuckling, “I think it was about time!”

“Well… yeah…” he says, “but… I’m sick, remember?”

“No, you’re not sick…” she says firmly. “I just wish that he would have done it before, you know? Not waited so long…”

“I’m here, though… that’s all that matters…”

Figure 40. The Mathes family in Siesta Key, Florida. (Standing, left to right) Courtney, Zach, and Shawn. (Sitting, left to right) Curt, with Charley on his lap, and Christie.
Chapter 10. Dharma

Foreshadowing

“‘Excuse me, are you from Ithaca?’ …

‘I will be because I’m going to live with my fiancé in Ithaca,’ I replied.

‘So that’s why you look so happy,’ the stranger stated.

I nodded ‘Yes,’ pleased that my delight was so apparent. ‘I’m beginning a whole new phase of my life.’

He, too, was bound for Ithaca. After a ten-year period of medical research in India, he was returning to Cornell University for a college reunion. His gentle voice attracted me, as did his kind and forthright eyes. Yet more than this, I was impressed by his sincerity and warmth. He had done something purposeful with his life while I, at 21, was just beginning to give meaning to my own. I told him I had just graduated from Ithaca College, which would allow me to teach speech, drama and English in the fall at a nearby junior high school. I then told him how confident I felt about teaching because my speech professors called me a ‘natural.’ He nodded affirmingly as I spoke. Then he told me about his life in India, his wife, his work, his child. Pulling a wallet out of his jacket pocket, he produced a photograph of his son, a child of five who had a bright, open smile very much like that of his father.
‘He’s beautiful,’ I said, admiring the child’s big, bright eyes.

‘He’s perfect,’ the doctor murmured, ‘even though he has cerebral palsy.’

I was visibly shocked. ‘It’s hard to tell from the picture,’ I added, hoping to soften the knee-jerk response to this information. ‘Was he born this way?’ I asked.

‘Yes.’ The doctor’s expression turned subtly reflective. ‘India is a strange country. It is difficult to assimilate the peculiar attitudes the people there have toward life. One of their customs is that when a child is born imperfect it is sometimes rejected at birth and killed.’

‘What do you mean?’ I said rather alarmed. ‘Who sets the standard for what is and isn’t perfect? What right does society have to prejudge innocent people?’

The doctor whispered almost to himself, ‘They’re scared of anyone different – whether one is ill or deformed really doesn’t much matter. Society shuns that person, ignoring their feelings and what is inside their soul. Many times a person who is disabled takes on the image that others create for him. He thinks that he doesn’t matter or that he is helpless. It is up to us to give him confidence and independence, and most of all a chance at happiness. Our attitudes about treating everyone with equality can make all the difference.’
Unconsciously, he rubbed his thumb over the photograph, saying, ‘He’s perfect to me. Even without speaking or walking, he has so many gestures and expressions. He learns something new every day.’

Then there was a silence. I was unsettled by this information. I looked out of the window, thinking how protected and fortunate I was. I could not imagine anything this painful, this permanent. In my short life, tragedy had never been part of my experience. I had never known a real crisis. I had been cushioned by loving parents, by financial security, by an abundance of friends and romances. I did everything I wanted to do. There were no obstacles, no hitches. My experience of fear and struggle were limited. I was deeply touched by my companion’s capacity for understanding, but more important, I was awed by his graceful acceptance.

I looked into his eyes, then looked again at the photograph of his young son.

‘How do people of your village treat your child?’ I asked.

‘The people are afraid of handicaps, so they avoid him,’ he answered. ‘I don’t know why exactly.’ He stopped, then after a thoughtful pause added, ‘Maybe they think he has a contagious disease, and if they come too close, they may catch it. It’s kind of superstitious thinking.’ He hesitated, then sadly murmured, ‘They’re wrong, you know. They’re very wrong.’” (Barbara Newborn, Return to Ithaca.)
“No wonder she majored in English,” I muse to myself as I re-read one of my favorite passages from Return to Ithaca. I have always found foreshadowing to be a powerful and clever technique in literature – you tell your whole story in a premonitory nutshell at the beginning of your narrative, adding layers of complexity to the fabric of your plot. To the inattentive reader, events will seem to unfold in a linear and unpredictable progression. To the observant reader, however, a hidden and spidery web will be revealed with every page, allowing them to uncover the inner workings of the plot several chapters in advance.

I mull over the passage, once more. “Could it be that this was only a poetic license in her narrative? Or was that indeed the way events unfolded in real life?” I look back through my notes, and notice I never actually asked her about it. “In any event, if those were really the facts” I ponder, “one has to agree that the world does have an ironic sense of humor sometimes.”

**Discovering Newborn**

I first heard about Barbara Newborn as a beginning graduate student. “She had her stroke at the age of 21,” mentioned my clinical supervisor, “and wrote an autobiographical account of her experience with aphasia. Her book is called Return to Ithaca.” Fascinated and curious, I searched for her book and read it in a single breath. I was enthralled by her beautiful prose, and impressed with her courage, especially at the end, when she returns, alone, to Ithaca. I remember thinking, as I got to the final pages, “What happened after that?” But the book gave me no more answers.
Looking back, I wonder what attracted me to her story so much. I believe I was eager to discover what the inner experience of living with aphasia was like prior to having my very first client. But that was not all… In some ways, her story exposed me, vividly, to the frightening possibility of “losing control” of the future. Despite the statistics and the average profile of who may be at risk for strokes, in real life we have little to no control over when our brains may experience a short circuit. It could all happen in an instant.

With a chill running down my spine, a little voice whispers inside me. “I could fall on the ground in a whirlwind one day… in a split second. And if that whirlwind were to catch me… would I have half her strength?”

Speaking Out!

Friday, June 4 2004. Hoping I had wings on my feet, I zoom through the wide hallways of the Hyatt hotel, looking for the room where Barbara Newborn was the keynote speaker. Her presentation “Since my Return to Ithaca” had been highlighted in my conference schedule several weeks prior to the actual event. “I guess I’ll finally know what happened after the end of her book,” I thought to myself, in anticipation.

Quiet as a mouse, I enter a large auditorium where a petite figure, with long brown curly hair and a long red dress comfortably addresses a large audience from a podium. I take a seat in one of the last rows, and tune my ears to her presentation only, shutting out all other external noise. It does not take me long to recognize one of the passages from Return to Ithaca. Although reading the book had been a powerful experience for me, listening to it as read by the author, in the company of an audience
who shared and understood her journey better than anyone else was an unforgettable experience. I close my eyes quietly, and allow the narrative to take me years into the past.

Figure 41. Barbara Newborn at the Speaking Out! convention in 2004.

After the presentation, I shyly approach the group of people surrounding her and wait for an opportunity to introduce myself. I could not believe she was in her 50’s. Her graceful walk and contagious smile made her look much younger, despite the occasional white thread which meandered through her brown curls. I notice her ability to listen intently to each of the various people surrounding her, devoting to them her whole attention. I wonder if she had developed such skills because of her aphasia (as a compensatory strategy to follow the conversation more easily). But somehow I don’t think that’s the case. She seems to listen to each person more like a trained and experienced counselor would do. Her voice has a soft but firm cadence, and a melody
which is cheerful and serene. I admire her secretly, hoping that some day I would become as good a listener as she was.

When I am finally able to approach her, she greets me warmly. I am surprised when she mentions she had relocated to Tampa, where she was working as a yoga instructor for persons with disabilities. Her studio (which was in her house) was called Gardens of Yoga. I tell her I am in graduate school and briefly explain that I am working on a thesis project related to identity and aphasia. I ask her if she would agree to participate, and with a broad and generous smile she replies, giving me her card “Call me when you start your interviews: it does sound like an interesting project!”

**Going to the Gardens**

July 30th, 2004. After meandering through the streets of South Tampa, I find Barbara’s house, in a hidden and peaceful nook. She meets me gingerly at the front door. Her eyes are bright, with a mixture of warmth and wit. I gather all my gadgets and she invites me to come in. As we walk into her house, I catch a glimpse of a beautiful ceramic bowl with a cat painted on the inside.

“Do you like cats?” I ask her. She smiles and points to her three cats, blending in serenely with the environment. One of them, Shiva, was the most lovable and adorable cat I have ever seen (I have a cat myself, but mine is not usually that loving and open to strangers). From the cats, my eyes travel around her walls. I notice a vertical set of black and white photographs, showing Barbara playing freely on a swing with her bushy and endearing curls. I think to myself that she’ll never ever grow old.
She invites me for a tour of the house, and introduces me to the small yoga room, the office, the bedroom, the kitchen, and the big yoga room, which opens up to a serene garden in the back. The big yoga room has no furniture in it, except for a small table and two chairs in a corner. The sound of a soothing bell rings peacefully in the background, at the will of the blowing wind.

“Where would you like to sit?” She asks me.

“Anywhere is good,” I answer, hoping to follow her lead. We move towards the table in the corner, and I start getting my recorder and camera set up.

Infused with the atmosphere of the room, I ask her, “It must have been a huge transformation for you, to find yoga in your life. How did that happen?”

_I found the journey, and the journey found me_

“It was deep into the fifth month that my fate started to change. One day stands out, different from all the rest. In therapy, as usual, I tried to move my flaccid arm. Like all the other attempts, it would not budge. My body immediately filled with tension. This time I had to find a way to calm down. Taking one long breath, I shut my eyes and concentrated one more time. Totally unaware of everything else in the room, I found myself focused on the electric current running through my arm. I saw the movement before it happened. As time stopped, my mind connected with my arm’s energy. In slow motion my arm became aware of this signal and hesitantly moved an inch. I was amazed and thrilled at the impact of this magic.
The next several months a whole new world opened up for me. With the same damaged brain, I began to discover that I could connect with my innermost self, that core self which remained undamaged. I learned that I could close my eyes and just focus on my breath. I would slow it down and begin to listen to the sound. In that peaceful stillness, I could hear what my intuition was telling me, that everything was all right and the way it should be. I held onto these words and they became my mantra. It was as though my mind was never injured, or that the injury brought me to this place – a place where I always belonged, in a state of total oneness with everything, where I no longer felt separated. In that silence, the terrible isolation I felt simply did not exist. That special time in the morning gave me strength and courage when I needed it most during the day.

Breath and meditation began my journey to freedom.”

Barbara Newborn, “Disability, Yoga, and Transformation”

Sitting comfortably on her chair, Barbara thinks for a moment and then replies, “I think that my search to move again brought me to yoga. I used to play touch football, baseball, basketball…”

“You were very athletic?”

“Yeah! I was a tomboy! I was a flirtatious tomboy! I knew what I was doing!” she says. We both laugh, and she continues,

“My body, so young, had to move! It wasn’t as if I was 80! On the Cornell track, I had to run, you know? Even though my leg was limping along, I had to move my body in so many directions, and that was part of the recovery.
“What yoga did to me, eventually, was it made me connect to myself, on the inside, which was contradictory to myself on the outside: the material things, the wants, the desires. I learned to meditate, transcendental meditation (TM), early in my journey. I think about five months after I had the stroke. In TM I would say my mantra on the bed, and it would put me in a state where I found a place in my mind which was very peaceful, a place with nothing there, for fifteen minutes, morning and night. And that peaceful place helped me to find… myself. It helped me have the courage to deal with the problems in the day. Everybody talking, without me, you know? Not including me. And from there, I connected more to the outside, the trees… because I felt so peaceful with nature. I think that it also helped me have the courage to talk to people.”

I nod as I listen, silently. After a brief pause in the conversation I ask her,

“Did you ever travel to India?”

“Yes,” she replies.

“What prompted you to travel so far? I mean… to me, it seems that… the way you are… Yoga doesn’t seem to be just a profession or a job.” I comment, trying to organize the thoughts in my mind into a coherent question.

“Well, I went to New York to study, and the Sivananda Center was a block away. Since I felt like I’m anxious, in a new situation, I started taking yoga again, after my illness, after the meditation part and the yoga experience I had at twenty one. I was about thirty two then. It just so happened that, six years later, they were going to India. I really loved the Swami, he was so much fun, and he was such a storyteller.”

“Who’s a Swami?” I ask.
“A Swami is a master, a guru who has the knowledge of Indian sutras, and the Indian philosophy, and follows it, and teaches it, and is ethical, you know?”

I nod, and Barbara continues,

“He was bringing a group of people to Kerala, India. So I just went. It was at a time when my job was through, I could leave my job, my apartment rent was through, I had no major relationships, so I could just… hang out the shilling, you know, and leave! And so that’s what I did. I did not know anything about India!”

“What was your experience like?” I ask, intrigued.

“It was… I really feel I was home.” Barbara replies and smiles.

“Really?”

“Yeah, it was beautiful. It was tropical, in Kerala, the southern part of India. It was a lot like this climate. And it had a dam with lions, an island of lions. I felt so peaceful. But I had to work! We were working eighteen hour days. We get up at 5:30 for meditation, and then we do yoga asanas two hours, and then we do karma yoga, cleaning up our bathrooms, and sweeping, or digging, or whatever the land needed. And then we’d have lunch all together, and we do this on a routine, but… I felt it so calming to the spirit. For three months I was there. And then I went to NY city, and couldn’t take NY city at that time, so… I went up with the group to upstate New York to live, for three months more. It was so… Protected, you know? I felt so protected and so safe. It felt like being a child, where you’re protected and safe by your parents. But it was more than that… It was… the beauty of the land! I felt so spiritual, at home!”

As I listen, I try to picture Kerala in my mind, with the sound of the water, the physical work, and the opportunity to be immersed in silence, in deep meditation. What
an incredible contrast to the usual fast pace we are normally engulfed in, in which reflection and introspection are sometimes considered expensive commodities which are “not billable.” As I listen to her narrative, I remember that in one of her articles, she mentions: “On my new journey into the unknown, I learned to depend on the Yoga principles of living in the present, following my intuition, and having faith.” (Newborn, 2002, p. 3).

**Intuition**

“Speech – natural speech – does not consist of words alone, nor (as Hughlings Jackson thought) ‘propositions’ alone. It consists of utterance – an uttering-forth of one’s whole meaning with one’s whole being – the understanding of which involves infinitely more than mere word-recognition. And this was the clue to aphasics’ understanding, even when they might be wholly uncomprehending of words as such. For though the words, the verbal constructions per se, might convey nothing, spoken language is normally suffused with ‘tone’, embedded in an expressiveness which transcends the verbal – and it’s precisely this expressiveness, so deep, so various, so complex, so subtle, which is perfectly preserved in aphasia, though understanding of words be destroyed. Preserved – and often more: preternaturally enhanced…”

Oliver Sacks

“Do you feel you have become more intuitive after you had aphasia?”
“You know… I believe the innate intelligence is all there. We know it all. But it takes a hard circumstance to make it come out. And silence! Aphasia is the perfect circumstance because you are more intuitive.”

She looks at me with a smile in her eyes and says,

“No one can lie to a person who has aphasia, because we know, you know?”

She chuckles and continues,

“You know, very few people can pull the wool over my eyes… I am a tough cookie, you know? Compassionate, but tough. I really feel you have to be, especially in this world of scams. So it’s yoga, yoga is being aware of your senses, and being aware of other people, when they’re deceitful, when they’re not. You know?”

I smile and nod. That helped explain the spark in her eyes that I perceived earlier – compassionate and warm, but also penetrating and witty.

“But, your intuition,” she continues, “My intuition was heightened, as a problem solver also. I knew, innately, what to do. I new innately to take a tape recorder wherever I was, and to tape, at my own time, when I was alone, language, to read, little kid books, to write over and over what I saw, and what was in my mind, as a journal, and even though I made mistakes, I had to get myself on paper. I had to see that these feelings are real, where do we go from here? And, you know, I think that… I don’t know how I would be if I didn’t…”

A foreigner in a strange land

An analogy is to imagine yourself a stranger in a foreign land, not knowing the customs of the language. Your vocabulary might be limited to
a few words – not even enough to order food or ask for directions. Your first utterance would be a conscious, effort-ridden response. A native, not comprehending what you were trying to say, would be apt to interrupt or even ignore you, and you would feel lost, alien and helpless as a result.

Such is the case with aphasics.

They are always strangers in a strange land.

Barbara Newborn, Return to Ithaca.

“I remember you saying that Yoga and meditation also gave you the courage to talk to people, especially after you moved back to Ithaca.”

“Yes… mostly with foreign accents!” She adds.

“Is that true? The foreigners?” I exclaim.

“Hmm, hmm, it was a lot of foreigners! But you know, like, we …. As English as a Second Language, we don’t really know the correct grammar, and the slowness of saying something, and listening all the time, and patience, you know?”

“Yep, I know!” I reply, drawing on my own personal experience.

“You got it!” She smiles, realizing what was going through my head. “So I really could relate to that! I was that! Actually, I was pretty enough, you know, at that time…”

“And are still now!”

“To really have people attracted to me, and just talk to them, as we are talking! But it’s the spirit, it’s my thing, it’s the eyes! What really made people talk to me, or be with me, it’s not the things I say!”
“I think I get it!” I smile. “That is very funny that you mentioned the foreign language,” I continue, “because with the USF group one day one of the topics was ‘traveling’, and there was me and another student who were both foreigners…”

“Yes!”

“And we were telling the aphasia group about all the embarrassing moments we’ve been through when we moved to the U.S.! The things we didn’t know, the things we’ve said that got us in trouble…” We both laugh. “Sometimes I see it as having a milder version of aphasia…”

“Exactly!!” Barbara exclaims. “You know, my husband is Bulgarian! One day he was writing on the computer ‘eggs and pain’. He meant ‘aches and pains’!!!!” We both laugh to our hearts content, knowing we’d both been there several times before, through different routes.

“You know, laughter is so much better sometimes, in many times, than crying in frustration… you know?” She continues, “Seeing that we’re not alone…”

“That makes a huge difference!”

“Yes! And seeing that you’re just a foreigner in your own land! All the time!”

Relationships

9/6/73

This is the most difficult time of my life. I am recovering from a stroke, but the progress is going very slowly. I lost John, I lost my teaching job, and I haven’t the faintest idea on the direction that I’m headed. I’m 22 years old and I’ll be 23, 24, 25, by the time I’ll recover. I just can’t afford to waste
those years. I want to be teaching right now, I want to be with John right now, and have everything perfectly planned as before. It can never be, for my relationship with John has changed. I no longer feel I could spend the rest of my life with him. We’re too different. The awful realization I’ve come to is that I’ve centered my world around John. I was sure I was going to marry him. The teaching job was in Ithaca, so we could live together ... I hope I recover in less than a year. So I could go on planning my life. My life holds no answer of what’s to become. Life = ?”

Barbara’s personal journal entry.

“One question I had,” I continue, “And if it’s too personal, let me know…”

Barbara nods, indicating I could go on.

“How did you feel you had to redefine your relationships? You were just engaged when you had your stroke, right?”

“Yeah…” She answers. “Well, you know… It’s not redefine, it’s going on… My… fiancé, who was terribly insecure… even though he was a pre-vet student at Cornell, and gorgeous, you know? Hmmm… He was terribly jealous. So… it turned out I had to break up with him. When my ex-boyfriend came to town, to see how I was, he was very jealous! So… I had to have courage to break up. And… just go on! And meet new people, which I had no difficulty doing, with or without speech! So that’s the way I was!”

She pauses for a brief moment and then continues.

“When I went out, about five months into my recovery, from Altoona to Ithaca, to... live my life again, alone, away from my parents… I broke up with him. And... had
moments of depression… because very frustrating not being able to talk… hmm… but, I think that… just got through that I had to prove on me, again, the spirited, courageous woman that never says ‘I can’t!’ So it’s not in redefining relationships… it’s just… inventing new ways to connect with each other.”

“Did you ever hmm… get in touch with him, years later, after everything?” I ask.

“No, you know, I haven’t had the curiosity, and there were so many other men!” I laugh, delighted by her straightforwardness. We both laugh together.

“No, true! You know? There’s been so many other people, I forget, you know? Whoever I dated, you know? But… You know, and one thing is, I had to have people say to me ‘you’re incredible, you’re the most beautiful woman I’ve ever met’ to me, and giving me self-confidence. So… I’d say that I had to redefine my image, OK? In self-confidence… In just… I had to have people, and men especially, tell me, that I was incredible!”

“I think every woman needs that!”

“Especially at 21!”

“Hmm hmm!”

“And so I did! And one by one, I got my self-confidence back.”

**Professional life and Dharma**

*I finished 1974 in Ithaca, going on to earn a masters degree in speech communication at Pennsylvania University. I was aphasic all through graduate school, and my thesis was on this subject. It was quite a struggle.*
but I had many wonderful people to help me along the way. In fact, my
committee chairman’s family edited and typed my paper for me ...
The next summer, while visiting a friend in New Mexico, we magically
founded a camp for teenagers with head trauma. I developed and co-
directed various programs during the next five summers for these young
adults. That helped me realize what I was destined for. I wanted to be of
service to others in similar situations. I then entered New York
University’s Graduate School of Rehabilitation Counseling, and became a
professional in this field.

For the past 11 years, no matter how many clients I have counseled, and
regardless of their physical disabilities, we have discovered new ways of
adapting, adjusting and finding a fuller self. In doing that we brought
independence, fulfillment, and dignity to our lives.

In my private practice, workshops, and position with the NSEI [National
Stroke Medical Institute at Columbia Presbyterian Medical Center], I
have had the privilege of knowing many courageous people, who despite
their physical disabilities are tremendously enabled in spirit.

Barbara Newborn, Return to Ithaca.

“What made you decide to become a counselor, working with folks who had had
traumatic brain injuries (TBI)?” I ask.

“Well, I thought the only way to cure my… not cure, but to get better my aphasia
was to go back to school. So I went back to school and got one MA in Speech
Communication, and then ten years later I got another MA in rehab counseling. And…

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you search and search for what you can do. And I narrowed it down, because I still was insecure as to full body people. I couldn’t type, I couldn’t be a waitress, you know? There’s so many things I could not do that the things I could is… working with people. So… This happened after three days of retreat, being silent. Going to upstate New York, I met someone who was an occupational therapist in one of the hospitals in New York, so she told me about the schools, and then it happened that… It just happened, where I called the school [University] that day, got an interview, and they said I’m in! So in a month, I had to write the outline of my book, I had to… Go head a camp for head injury… And… I had to finish up what I was doing, pack, and go to New York to live and to NYU, in rehab counseling.”

“How did you like rehab counseling?”

“I really, you know, it was the… I stumbled upon this! It was the thing I loved the most!”

“Really?”

“Yeah! I think that we’re… You give up, it is when it comes! You’re not looking is when fortune comes! I was always on the search, but I didn’t know what I was looking for, having not had that experience. But then I became a rehab counselor. I didn’t want to do stroke because it meant older people, and I was young. So I did head injury.”

“What was it like, working with…”

“Head injury? It was delight because of the compassion. I think that it’s just like working with people who have aphasia or younger people who lost their way. And… by talking to them, and by being with them, you both find a new way to be, with the hope
that they can do things, or find the things they want to do. And that happened time and
time again.”

“That must be very rewarding!”

“Well, I think that… rewarding is a word that… it’s… is the only word we use for a
great experience, but I was doing my dharma.”

Looking at the puzzled look on my face, Barbara explains.

“Dharma is cause and effect. Everybody has a journey, and everybody has work they are meant to do. And I found my dharma. It was always working with people, being a liaison between the professionals and the physically challenged: I was in the middle and I can relate to them both. Now, working with the injured and yoga therapy, that’s perfect for me too! I found that I only have to create and only have to be, at the right time, the right place. But it will all happen, what is meant to happen, will happen anyway, I just have to be open to it. The thing I like and don’t like in this world is that there are divisions. Stroke – aphasia, professionals – layperson, but we’re all one, and we’re all in the same place. You know? We have to know that we’re not alone. I think it takes patience with your own life, and it takes a kind of… confidence and security, that you’re going in your journey, and that when things are ripe it will happen!”

Overcoming hurdles in the present

“Do you ever feel afraid now?”

“I have to say… I still have aphasia now, and I’m 53… My memory is not so good… you know? And I… it’s sometimes difficult to remember first names, last
names… What I did yesterday is no problem, but… linguistics is… in putting words together!

“There’s a … question about, now at my age, in the “All timers,” and just dementia, hmm… am I going to have? You know? That is… not a real concern, but a question in my mind… When I’m tired… I don’t really focus, and although these are… questions in everybody’s mind… It’s more a concern when you have aphasia then when you don’t.

“One of my clients is head injured, so she can’t get insurance because… you know, just there’s a question of she’ll have most likely dementia or Alzheimer’s. And so… I have to remind myself that living in the moment is the best. That I am taking supplements to relieve, to up my intelligence, to up my focus. And I don’t know what’s going to happen in the future. You know? Hmm… but it never goes away, you know, that you are aphasic.”

**Language and Self**

*September 19, 1973*

*I can’t make any future plans. Just live in the present; trying to get well.*

*At least that’s what my parents expect me to do. But that’s impossible. I must bring both the past and the future into my life. For I live on memories of who I once was so I can become that person again (or better – hopefully).*

Barbara’s personal journal entry.

*September 28, 1973*
I ... decided not to lay out my future goals as yet. For when I do I just worry about them, and I feel I’ve got enough to worry about right now. Like getting a lot better for one. So I’m just going to get back in touch with Barbara Newborn and find out who she really is now: in the present form, in order for her to live on with the present and the future. And I wouldn’t be surprised if she finds out that she likes herself as much as before. After all, all the way we are to others is the image we give to ourselves. And I’m going to smile like I used to and really mean it when I do. And laugh and run and shout to the wind, “I’m me and I’m not ready to die!

Barbara’s personal journal entry

Only when I gave myself permission to grieve for the loss of myself could I go on with the rest of my life. From the day of my stroke, 7 June, my former identity died to make way for a more purposeful life. The paradox was that the old me, with all its intense wants and desires, was the means for discovering my new fuller self.

Barbara Newborn, Return to Ithaca.

“Looking back, do you feel you are still the same person you were at twenty-one?”

“You know, in a sense, now from my perspective in spirituality, in being a yoga teacher, a yoga therapist, you’re always who you are. And you’ve got to redefine that person again, even without language. Your soul is always the same, and you operate the same personality. You know, you’re just as stubborn, or just as nice, just as willful
without language as you were with language! And so you operate on the same conditions, with or without language. You manage… I managed to get things without language as I did with language. I managed to make friends without language, as I do with language, because of who I was, underneath. But… the person feels an unbelievable loneliness and solitude when he is first aphasic, he or she. You’re really cut off. I guess that, since everybody else is talking and understanding, you feel terribly left out. You can’t contribute anything in conversation. You can’t even listen right, because sometimes you can’t understand! And it’s terribly… You know, unless people have had aphasia, or if like in your situation, working with people who have aphasia, it’s a terribly lonely existence, a not-understanding existence, where really no one understands.”

**Grateful for aphasia?**

“Some people, when I read personal narratives of people who have had aphasia, they say in a way, that they’re grateful to everything that happened. Do you feel that way?”

“I don’t know whether I’m grateful…. But… It’s just gentle acceptance…. You know, my life would be tremendous anyway!” We both laugh!

“I don’t doubt that!”

“In adventures and unfoldings! You know, I think that… because of my absolute loneliness, and depression, it helped me write a journal, that helped me write a manuscript, that helped me write a book, that helped me help others. But I was in the teaching profession, anyway! I would have been… you know, a really heartfelt teacher. But this happened, so… I dealt with the cards. And in just being really realistic, in just
saying ‘Ok, well this happened, what to do next?’ You know, I think that… I really appreciate the miracles of life, and I also appreciate the healing.”

“I can see that! It’s all over the place” I mention, referring to her home.

“But I don’t know what I would have been if this hadn’t happened to me. I probably would be just who I am today anyway, finding another way to do it!” She laughs. “Playing, you know? I think that in my profession, in just dealing with healing yoga, you know, you would deal with so many clients who are ‘normal’ that are depressed, that have no laughter, and that miss the nurturing. And so together we form a loving relationship with plenty of nurturing and plenty of fun, and plenty of definition in stepping back, ‘Who are you?’ But… there are so many people, regular people, who are… in their past, you know? Childhood or something that happened to them… not having the happiness… and I really feel that… the joy, with compassion, are very much treasured… and people are looking all over for this!”

“I agree…”

“Hmm hmm… And, you know, I… I really have many times joy! It’s in me! And compassion… I think that I would have discovered that, or would have uncovered it every other way too if I didn’t have… but I think that I took a faster route” she exclaims and chuckles.
Chapter 11. In Exile in One’s Own Land

Moving On

“I think that… Once Bob really realized and accepted the fact that he could not go back to work there didn’t seem to be a reason for us to be in Atlanta… We really only had moved there for… for his job…”

“Really, yeah…”

“And we had always talked about coming down here for retirement, so… A couple of years before that, we had started… looking down here, so it was a slow transition… It was a process…”

“Right, right…”

“It was time to look into starting to build a new life. Like you say, as an immigrant person, there is a point in time where you have to kind of…”

“Moving on!”

“Move on… And leave that life behind, and build a new life.”

Bob and Diane Lombard

Same But Different

As seen in each of the narratives, the seven survivors in this project found unique ways of coping with disruption and “moving on” with their lives. Interestingly, several of them reported they were still “the same person” as they “had always been,” several years
after their strokes. This view may not have been concurred by all family members (e.g. Diane in Bob’s story), but it was expressed by most survivors, to varying degrees. Interestingly, however, all survivors also acknowledged they have been profoundly changed by the experience of their strokes and their struggles with communication. A conundrum is thus created. How can one be “the same, but different” (as expressed by Bob in one of his interviews)?

In revisiting James’ (1910) and Kirmayer’s (2002) definitions of the self (the “Me” and the “I” as suggested by James and the “transactional” and “adamantine” selves as suggested by Kirmayer), along with the role played by narratives after significant life disruption (Becker, 1999), the concept of “same and different” is exposed in a different light. Although the “Me” (or transactional aspects of the self) of the seven survivors was disrupted and reconstructed over the years (e.g. changes in body image, reversal and restructuring of family roles, substitution of previous occupations by other vocations and professional aspirations), something in the “I” (or adamantine self) was perceived by all participants as remaining the same.

If narrative is indeed a means of linking the past, present, and possible future into a fluid and “continuous I,” perhaps the fabric of each individual’s narrative may provide clues as to how each one of them has reconciled their presents and their pasts and “moved on.”
Vicki and Larry

Although their motivations were circumstantially different, Vicki’s and Larry’s narratives were marked by a common and unifying thread: their search for restitution (Frank, 1995) and their desire to “fight this disease [aphasia].”

Differently than the other participants, Vicki and Larry were the only two survivors who made a point of showing the investigator their archived homework files. Other participants (e.g. Curt, Tom) volunteered copies of their Speaking Out! presentations in addition to personal photographs. Vicki and Larry, however, were specific in their offer: they volunteered the documentation of their stamina, endurance, and perseverance in trying to regain their language skills. As pointed out by Becker (1999), “perseverance is a key part of the cultural discourse on continuity in the United States.” (p. 151).

While Vicki documented her journey on her calendar as well as on Post-it notes placed on flashcards, indicating when they were first and last used, Larry used a notebook as a journal, in addition to volumes of folders containing his homework, organized chronologically. Both survivors kept a concrete and thorough chronicle of their rehabilitation efforts. However, differently from Barbara’s journal (which contained several poems and reflections on the nature of her communication difficulties and their implications for her sense of self), Larry’s and Vicki’s chronicles were intrinsically linked to their rehabilitation process (i.e. Larry’s last journal entry was linked to his last days in rehabilitation in the hospital; Vicki’s calendar, six months post-onset, contained no more notes). Thus, their documentation revealed objective landmarks in their fight for
restitution, as opposed to reflections on the nature of life with a disability and their struggle for adjustment.

In *Disrupted Lives*, Becker (1999) comments on the importance of routine and structure during the process of re-establishing continuity in one’s life after a significant disruption. As she discusses,

“Markers of continuity emerge from life experience and the layers of meaning people attach to their lives over time. Indications, no matter how limited, of the ability to return to activities engaged in before the onset of disability are cause for hope.” (p. 151)

In some ways, Vicki’s and Larry’s chronicles reveal a desire to document how continuity and structure were reestablished in their lives. As Vicki stated, her notes and cards are testimony of how she relearned “everything;” or, in Susan’s words, how Larry: “had to start with ABC, 1, 2, 3.”

In addition to their desire to document their recovery, Larry and Vicki have other aspects of their stories in common. Both currently have little to no physical impairment as a result of their strokes (Larry has some mild residual weakness on the right side and Vicki never presented with any motor deficits), and both have progressed to a mild severity level in their communication difficulties. Thus, their sequelae are much less visible than those of other participants. However, continuous reminders of their history still remain (e.g. both participants need to check their Coumadin levels frequently and Larry needs to constantly watch for any vegetables containing vitamin K; Coumadin restrictions also prevent Larry and Susan from traveling as often as they used to). Therefore, although life has been restituted to a large extent, the disruption brought about
by their strokes is constantly acknowledged and respected, and every precaution is taken to prevent such disruption from re-occurring.

Bob and Edie

Differently than Vicki’s and Larry’s stories, Bob’s and Edie’s narratives are permeated by a thread of disruption and upheaval. Both Bob and Edie were the solid rocks of their families. As an Air Force veteran, an engineer, and “the man in charge,” Bob was a role model for his daughters (both of whom became engineers) and his younger siblings, as he was the only child in his family to go through college. Edie, on the other hand, had the healing and calming touch of a nurse, and was the unifying and sobering element in a marriage permeated by constant change.

At the time of their strokes, both Bob and Edie were in their fifties and at the peak of their careers (Bob as a CEO Vice-president in Georgia and Edie as an experienced nurse in Florida). When their lives were suddenly disrupted by illness, their whole families plunged into an initial period of chaos, marked by role reversals which collided with life structures which had been developed over decades. Thus, as indicated by Becker (1999), in Bob’s and Edie’s contexts, not only the survivors but also the co-survivors needed to undergo the process of biographical reconstruction in order to restore coherence into their lives.

In Bob’s case, the stroke afflicted the very core of his identity. He could no longer resume his job due to his language difficulties, and he gradually abdicated from playing the guitar due to the frustration he experienced in trying to use his right hand. To the surprise of the other Musketeers, Bob once stated his greatest desire was to regain the
ability to play the guitar normally (more so than the ability to speak fluently). As a spouse, however, Diane witnessed Bob’s lack of motivation and struggled to reconcile the Bob of the past (a “go-getter”) with the Bob of the present. As a result, their views on recovery and change, as portrayed in their narratives, were in sharp dissonance (“me, 90 degrees – Diane, 180 degrees” as Bob expressed).

Becker (1999) once indicated that for some individuals, “continuity depends on the fulfillment of a specific role that is key to their self-definition; the loss of that role may prevent the reestablishment of a sense of continuity.” (p. 152). In some ways, the job and the music connected Bob not only to his immediate past and self-image as an adult, but also to his family roots. As he stated in his narrative, his father was “the work,” and his mother was “the music.” When those two cherished elements of his life were sequestrated by his stroke, the pain was probably too much to endure (or to motivate him to change). Thus, if viewed from within the context of his life history, Bob’s “lack of motivation” acquires different meaning.

It was only by grappling with (and accepting) the irreversible changes brought about by his stroke (as Diane expresses in the beginning of this chapter) that Bob was able to re-establish a new sense of coherence into his life. As he stated, key elements in his transformation included: being able to drive again (his greatest moment of hope, as he stated, was when he stepped on the accelerator, several months after his stroke) and establishing new friendships (the Musketeers, the aphasia groups, and volunteering at nursing homes). In Diane’s view, however, the present and the past still remain disconnected, and longing and yearning for the “Bob of the past” still remain.
In Edie’s narrative, the disruption brought about by her stroke had wide repercussions throughout the foundations of her family. As her husband experienced a psychological breakdown due to his difficulties in coping with the demands of becoming a caregiver, Cathy (Edie’s daughter) was gradually confronted with facets of her father’s past, which had remained largely disguised under the semblance of personal eccentricities until that point. Thus, disruption was experienced on two different fronts: by Edie, on the one hand (as a stroke survivor) and by Cathy on the other (as a daughter suddenly confronted with unknown facets of her family’s past and as a caregiver for her mother).

With Cathy’s support, Edie was able to make the life adjustments she deemed necessary at that stage in her life. Pragmatically, she not only opted for a divorce, but also opened herself to the discovery of a new vocation: painting. As Edie has expressed in her narrative, painting (and attending her painting classes) gave her a space where she can be centered, focused, and in control, which are feelings she also experiences when she has the opportunity to sail, a sport she has always loved.

Cathy, on the other hand, is more emotional about the changes her family has undergone. When the investigator read the draft of “Light Bulb” to mother and daughter together, it was Cathy who had her eyes full of tears, while Edie sat strong by her side.

Thus, in Bob’s and Edie’s narratives, while survivors have managed, in their own terms, to reorganize their life histories and reestablish a sense of continuity with their pasts, their family members (even years after the onset of their loved ones’ strokes) still struggle with the task of bridging their pasts and presents into a seemingly coherent whole.
Tom

In Tom and Erika’s story, two elements have played a central role in establishing continuity and coherence to the self after the onset of illness: the nurturing of their love for each other and their strong religious upbringing. Differently than most other participants in this study, who either maintained a longstanding relationship or experienced a marital disruption after the onset of their illnesses, Tom and Erika got married a few years after Tom’s stroke. As a result, their roles as husband and wife developed concomitantly with their identities as survivor and co-survivor.

As they faced the challenges and life adjustments brought about by Tom’s stroke, both partners constructed, nurtured, and incorporated aspects of their identities which they had been previously unaware of. In fact, as both stated in their story, their commitment to each other, instead of weakening, deepened significantly during periods of great stress. As stated by Erika,

“If you had told me this was gonna happen, I don’t know that he would have been able to handle it…. plus, I didn’t really know him… I knew him, but for one year and a half before, but we were only together as a couple for a few months… So… I didn’t know that side of him, but I didn’t think that he would have been this strong… I mean, now he’s just like… super strong! He has his moments, but his determination is just incredible…”

The mutual admiration they devoted to each other prompted them into a journey of discovery of their selves through the eyes of the other, almost as reflections on a mirror which became clearer and less foggy as the years progressed. As a result of this
journey of discovery, threads of continuity with their pasts were reconnected, and a solid foundation, based on mutual knowledge and respect, was laid for their future.

The second source of their strength was their religious upbringing and faith. As Erika recounts, it was only after calling her mother and being told “how to pray and what to ask God for” that she felt certain that Tom would survive and recover. Currently, as both partners carry on with their lives and intone their mantra (“God provides”), hope is continually renewed in their quest for improvement and adaptation.

**Curt and Barbara**

*Quest stories meet suffering head on;*

*They accept illness and seek to use it.*

Arthur Frank

As one approaches Curt and Barbara’s narratives and contrasts them with those of the other five survivors, a different perspective into the world of disability and illness is attained. Although hope for recovery remains present in their stories, it no longer occupies the foreground (Frank, 1995). Instead, their search for renewal and change has taken the front stage. The manner in which they have delineated their journeys is intrinsically and personally different. However, in both stories, the wounded storyteller, as presented by Frank (1995) is strongly present.

In Barbara’s narrative, what was once pain and sorrow was transformed into a path of healing and recovery for herself as well as other survivors. As a counselor and yoga instructor for individuals with disabilities, Barbara Newborn has explored the depths of her strengths and limitations, and has used them as healing instruments in
reaching out for others who may have been engulfed by the limbo of their own transitions. Although she may have followed a similar path with or without a disability, Barbara insightfully acknowledges that the stroke provided her with a faster (though more painful) route.

In Curt’s narrative, the reader is confronted with a survivor who, after a period of silent waiting and withdrawal, started to work towards becoming a motivational speaker. In some ways, his desire to understand his own weaknesses and transform them into strengths has been a thread woven throughout the fabric of his biography. In attempting to overcome his shyness, he became a university instructor; in confronting his addiction to alcohol, he became a counselor; in recovering from the effects of his stroke and aphasia, he has challenged himself to become a motivational speaker. Possibly, at this stage, one additional goal he has posed to himself (perhaps not quite as explicitly) has been to become “a good father and husband,” as he constantly strives to make his spouse proud and gain the praise and respect from his children. Thus, in some ways, the stroke may have been a catalyst for change for the Mathes family as a whole, where issues which had remained buried under years of disappointments and unspoken hurt were gradually unearthed, brought to the surface, and addressed.

Moving Out of Exile

In “Talking to ourselves: dialogues in and out of language,” Black and Ireland (2003) discuss the similarities between their experiences as a foreigner (Black) and as an individual with aphasia (Ireland). As stated in their initial remarks, “Sometimes Maria [Black] feels in limbo – between two languages. Sometimes Chris [Ireland] feels like she
is in a foreign language that she can’t quite grasp.” (p. 21) Their observations are concurred by Barbara Newborn in *Return to Ithaca*, who states that having aphasia is, in many ways, akin to being a “stranger in a strange land.” (Newborn, 1997)

As one revisits the narratives of the seven participants, the parallels between being a foreigner and having aphasia may extend beyond the linguistic realm. The similarities are in fact greater when the experience of “foreignness” is embodied in the form of exile. According to Skultans (2004), exile constitutes “an unwanted separation from a place one is no longer able to inhabit. As well as physical separation, war and loss, desire and longing serve to construct exile as a moral space characterized by absence.” (p. 295). Thus, for many individuals in exile, the only connection to their homelands and their pasts is their crystallized memories, as they remain frozen in time (Skultans, 2004). In many instances, it is only after re-visiting their home countries that several individuals are first confronted with the reality that not only have their homelands changed, but also their transactional selves of the past and present are no longer in agreement. As stated by Skultans (2004),

“Earlier stories [of exile] spoke of a golden past a lonely and disconnected present and a future return to the homeland. Contemporary stories [after revisiting the homeland] speak of a search for a missing past and a return to the safety and predictability of … [the host country].” (p. 306).

In many ways, the experience of living with aphasia also involves the disruption of current routines, the crystallization (or idealization) of the past (as suggested by Brumfitt, 1993), and the gradual realization that “life goes on.” However, for many
survivors this realization only takes full effect after the past is revisited and a thread of continuity is envisioned between the memories of the past and the reality of the present.

Establishing this thread of continuity without language, however, may be especially challenging (both for individuals with aphasia as well as persons in exile, if they are not familiar with the language of their host countries). In discussing her experience as a Latvian child living in exile in England during the late 1940’s and 1950’s, Skultans (2004) stated that “A central problem for refugees is communicating and sharing a credible past. The present is meaningless unless it can be seen as connected in some logical way with what precedes it.” (p. 300).

In most cases, speech and language pathologists (as well as other rehabilitation professionals) working with individuals with aphasia have little to no information regarding who the individuals they are working with truly are. What have they experienced in their pasts? What were their life-histories until the moment of their strokes? What were the turning points in their lives? How much disruption has the sudden onset of their disability brought onto them and their families? In most cases, as pointed out by Black and Ireland (2003), most individuals (and therapists), when confronted with disruptions in language, tend to feel obligated to correct surface or structural errors (i.e. pronunciation or grammar), even when these corrections result in little to no difference in the content of their messages. As Black and Ireland (2003) state in their candid question, “If people knew what I am trying to say well enough to correct, why bother?” (p. 25)

Is there a space within the field of speech and language pathology, for the incorporation of personal stories into aphasia therapy? If so, what would that entail?
Chapter 12. Where do we go from here?

Conclusion

In discussing his experience as an individual with aphasia in speech and language therapy, Alexander (1990) commented that

“A major barrier to gaining insight into the aphasic’s condition is the reductionist approach to the ‘teaching’ of aphasics… In these reductionist conditions, the aphasic gradually begins to believe he is dim-witted, that he is treated as what he really is. Since the ethos of the bureaucratic institutions encourages belief and dependence on the medical system, and since rebellion is not generally approved of, the average aphasic under this kind of stress, with no means of articulate protest, is under constant pressure to accept that he is, indeed, stupid. It is no wonder then that some patients give up the attempt to regain language. A vegetable has been created.” (p. 8 - 9)

This statement may shock several practicing speech and language pathologists. Causing this level of disappointment and frustration in patients is certainly not the intention of any professional working in the field. However, one cannot but wonder if at times clinicians do not have the awkward sensation that this statement may be painfully true. Dealing with the emotional turmoil and anguish experienced by the patient during rehabilitation may not be as comfortable as addressing specific components of their
speech and language impairment. Why is that, however? Why are clinicians, in so many instances, afraid of opening Pandora’s Box?

The roots to this dilemma may lie in part within the structure of our professional education in the United States. In discussing the differences between social vs. traditional approaches to rehabilitation, Sarno (2004) stated that

“… the abandonment of a medical model calls for a major shift in the underlying bases of the training of aphasia clinicians. If we adopt a social model, the academic curriculum will need to incorporate a far greater emphasis on the social sciences, sociology, and psychology than it does at the moment. It will perhaps even include some supervised clinical practice in counseling. A social model calls for a revision of intervention practices away from the traditional focus on static, non-interactive techniques intended to repair the language deficits manifest in aphasia, to approaches that acknowledge the social, interactive basis of human relationships.” (p. 26).

Changes in rehabilitation paradigms certainly do not occur overnight. However, how many practicing clinicians believe there is a need for change in the first place? Little research has been done within the U.S. regarding how speech and language pathologists interpret their role in therapy and the differences that may exist between their perceptions and those of clients. In a powerful essay about his experience as a survivor, Clarke (2003) indicated that

“It was … the quality of the relationship between myself and the speech therapist that I was to learn from. A quality that was just not present with
other therapists. This was greatly enhanced by these sessions being on a one-to-one basis. It would be gratifying to hear her door close and know the focus for the hour was on improving my communication. I had quickly realized that my time with her was all-important. It was not surprising then that it was to her I brought all my fears.” (p. 82)

What beliefs and values do speech and language pathologists pass on to clients during therapy? Do we transfer the responsibility of recovery mostly to their shoulders? (Becker & Kaufmann, 1995). Do we encourage narratives of restitution? (Frank, 1995). Who are the clients we label as “de-motivated”? (Becker & Kaufmann, 1995). Do we often take a role of authority during therapy? Are we open to negotiating the terms of therapy with clients? Since some aspects of the self are defined during social interaction, what role is played by clinicians during the client’s narration of the self after illness? How do clients portray therapists after their rehabilitation?

In comparing clinician and client views, another possible follow-up for this study may include the comparison of clinician reports with client narratives. How is experience registered within the two discourses? What are their points of contact? Where do they diverge? What do these textual discourses reveal about the perceptions of the client and the clinician?

Additionally, the current study was conducted only with individuals who were years post-onset and had a highly functional level of communication. What is, however, the progression in the changes of the transactional and adamantine selves from acute care to the chronic stages? How do individuals (and their families) change their perceptions
over time? What happen to individuals who do not regain much of their language functions? What is the experience of their families?

Finally, during this project all individuals revisited their life-histories several years after the onset of their strokes. What would be the effect, however, of developing these narratives during the process of rehabilitation (e.g. during outpatient therapies)? Pound et al (2002) have written extensively on the use of life-history portfolios with individuals with aphasia, within the context of therapy, but no studies involving their development and use have been conducted within the United States (see refer to the appendix for an example of a life-history portfolio developed with a patient at the James A. Haley VA Hospital in the spring of 2005).

Given the nature of this project, all narratives and descriptions are particular to each individual survivor and their families. Thus, findings may not be “generalized” in the traditional sense of the word. However, it is hoped that by reading or listening to the narratives of these seven survivors other individuals with aphasia (and their families) may find hope, inspiration, or solace as they carry on with their journeys.
References


Websites

Appendix: Mr. Johnson’s Life History Portfolio
My Childhood

Grandma Fritz’s doll

Paul, the mechanic

The Youngest Eagle Scout
My mother took this picture.

I can still remember the smell of my doll. My mother’s mother made it for me. Grandmma Fritz.
The mechanic!

My father, my older brother Hank, Donnie, and Paul, the mechanic! Paul – probably 2 years old.
Article in the paper.

You have to be 12 years old to be boy scout. 14 years old: Eagle Scout
Youngest Eagle Scout on the Gulf Ridge Council.
I had lifeguard training at the Aquatic Club, East side of the river, Lowry Park. There was a spring that they had walled off. It was a natural spring. It was 3 pools. Way before there was a zoo... It was a big picnic area. Tin can tourist camp. This is what they used to call.

Hank and I was boxing. I had 3 rounds and I was little. We put on huge boxing gloves and three rounds and we have 25 cents prize! My
brother was 5 rounds and he got 75 cents!

Boy Howdy! The tourist club sponsored it. It was fun!! After fighting, we jump in the spring – cold!! It was nice! That was fun, yeah!

I was lifeguard at the girls and boys camp. It was a sacrifice, but someone had to do it! I remember the girls camp better! George Beakley and Me had a cabin together at the girls scout camp. Boy Howdy! The sponsors
of the girls would coming on and
“Soup on”!! 2 weeks! Boy Howdy!
Good vacation, hard work! George got
into the submarine service and was
killed in the war.
The Navy

R.O.T.C.

The Square Knot Admiral

& Boot Camp

WWII

Brothers in Guam
1st lieutenant in R.O.T.C. Jefferson High School. I was in 11th grade. In 12th grade, I was captain of R.O.T.C.

1 start = 2nd lieutenant

2 starts = 1st lieutenant

3 starts = captain.
Boot camp:

Because of R.O.T.C. I was leader of my boot camp group. They called me The Square Knot Admiral.
Classmate of mine from high school! That was boot camp and he was stationed next to me in boot camp. His father was a minister and he became a
minister, too! On the 60th class reunion – I had an address, but I never got an answer from him. He may have deceased. But I tried. Look at his boots! Good for BOOTcamp! And no hair! He used to have wavy hair – all out!

My best friend Bunky was in the same group. I had to appoint him mail orderly! That way he did not have to stand watch.
This was the first trip I made in Honolulu.
This is invasion money used in the Philippine Islands. We have to save our cigarettes (we could buy as much with cigarettes as we could with money!) China, and Japan, boy, howdy!!
We could have only 2 packs of cigarettes. And 1 of them open! But we would put them in our socks, everywhere, to have more to bargain! I bought a kimono (beautiful!!) and silver chopsticks with cigarettes! They don’t eat with silver chopsticks, that was tourist... My bathroom, my Mamma... I brought her one... It was beautiful (one kimono) One for Mamma and one for Janete (my sister in law).
My brother, Japanese rifle & bayonet... and I don’t know what happened to that... I had this Bougainville Island (that’s where I got the rifle and bayonet). Japanese were POWs at the time and they had to get rid of their weapons. That’s how we got the rifle and bayonet. I don’t know how many Japanese (lots of them, though). The rifles, and the bayonet, and samurai swords... and all the
weapons, all that, put them in a pile. And that’s how we got them.

How did I bring it home? I had a seabag, I had my clothes and I stuffed my weapons in there. The battleships, 16 inch guns... and we were having to shoot and and the you could just feel it, when things would shoot (the noise, you could feel it in your body!) No wonder now I wear hearing aids!
McNeal was in the quartermasters with me. He is lying on the ready box (box of ammunition of the 20 mm guns!) He was the one who had liberty on the boat and he phoned my brother in Guam.
I was going to check on Don when I was on liberty, but McNeal helped me do it earlier. I knew my brother would be in Guam with the 34 Engineer Division.

Oh, boy howdy! This was our ship in Guam. My brother was in Guam and took the picture. My brother had 2
days, and I had duty on the ship. My brother took the water taxi and came onto my ship!

I had taken a bath, and my buddy said “You have to see the dog face on your ship! I think it is your brother!”
I had the towel on me, and I went up the quarter deck and gave him a hug!

The officer of the day said “What the hell are you doing in my ship?” But I didn’t care!! “He’s my brother!” I had to take him off to the chaplain, and my brother was on the ship all the night! We had liberty next day, so we went ashore! Landing Craft Vehicle and Personnel (LCVP) Put the
ramp!! My brother took the picture from the LCVP!

My brother took a picture of me holding a beer. You can see my ship in the back in Apra Harbor in Guam.
My boat division!

Ernie Pyle

Officer of the Division
We had 4 boat divisions.

We had 2 boats in the whole ship that kaput!

All the men in my crew survived!

• The crew of the boat (LVST):
  • Motor mach (working in the engines)
  • Bow Hook
  • Stern Hook
  • Coxswain – Myself and all the men with (Good men – Macho!)
This one Louis Wyss and me on the ship. He was shipmate and he was New York, but he was a motor mach
on the ship. He kept me from getting a tattoo! (I am ever so grateful to him, says Ms. Betty!) I was only 18, he was 21 or 22. He was already married. We have been friends for life. We still see him. He moved to Indian Rocks Beach and he had a motel.

***

Don and I had a boat, a sailboat. We built it. I was probably 15. It was on Lake Carroll.
At the time it was called horseshoe lake! Now it is Carrollwood. Before it was only woods, nothing but woods!
The war was ended, and I was quartermaster (Don took the picture).

I was the helmsman of the A-1 condition (when they were entering or leaving the port).

There were several other helmsman. In the ship I did not do it.
You could not tell on there, but in the picture it is turned off! I was just posing...

The compass was right in front of me (see arrow).

I was a good helmsman! I had lots of training!

We had to give way to the Japanese hospital ship, the war was over.
After the War

University of Florida

Fraternity Delta Chi

Falling in Love

Munchkins
1947, University of Florida.

Fraternity Delta Chi.

I had GI bill to go to college.

Forestry and Game Management.

I met Mrs. Johnson there...

This one (see arrow) was dating Betty. And I took her away!!
He was lackadaisical. My father-in-law called him “a hairpin.” Ms. Betty’s dad was afraid Betty would marry the hairpin instead of me. He liked me better! He was my friend!

We went to high school together and we went into the Navy. He went into the Navy 2 or 3 months after Bunky and I. He had some kind of spine inflammation and spent a long time in the hospital.
I think he never saw active service!
He had a medical discharge.

His name was Frank. He was undecided. We went fishing together and I was asking him what his intentions to Betty.

“What is your intention to Betty?”

“I don’t know”

“Boy Howdy, I was going to tell you, I was going to marry her!”
And so I did!! But 2 or 3 years later!! Anyhow, here are my 2 girls, my 2 daughters.

Linda and Debbie, 2 and 4 years old
Linda and Debbie all grown up!
And well educated!
My Mom said, he was good at fishing, but Betty was the best thing he ever caught.
My family in 1956. It was a family reunion.

- My mother and father
- My brothers Hank and Don and their wives
- My wife and I holding Debbie
• And all the little munchkins!

• Now the munchkins are:
  • Teacher
  • Physician’s assistant
  • Lakeland – air conditioning business
  • Cabinet shop
  • Surveyor - a lot of land + an island!
  • Eye doctor
  • Caterer
  • Policeman (Tampa)
The munchkins grew up and did well.

Don is my middle brother. He is sharp, he can make anything! He was an engineer in a telephone company. All of Don’s children can make anything!

Hank is my oldest brother. He has 5 B.S., 3 Masters. But he has no Ph.D. He was working for the government after the war.
He was paratrooper during WWII. He had 25 missions over Europe in a bomber.

He was in Luzan and I was in Manila. But I didn’t know he was there!

He was a teacher after the war. He studied all of his life. Agriculture, Agronomy, Economics, etc.

He and his wife have a big farm. G.I. bill, he had on the farm training, and he was the teacher!
He had the airplane and he had to fly to the farms because the farms were too far apart.

He had a heart attack in 1960 and he stopped flying. He started to teach and moved to St. Paul.
Archery & Championship

This Certifies

PAUL JOHNSON

by shooting the highest score of any archer
participating in the Championship Tournament held at
HOLLYWOOD
on FEBRUARY 11th & 15th.

has won the
National Field Archery Association's
recognition as Champion of
for the year 1959.

National Field Archery Association
From the archery club
1959 Championship in Florida.
The side of the cap – many medals.
I started in the Boy scout.
I taught archery to boy scouts, too.
I joined the Archery club in 1952.
President of Archery club 2 times.
I taught archery in the parks of Tampa 1 year.
Fraternity brother had the championship and I beat him! I got
the championship! That was good! He was in the tournament that I beat him! State champion tournament in Lakeland, Florida.

I had back surgery and I had to stop archery. I had to quit archery.

Good while it lasted!

And I got the championship!
Hunting Expeditions (Minnesota, 1992)
My brothers on a hunting trip. Don and Hank. Don did not care to hunt, so he took a camera. He was filming everything!

That was Minnesota, 2 ½ miles to Canada.

My brother Hank, he was after the war, after WWII, he had to go to North Dakota and Minnesota! He loves it! His wife is from North Dakota. She was the secretary of Senator Langer of North Dakota.
My brother and sister in law met in Washington, D.C. I think that was in the apartment house. The Florida house! That’s what it was called!

Mary, Hank’s wife, had a stroke too... 10 years ago. They were down here visiting in Florida at the beach, and she just collapsed! We took her to the hospital, and her whole right side was paralyzed, she could not walk, talk... she had aphasia too! They rushed her back to MN and put her in
intensive therapy. Today she is walking and talking just fine! You can only hear a little slurring when she is really tired. Other than that, she is fine!
Hank and Don holding an icicle in front of the cabin. Behind them: Olsen’s cabin.

The cabins had kerosene heaters and wooden stoves. It was good!

We had a refrigerator but the beer was on the outside – it was cold!!! BRRR!!!!

Brother Hank and hunting partner, Mike Ness’ father. He passed away 2 years ago. Good guy!
This was the back door of the main cabin. The name of the cabin was J.O.N.:

- Johnson
- Olson (also passed away)
- Ness (in the picture with orange coat)
The J.O.N. had a trailer.

There were 12 men in there! And only 1 bathroom, outside! In the bathroom we had a heater light, like a sun light (to keep us warm!)

That was the bag limit of the trip.

That was one year. One year have we had 12 deer! This year we had 10. It
was good! Everybody got a lot of deer. No one went home with empty hands! This was one of my 1st hunting trips!

Me, brother Hank, Hank’s grandson Mark, and two of Hank’s children, Tommy and Mike. This was from a different trip (not so much snow)
Chickadee was eating the leftover bacon grease!

Hank always left a slice of bread out for the birds!

One time I was holding my gun and "Oh!" There was a Chickadee standing right on top of it! It was not afraid!

The grouse was plentiful and the grandsons would shoot them and bring them home for supper! They were twice as big as the quail! They
were very good to eat! As good as quail or better!

They could walk on the snow with their feet. They were funny shaped!

They would walk on the snow without making a crack!
Adventures in Dog Sledding – Ely, Minnesota – February, 2002
This is me and my son in law, Ronnie (on the right). Ely, Minnesota.

Dog sledding. I think it was in February, 2002.

4 days of dog-sledding!
This is my guide and his favorite dog. Ronnie is the one in the middle, and Dan Brown is on the right. He is a friend of Ronnie’s. He is also a doctor.
This was the yurt. It is like a tent-house. That’s where we stayed. It was my home away from home!
This is inside the yurt. See the screen on the top? It was a drying rack! This is where we put our wet hats, shoes and coats, and they would dry and be out of the way. It could be folded and put away, when we were not using it. The heater was facing up, to help things dry.
This is the back part of the sled.

You put your feet on the sides and the brake is that black thing in the middle. You hold onto the handles (you can’t really see them in the picture). This pocket I had the treats for the dogs! I was treating the dogs for a good job!
This one (the black dog) lead dog, and this one (behind him) was named Birch. But I named him Lurch.
He would always try to go faster, and the lead dog would “All right, all right! Quit pushing! Look at me!” The lead dog trained the other dogs! He was wonderful! Smart dog!

This one... shows pretty woods.

Oh boy, howdy! It was good!

I think that is me and my dog. And see Lurch! Always pushing!!
31 inches of ice! How about that?

Deep this!
This is drilling a hole in the ice.

Anyhow... we had to get water for the dogs! And I wanted to ice-fish!

I did not catch anything... (What on earth would you use for bait?) The
guide had minnows... He had a bucket of water in the cooler, to keep it from freezing! Oh, gosh, maybe 2 dozen! My water was... All the guys had thermos, and... heating pads on the bottom! You had to do it! Or you could not drink it!
The swamp between two lakes. All the water is iced. The frozen swamp!
This is my lead dog, Hester (the black dog) & Thor. This is the trail head, where we started. This is when we were going back. This was the truck and trailer for carrying the dogs.
Ronnie and his team!
All the dogs tied and waiting for supper!

One day I was giving a treat to one dog. The other dog, saw it and bit me!
This guy, Danny, he was an attorney! He had training and decided to... doctor! After he was a lawyer!
My Stroke – November, 2004
My stroke, I don’t know how it happened. I am glad that Mamma was there. She stood by my side all the time. I was not working, I was retired. I was glad for that. I don’t know what I would have done if I needed to go to work.

Betty remembers: I had my stroke in the front yard. My shirt was soaking wet and I could not move anything.

When I first had the stroke – Not so much weakness, but I could not
feel anything... I could use my right hand, I could shave... Betty would bathe me and shave me when I was at UCH. I was at UCH for 4 days. We tried, through my PCP to get therapies. They sent us to two different places, it was a joke. And it was 30 dollars every time we went through the door! It was absurd! Our older daughter, Deb, figured out the VA. On Monday, the 29 of November,
I got admitted to the rehab unit in the VA.

Dr. Ochipa saw me at the rehab unit. She started with me the singing
therapy. My first few words were: no, yes, and damn it! That was about it! I could not say what I was thinking, and “damn it!!” I was frustrated I could not say! I was very emotional – when people came in to see me I would cry. The VA and Dr. Ochipa and Lini and the therapists, all helped me so much!
I worked with Steve Wilson (Rec Therapist) and Ryan (OT).
My PT was from New Hampshire and she went back to New Hampshire: Melanie Pamasco, that’s her name! Jim Switzer was her supervisor.

After I was discharged from the therapy I came in just for speech outpatient therapy.

Fine motor is still not quite right. But I write with my right hand, which helps me a lot (I use writing a lot for communication). But before I could
not even hold a pencil! I had no sensation

Oh, and my nurse, Mary Ann, she was so great! All the nurses were great!
One time, on the first or second week, at 4:00 am, they were like “you have to take your pills!” and I said “No!” It was the wrong pills, it was for another guy! Then she said “oh, thank you!!”

This is Susan Modi.
My daughter Deb knew Susan from Tampa General Hospital. When I was transferring to the VA, Susan was great help!

I could feed myself and I could take my own pills! I could do anything but talk!

I couldn’t talk! In two days, I couldn’t remember numbers! Still numbers are harder for me to say, but I can write them better than I can say them! Boy Howdy! We get stuck into
some funny number confusions sometimes!

    Betty says it’s almost like an accent! (it’s just so cute, she says!)

Golly!

    But we communicate, I pass my point across!