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CHAPTER 4

Narrative Processes

One basic premise of this text is that life is essentially storied. As one of today's leading theorists, Jerome Bruner (2002), suggests, "There's some kind of underlying thing that gives a kind of unity and sympathy and possibility for the human condition continuing" (p. 3). This quote is particularly intriguing because it is remarkably inarticulate, a surprising observation given the usual eloquence of Bruner's writings. What the inarticulateness suggests is that narrative is not a simple construct. In the previous chapter, we introduced the raw materials that are available for self construction—cultural, roles, interactional, and biographical. In this chapter, we discuss how an individual's life story weaves together these raw materials to create a coherent narrative. Our goal is to understand the impact of neurogenic communication disorders on narrative self.

Exploring Narrative

The term narrative can be understood at many levels and in multiple theoretical contexts. On one level, typically addressed in speech-language pathology, linguistics, and developmental psychology, the term narrative refers explicitly to storytelling. The ability to understand and reproduce the key

elements of what some call story grammar is a fundamental tool in formal education and informal learning about life. We study how children's narratives or stories develop, and we target narratives in speech-language treatment if children lag behind their peers in using the necessary narrative skills. We define those elements that must be present in a fully developed narrative structure, and we devise strategies to help children acquire and use those elements. The key elements of stories include setting, characters, initiating event, attempt to resolve, consequence, and reaction. Thus, narrative involves placing a series of events in some sort of order that implies chronological sequence and postulates causality. What is critical in this understanding of narrative is the fact that stories are creations, and the teller of stories can alter story elements to change the underlying coherence of the narrative. As Chambers and Montgomery (2002, p. 78) indicate, "... there are no unplotted stories."

Narrative can also be understood from a broader perspective of entertainment and socialization. As we mature, we begin to tell narratives to entertain and amuse others. On the surface, these stories may not seem to carry much weight in terms of sharing information about ourselves, but the choice of stories to tell often informs the listener about who and what we are and what we

value. It has been suggested that much of our everyday conversation consists of some kind of storytelling. Some of these everyday stories are also told to communicate a message, based on sharing of a particular life experience.

Beyond this level of storytelling, we reach a more powerful understanding of narratives as life stories. McAdams and colleagues (McAdams, Josselson, & Lieblich, 2005, 2006a, b) point to the fact that humans are fundamentally storytellers, and Bruner (2004) notes that: "We seem to have no other way of describing 'lived time' save in the form of a narrative" (p. 692). At this level, narrative is viewed as an enculturated meaning-making process (Sarbin, 1986a, b). In other words, life is narrative and life stories are ongoing (Bruner, 2004). Common terms to describe this process include biographical work, framing of biographical particulars, meaning-making, and sense-making. As part of the meaning-making process, narrative can be viewed as a tool for expressing wants, needs, perspectives, and priorities.

McAdams (1988, 1993) suggests there are two primary drives underlying our life stories: communion (relationships, intimacy), and agency (issues of power, mastery, and achievement). There is a dynamic tension between these two drives. People whose life stories are built around agency are those whose life activities are oriented toward the acquisition or display of power, autonomy, mastery, and achievement. They need to be strong, to have an impact on the world, to achieve success. In contrast, those whose life stories are framed around a desire for communion present life stories in which relationships with others play an important role. Such individuals are valued for their friendship and support. They belong to multiple social communities and act on communally held beliefs. Balance between the two drives is optimal.

When communication disorders disrupt the ongoing storying of self, it is important to understand the degree to which communion and agency figure in an individual's narrative self and the extent to which these processes are affected by impaired communication. Often, the stories that people attempt to share are designed to underscore the agentic or communal aspects of self that have been threatened by the illness. Those with a dominant drive to express and live agency will attempt to tell stories that support their view of narrative self as strong, independent, and accomplished (or express the loss of those elements). Those whose life stories are framed around strong needs for relationship and communion will try to share stories about people and relationships and caring (or about perceived losses of intimacy).

Bruner (1999) suggests that characterization of self or selfhood "rests upon a good story, a plot with Self as the agent that heads somewhere and gives continuity . . . we manage a certain autonomy while at the same time adhering to cultural forms" (p. 7). In this text, what is particularly important about this broader view of narrative is that it is inextricably linked with the process of development of self and identity. Damasio (1999) suggests that "consciousness begins when the brain acquires the power of telling a story" (p. 30). McAdams (1993) provides detailed accounts of how our personal self or myth evolves through stages from premythic (childhood) through mythic (the realized and evolving self) and ultimately to postmythic (looking back from the perspective of advanced age).

The idea of a personal myth may be crucial in understanding the experiences of persons with communication disorders. One's personal myth is a self-created history of self, one that explains how and why events occurred and what they mean. The

personal myth must be modifiable, because as our lives move on, different interpretations of life events must be constructed to be consistent with an evolving sense of self. Development of life stories and self results in greater focus on “I”—the self as storyteller, as contrasted with “me”—the self as the tale told (James, 1963). It is possible that one of the most destructive outcomes of an adult onset neurogenic communication disorder is people’s inability to frame the “I,” which leads to their dependence upon others and the environmental context for a definition of “me.”

There is no question about the statement, “Stories matter” (Charon & Montello, 2002). The meanings we derive from our shared life stories become pivotal in informing the next stages of our lives (Singer, 2004). In discussing humans as meaning makers, Kitwood (1997) highlights that our social lives can be viewed as a series of narrative episodes, and the actions we take in new episodes are informed by the schema understood and the meanings assigned in previous life episodes. In one sense, our life stories are autobiographical, but autobiography is much more than the factual recounting of life events. More broadly, as Bruner (2004) suggests, the telling of a story is a truly challenging cognitive achievement. We must structure our experiences, organize relevant memories, segment and scaffold events. In doing so, we strive to empower ourselves in the present and in projected future circumstances.

Clearly, narrative, the telling of life stories, is a fundamentally social process. We create stories to meet the needs of our varied social roles (Singer, 2004), and we seek recognition and validation of our stories by those social others with whom we interact. Our stories are constantly being shaped and reshaped to meet the challenges of different listeners and different contexts as well

as alterations in the biographical particulars of our lives. In effect, as Beck (2005) suggests, “all narratives contain the voices of others, and require recognition of the identities of others” (p. 61). Not only do we require the recognition and validation of others, but they are also actively involved in the construction and reconstruction of our sense of self. In the context of illness, and even more specifically disease processes that affect our ability to communicate and render us metaphorically voiceless, it may be literally impossible to reconstruct a continuing life story and narrative self without the participation of others in this process.

Implicit in the preceding statement is the concept that social narrative requires the use of communication as the primary tool for conveying and modifying life stories. Narrative is a form of discourse, and narrative discourse typically occurs during the normal give and take of conversational interactions. These interactions can be viewed as negotiations. Each participant takes stock of what is known or presumed about the conversational partner, as well as the context for the conversation and the underlying purpose or need being met through the interaction. With familiar partners, little work is needed to make the necessary decisions about how the story is framed. With less familiar partners or in new environmental contexts, greater flexibility may be required, along with some trial-and-error negotiation of acceptable symbol sets and probes of shared experience.

The use of the term story should not be interpreted too narrowly. Story or narrative refers to any shared communication that provides the listener with a better understanding of the person who is communicating. Similarly, the concept of life story must be interpreted broadly. Although there are a number of approaches designed to elicit a life story or life history (cf.,

McAdams, 1988, 1993), it is not necessary to formally request the telling of the “chapters” of one’s life to date. Bits and pieces of informal narrative can be interpreted in the context of life story and used to understand the self that is being presented in the interaction.

In fact, these bits and pieces, often called episodes (McAdams, 1993), are the primary elements that are shared in a natural communication interaction. Gubrium (2003) has attempted to define what constitutes a “good story” in the context of support groups for caregivers for persons with dementia. On the basis of his work with such groups, he concludes that the good story (a) rings true, (b) is engrossing, and (c) provides adequate but not excessive detail. By “good,” he means successful in sharing of narrative self.

Our sense of self is being recreated and reordered constantly against the backdrop of daily experiences. At everyday crossroads in life, we create appropriate versions of self to maximize our success in interaction and managing small challenges. We do so through the narratives which are conveyed in conversation. Thus, communication in everyday conversations is a forum for self-narration. The success of these interactions depends on a number of factors, including the conversational partners’ perception of the storyteller’s competence and power and communication skills of the narrator.

In Chapter 1, it was suggested that presentation of self through narrative is only effective if the identities we project fall within some societal understanding of normal or acceptable. In part, the parameters that define normalcy or acceptability are being constantly negotiated. As Gubrium and Holstein (2001) state: “Broadly speaking, the self emanates from the interplay between circumstantial demands, restraints, and re-

sources, on one hand, and self-constituting social actions on the other” (p. 9). Being different, however, does not totally disenfranchise the individual from participation within society. Being different may simply mean that one shares certain attributes or interests with others who form part of a larger community with which we affiliate. To understand this statement, it is necessary to understand the concept of community narrative.

Part of the cognitive challenge of narrative is creating and sharing life stories that mesh with the broader community (Rapaport, 1993). Thus the cognitive and linguistic processes that guide our narratives are shaped culturally. Community may be as narrowly defined as the group of colleagues with whom one eats lunch once a week or as broadly structured as the context of the community within which we live, the community with which one affiliates through religious preference, or the political party that defines one’s beliefs. We can only participate effectively in these many communities if we understand the motives and characteristics of other community members, the reason the community exists, and the norms and practices for communicating what Holstein and Gubrium (2000, p. 12) refer to as discursive environments. However, our community affiliations influence our personal narratives.

If we reflect on people’s responses to any disruption to their life story, to their expected life course, it is common to find statements like, “My friends have been there for me,” or “The people I work with really stepped up to the plate,” or “The church women’s group reached out to me.” All of these clusters of persons represent groups, or communities with which one is affiliated. Paul Rusesabagina (2006) movingly describes the power of groups in talking about his

experiences living through Rwanda's darkest moments, stating:

We embrace the feeling of being dissolved into something bigger because at our cores we are lonely . . . we thirst for that unity, that lost wholeness. . . . That feeling of warm acceptance we get inside a group . . . is one of the most powerful human urges. (p. 73)

This concept of cultural group membership in one or more discursive environments is particularly important when the life story is disrupted by the diagnosis of a significant medical problem, such as those associated with the neurogenic disorders we discuss in this text. At these times, we are perhaps most needy of the understanding and validation of the larger social communities with which we affiliate—however we define those communities in connection with our unique narrative self. It is difficult to put into words exactly what it is we require from our narrative communities, because issues of self construction and the recognition of others are difficult to articulate. But the need exists and changes in community membership have a powerful impact on our sense of identity and self.

Ironically, as we experience the life changes that accompany a significant health crisis, when the comfort and familiarity of old ways of presenting narrative self are most needed, the communities that formerly recognized and supported a person's sense of self may become less accessible. These changes in social validation stem to a considerable degree from a breakdown in ability to communicate effectively who and what we are in the context of an unexpected shift in our life stories. Since communication remains a primary meaning-making tool, its impairment can be very

isolating. Thus coping with a neurogenic communication disorder may require definitions of the communities with which we choose to affiliate, as discussed later in this chapter.

Narrative and the Self

It should be obvious by now that it is almost impossible to discuss narrative and life story without considering the role of narrative in our creation and maintenance of self. Narrative clearly brings together the raw materials of self construction and weaves a whole story, one that will undoubtedly change as one moves through life or even from situation to situation. Since our focus in this book is on narrative self rather than either separately, it is important to combine these two concepts. Fundamentally, the cultural, role, interactional, and biographical elements of the self inform the plot one creates.

We exist within societies, within cultures that define appropriate and acceptable ways of functioning. Thus the term *cultural self* captures the many schema that govern how we are supposed to live together. While cultural symbols and knowledge are acquired gradually over time, they define expectations that govern one's understanding of one's self within the society. Culture also influences the expectations of others. Thus, we cannot really create a comprehensible narrative unless we start with the norms, values, beliefs, and ideologies of our culture. There are many cultural narrative processes that shape the cultural self. Examples may include laws and policies that govern behavior, cultural models conveyed through media and the Internet, and organizational procedures.

CHAPTER 6

Life Stories in ALS

In exploring the life stories of those with amyotrophic lateral sclerosis (ALS), we may need to begin with the end—with the reality that ALS is the ultimate disruptor of life. The experience is one of clear, gradual motor decline, loss of speech, and death—often at an age when life should seem fullest and narrative self is evolving in all its complexity. So, how does one construct a new narrative—and negotiate a new self—when one is facing the end of one's life?

While many people living with ALS (PALS) undoubtedly experience a drive to find purpose and meaning in the present or past, there does not seem to be a consistent perception of narrative wreckage, in Frank's (1995) terms, despite the biographic disruption caused by the disorder. Certainly, the knowledge of imminent death flies in the face of most people's expectations, but it also seems that clear knowledge of the end allows some to focus more clearly on the present or to make choices to develop priorities for living. One factor that makes this possible is the relative preservation of mental capacities in ALS, including language and self-reflection. Even when speech intelligibility deteriorates, written language remains an option in some cases. In fact, for PALS whose speech is affected early on (bulbar onset), some limb motor skills for

writing or for computer-activated communication are available for a considerable time period.

Relatively spared mental abilities are also critical for the significant others who share the burden of ALS. There is something fundamentally secure about knowing that one's loved one can communicate if needed, even if the communication process is awkward and time-consuming. Unlike family members of persons with severe aphasia, who often have literally no sense of what their loved one is attempting to communicate, the families and friends of PALS learn that they can work together to understand communicative content and intent. The potential for coconstruction of the remaining life story empowers all those who are involved.

The existing literature on impact of ALS focuses primarily on quality of life (QOL) for the PALS and their friends and family members (Bremer, Simone, Walsh, Simmons, & Felgoise, 2004; Chia et al., 2004; Goldstein, Atkins, & Leigh, 2002; Jenkinson, Fitzpatrick, Brennan, & Swash, 1999; Mockford, Jenkinson, & Fitzpatrick, 2006; Nygren & Askmark, 2006; Smith, Crossley, Greenberg, Wilder, & Carroll, 2000, among others). Most of these studies use questionnaires to probe facets of quality of life.

We approach the task of understanding life with ALS somewhat differently. In this chapter, we explore the way persons with ALS pull from different dimensions of self—culture, roles, interactions, and biography—to rewrite their narratives or life stories, when ALS has fundamentally disrupted the previous story. The words of persons with ALS and their significant others have been gleaned from multiple sources, including written or spoken comments elicited in response to broad probes of the experience of living with ALS (with focus on communication), interviews with two spouses of PALS, the written “diaries” of one PALS who journaled his experience from diagnosis until shortly before his death and of another who began an autobiographical document shortly after diagnosis, and finally observations from interactions with PALS and their family members in the course of ALS support group meetings and delivery of clinical services. On-line support forums also yielded useful material. The existing literature on life impact of ALS is limited. Thus the reflections of those living with ALS become our most important vehicle for understanding these lives and how health care professionals can reach out and support the maintenance of narrative self.

Before going further, it is important to introduce those persons who have graciously shared their life stories in this chapter. The person whose legacy was a primary stimulus for the writing of this text is Steve Kressen, a man who held a high level administrative position in a large international retail company, and whose wife Sylvia and children from both first and second marriages brought real joy into his life. Steve’s journals and e-mails inform much of this chapter. In the following brief quotes, it is easy to see why Steve’s story is so inspira-

tional. His words demonstrate the way in which the experience of loss of communication shifts over time with the physical changes associated with the disease and with the evolving understanding of the imminence of death. In the first quote, he is sharing his joy in finding a free shareware program called Click’it that would allow him to continue his work and his personal communications with friends and loved ones. In the second quote, Steve captures the heart of this exploration of communication and narrative self.

With my speech already a major source of frustration for both me and the listener, I had become increasingly reliant upon the written word. But as my arms and then my hands and in more recent weeks my fingers have weakened essentially to the point of paralysis, I had become more and more isolated, depressed, and not a whole lot of fun to be around. Vicious circle. Now I feel a sense of liberation, renewed energy and productivity, and general well-being. So get ready; I’m back. So little time, so much to say!

Barbara Taylor and Jim Jackson, married members of the University of Arkansas community, agreed to share their thoughts and feelings about the experience of living with ALS some months after Jim’s diagnosis and perhaps 2 years after first symptoms. As caregiver, Barbara’s explanation of the way Jim interacted prior to the disease onset is reflected in his current communication behavior. In turn, Jim describes the deterioration in his communication and intelligibility in rational, somewhat distanced terms in a manner consistent with Barbara’s comments about his pre-ALS communication, highlighting the highly individualized experience of communication loss in ALS.

Barbara: Jim was never a talker, he's not one of those people who needs to have his mouth open to prove he's alive. I know there are some people who talk incessantly and who talk to remind themselves that they exist and he's never . . . he's always been fairly quiet, speaking when there is something to say and I don't expect chatter. I don't expect a kind of narrative going-on about how the day has been, so it may have not be as major a transition for us because of that . . . One of the things that I've always treasured about him is his ability to be silent and our ability to be together and not have to talk so that is the kind of broad context.

Jim: I had slurred speech for a long time before I had the ALS diagnosis; at least a year. Although it grew gradually worse, people still seemed to understand me. I just sounded hoarse, and many commented that my allergies must be acting up. As my speech continued to deteriorate, a few people began to have trouble understanding me, but most could. Over time that has changed and few can understand me now. What has surprised me most is how many could understand me for so long. Listening to myself, I thought the listener wouldn't understand but they did. That is my overall impression. As to how willing people have been to keep working to understand me, that has varied as one would expect from not very much to quite a bit. I can still write or type, although slowly, so I substitute that for the spoken word when needed.

The other couple who shared their experience of living with ALS is Wade and Sarah Burnside. Wade is a retired physician

who is much loved and respected in the community. His wife Sarah was also extremely active in the community, particularly in her church. Sarah's life and values had been deeply influenced by her earlier years living with missionary parents in Africa. In her adult years, in addition to raising three children, she gave to many—always quietly and behind the scenes—and also managed to pursue her passion for theater through acting, directing, obtaining a graduate degree, and supporting theater in the community. In the following quotes, we get a glimpse of what living with ALS means to them, particularly to their life stories.

Sarah (when asked about her priorities at the time of our meeting): I wrote a book about growing up in Africa—I'm doing the editorial notes now.

(When further probed about how she felt her identity had been affected by the diagnosis of ALS and her deteriorating physical condition, her written response was simple and to the point): There's a lot of me in the book.

Wade (When asked to reflect on the life changes he and Sarah were experiencing, he offered the following.): One other thought I have had in the past is . . . one of the things that happen in a situation like this is your priorities change. Like it used to be a priority to bake bread once a week or something. It's a priority to keep the flower beds weeded, keep the weeds out of the flowers. Things like that you just let it go.

Penny and A.J. struggled with coping with Penny's mother's ALS. This couple sought help early on in meeting the mother's changing needs. They did not live near her, and felt the helplessness that

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comes from an inability to see and assist in managing changes occurring on a daily basis. As Penny wrote:

One thing that I feel is so lacking in the fight for ALS is any psychological help for both the patient/victim, and the caregivers/families/victims. There is no motivation, support, encouragement, or psych help at all. Everyone just fumbles around, trying to help, and getting very depressed.

Others in the ALS Support Group include Linda and David B. Linda's ALS has been slow moving, so she and David have had extended opportunities to reflect on their lives and their relationship and who share what they have gained from these reflections. Finally, Chris is a caring, affirming 71-year-old who has had many different jobs in his life, most recently owning a candle store in a nearby tourist town. His family is tight-knit; their love and mutual support are clear as he and his wife (Billie) and daughters join him at support group meetings. They often draw on their experiences with their hearing impaired child when dealing with the challenges of ALS. When Chris was asked to reflect on some questions about living with ALS, he volunteered the following in writing, showing his sensitivity to the plight of loved ones in addition to his own personal concerns.

What is surprising to me is I have seen several cases where the ALS person is mad or griping or fussing at their caregiver for not understanding them. They are not thinking of the predicament their spouse is in. I know in certain cases it takes time to learn what their caregiver is going through. The ALS person did not bring this disease on themselves but I think they also must know

that their spouse did not bring the frustration on themselves either. So I think it is important for those with any problems that require the spouse's help to be thankful for what they have.

More than anything, these articulate quotes underscore the fundamental mental integrity of these individuals, along with their preserved capacity to reflect on life changes and give expression to the experience, sometimes with great eloquence. While recent research suggests that some PALS experience cognitive declines similar to frontotemporal dementia as the disease progresses, the majority remain cognitively intact. For the most part, those who contributed to this chapter are among the cognitively spared.

A central premise of this book is that impairment of communication potentially disrupts the process of storying of self that is necessary if one is to maintain some continuity in the life story. This discussion may be particularly important in dealing with ALS, given the fact that the rapidly changing physical/medical status of the patient tends to focus interventions on immediate physical challenges, with limited attention to the broader impact of the disease. It is appropriate to begin with communication, since speech intelligibility will always be impaired and our interests lie with the impact of that impairment.

Communication in ALS

The nature of the medical condition amyotrophic lateral sclerosis (ALS) was described in Chapter 2, along with a brief description of the dysarthria that is the primary speech consequence of this motor disorder. Communication impairment is a common theme

in the narratives of persons with ALS. In a random selection of 20 entries on the Patients Like Me on-line forum, all 20 commented about communication loss, and 17 of the 20 discussed the powerful negative impact of this loss. It is not surprising that individuals who choose to participate in on-line ALS communities are those who value communication. However, in reviewing interview transcripts and clinical notes of interactions with PALS, it is apparent that the impact of loss of intelligibility is highly personalized, primarily due to premorbid communication styles, the role of communication in previous and current life activities, the responses of significant others, and the person's chosen ways of coping with the motor degeneration found in ALS.

One challenge in understanding the communication needs and experiences of persons with ALS is determining what people want to communicate about, and how they prefer to exchange this communication. Those whose stories lie at the heart of this chapter provide examples of how diverse and unique these needs and communication channels really are. For example, Chris began to write his autobiography shortly after being diagnosed with ALS. Sarah escalated her efforts to complete writing her early childhood autobiography, and Steve's priorities centered on continued work productivity, personal reflection, and connecting with important people in his life, primarily through writing. Jim continues to invest his energies in e-mail communications with a broad community of friends and acquaintances, and another support group member Dave devotes his time and communication effort to everyday interpersonal exchanges and activities such as playing card games and golfing.

As ALS progresses and communication becomes more difficult, both physically taxing and emotionally frustrating, people do

begin to make unconscious or conscious choices concerning what to communicate about. These choices are highly variable but are always consistent with life priorities, and these priorities may not always be the same as those of caregivers. Communication impact is also very situation specific (Ball, Beukelman, & Pattee, 2004). Increasing communicative effort (whether verbal or using a communication device) along with varying degrees of adversity across social situations influence with whom PALS work to communicate and when or where.

All of the individuals described here have chosen to communicate in relatively complete and sometimes complex utterances, even as the physical challenges of communication escalate. For a long time, Jim persisted in spelling out complete words on his alphabet board even when the visitor had identified the target word. As it became increasingly difficult for him to use this alphabet board, his wife shared some reflections on Jim's desire to finish his message. One insight she offered seems particularly astute in the context of this chapter. She raised the question of whether the act of completing words might reflect a corresponding mental act of finishing a thought. If this is true for some, it might explain a variety of behaviors. While Jim needed to communicate about basic needs (suction, pain medication, etc.), it was also important to him to share the nuances of communication. Several months before his death, he could only communicate by responding nonverbally when others pointed to letters on an alphabet board. Remarkably, with his daughter's help, he wrote several beautiful poems during that time.

In addition, choice of words is particularly important to some. Just a week before his death, Steve was visiting with two speech-language pathologists (SLPs) in his home. At this time, he could only use one

foot to activate a switch that operated his AAC device. Despite the effort required to communicate using scanning (moving systematically through letters and words and phrases to reach the desired target), he persisted in using complex sentences with elaborate vocabulary. When one of the SLPs figured out his intended message before the sentence was complete, Steve also persisted in spelling out the rest of the communication. The clinicians and Steve's wife joked with him about his love of words, and then one of the clinicians asked why he didn't take shortcuts such as just typing key words. Steve's response was, "That's not me." For Steve, his communication style was part of the self he presented to the world, and the decision to talk like he did pre-ALS was an affirmation of self.

Self and Life Stories

ALS is HOW I am, it will not rob me of WHO I am. (on-line discussion posting)

I have fought the good fight against the inevitable demise of the illness. I have prolonged my decline, I have maintained my dignity, I have continued to maintain an outward face. Now it is time to no longer do the things that promote my survival; rather it is time to do the things that will support my legacy. (Steve)

In these words, two persons with ALS characterize issues of selfhood and life story. Both quotes make clear that these individuals are determined to ensure that, regardless of the physical consequences of the disease, they retain the ability to create a self. In the second quote, Steve also presents a mini-life story, complete with elements of an illness narrative. This chapter section explores fur-

ther issues of self as intertwined with life narrative. The couples described here are engaged in construction of new narrative selves even as ALS takes its toll. Since the life stories carry the story of self, no attempt will be made to separate self and narrative.

Self and Culture

Some of the stories presented by PALS address the concept of stigma. Certainly, in Western societies, illness and disability are frequently stigmatized. Sabat (2001) speaks of the concept of excessive disability, noting that there is some point beyond which society's acceptance of disability does not extend. Perceived stigma limits our ability to use our cultural tools to construct a narrative self, and ALS typically exceeds the thresholds for normalcy and disability.

What, then, is the societal or cultural perception of ALS? For the most part, ALS is little understood, and the average person recognizes only the label *Lou Gehrig's Disease*. The behaviors that are visible are those related to physical decline, although loss of speech intelligibility may be perceived as an indicator of mental dysfunction and reduced cognitive competence. Sean Redmond (2003) uses the word *cripple* to attack the stigma associated with disability in general and ALS specifically:

I am one among some 30,000 patients of different ages, sizes and temperament who are under care for a disease, which has no known cause, treatment or cure. We're practically crippled. I say practically crippled because I've learned that being crippled doesn't necessarily mean we're emotional or mental cripples.

We live in a society where youth, appearance, and physical prowess are among

in the following section. After that, we will discuss how the four dimensions of self are challenged by aphasia, and how these in turn alter one's life story and influence the framing of one's illness narrative.

Aphasia and Life Impact

The first thing I remember was that it was the darkest black blindness very like a cave and then there was at some point a beam of light blue, yellow, and red I think, maybe green, like a shaft of light. And I think it's important for people to understand that there's no . . . it's simply a numb sense of observing without any feelings one way or another . . . it's like a camera . . . so for a long time, there's no sense of "oh my god I've had a stroke" or "I'm going to die." You don't think about those, and then I remember that in the darkness what looked like the top of telephone poles and I remember thinking that I could step a few feet from one of those to the other but again there was no sense of fear of falling, just observing. Then I began to realize that I was in a hospital but I really didn't know why I was there.

Welcome to Harry's world almost 11 years ago—October 12, 1997. As he begins his stroke narrative, it is clear this is a man of words, and images, and stories. He worked for many years as a case manager for the chronically mentally ill, serving as a passionate advocate, an instructor in dealing with life's daily challenges, and guide to taking control of one's life despite mental illness. We will rely heavily on the experiences of Harry and others as we explore the redefinition of narrative self post-apha-

sia. However, it is important first to establish some understanding of how the communication deficit in aphasia feels.

Language Loss

"I think it . . . but . . . but . . . where are . . . things . . . words . . ." (Ramon)

"Everyone needs to slow down . . . they hurt poor brain" (Jason)

"Reading was my . . . joy . . . now . . . work . . . too much work . . ." (Brenda)

These are familiar refrains from our clients with aphasia, capturing the essential nature of aphasic impairment. Understanding the language impairment and charting the recovery of language functions, however, reveals only the tip of the iceberg in terms of the monumental impact of stroke and communication loss on the lives of our clients and their families. As Wulf (1986, p. 14) states, ". . . such recovery is on the surface. Deep down is quite another story. True, it may be possible to write, to read, and to speak, though perhaps none of these abilities warrants close inspection. But internally?" Perhaps the iceberg is revealed better by the following quotes:

I don't . . . I not . . . I can't—all no, not—what is it I can? (Diane)

Everything has been taken away from me. (Dennis)

For some individuals, the aphasia is so profoundly impairing, the experience may be characterized as "living in a silent world" (Ritchie, n.d.). Ritchie has written at length on this experience for herself and her husband with aphasia, describing it as being

“like a bomb falls on all your hopes and plans for the future and you are reduced by Aphasia from a person who could talk to a person who just ‘talks in their minds’ but nobody can hear them” (Ritchie, n.d.). She acknowledges the intense anger and frustration experienced by all who are living with aphasia, along with a perceived loss of competence.

Many persons with aphasia share this sense of frustration with the fundamental gaps between their thoughts and their words. Harry refers to this as “finding ways around the stumps with communication.” Some individuals want to share the way the breakdown in communication makes them feel. Others simply disengage for a while. Harry says,

Okay, I could hear when I spoke that I couldn't say the words the way I wanted to say them, and that was very confusing. I didn't know what aphasia was at that point. And in trying to speak it was very frustrating and confusing so I didn't feel the need of wanting to talk very much. I wasn't aware of that at the time. I just I didn't talk very much.

And Wayne notes, in the support group:

I just go . . . smile . . . it's too much . . . I go away.

Another example of the impact of loss of communication is provided by Raskin's (1992) description of his reflections on the early days of dealing with aphasia:

My most valuable tool, I thought, was making sense of the turmoil. I was wrong. My most valuable tool is words, the words I can now use only with difficulty. My voice is debilitated—mute.

He goes on to describe what his aphasia felt like initially:

My understanding of simple conversation also seemed to be returning. I began to produce what I thought were words, but the puzzled look on the faces of my audience showed me that my long-awaited words were nothing more than gibberish. Then, little by little, people began reacting to my vocalizations. Imagine my relief at again being able to express my basic needs with a single word like “eat,” “drink” or “toilet.” Each utterance involved deep concentration and struggle to produce a somewhat intelligible word. Each “new” word was received with elation by my family and friends, motivating me to go on. A baby must be excited like that when he utters his first “mama” and “dada.”

For persons with aphasia, communication can be challenging and exhausting. One risk in focusing interventions too closely on specific language deficits is the degree of effort that becomes associated with using language to communicate. If this effort cannot be sustained outside of the therapy room, communication may become associated with issues of personal success or failure, and these perceptions may actually begin to interfere with communicative success. Thus it is not surprising to find that the idea of comfort in communication appears in many contexts. For example, in describing his participation in an Aphasia-Talks project (Levin et al., 2007), Len states, “I was very comfortable—a safety zone. I knew that [other participants] couldn't find the words either. . . . They aren't going to judge me.” And at the 2006 National Aphasia Association's Speaking Out! Conference, Tucker (2006) described the Adler

Aphasia Center as “a place where people can comfortably communicate. . . . And what we’ve found is when people are comfortable, they’re willing to try to communicate. And the more that they try to communicate the better they feel. The better they feel, the more they try.”

Communication also allows us to navigate the complex challenges of life’s social actions and interactions, because it is fluid and capable of subtle nuances. Thus one major loss associated with aphasia, even in its mildest form, is a loss of resilience and flexibility, of resourcefulness and creativity, in using communication tools (Holland, 2007; Walsh, 2007). Pasupathi (2006) discusses the way in which communication affirms the texture of our lives in the small, daily exchanges, what he calls the *everyday self*. He highlights the fact that much of our communication occurs over breakfast, between loads of laundry, while reading the newspaper. These moments of small talk or chit-chat may not be major meaning-making exchanges, but they are the *communicative backdrop* for living out our lives, and thus our life stories. The simple act of sharing a conversational moment may be as important as a fully formed illness narrative in storying of the post-stroke self. Such moments are those in which people seek collaborative opportunities for recognition and validation. Certainly, they depend on the ability to effectively use one’s cultural tool kit. At the level of chit-chat, changes in timing, in flexibility of message formulation, of responses to cues signal that something is “off” about the person’s presentation of self. Even the best language therapies are challenged in addressing this loss of subtle facility in everyday conversation.

There is another communication level that is more difficult to describe. Liechty (2006) writes that, despite his recovery:

I yearn for the possibility of in-depth discussions with fellow professionals. . . . I would like to pursue a relationship with a woman, but it is hard to find things in common or build relationships when there are such great communication barriers. This applies to all of my relationships, not just with women. Although my family has been supportive, I find I need more than my brother, sister and mother can provide (p. 33).

What has been lost is the ability to function optimally in certain roles (whether professional or relational). It is certainly difficult to address this sense of void in the core of who we are and how we use language to frame those moments in which we share our multiple selves and receive validation. What is also challenging for persons with aphasia to communicate is a sense of what is important, what is valued, and why. Armstrong (2005) suggests that an inability to use language effectively for these functions may actually impair the ability or desire to engage in and contribute to previous social networks and current social activities (both personal and societal) and may also lead to the sense that the person with aphasia has little of value to contribute.

In recognition of perceived limitations, some persons with aphasia feel a sense of responsibility and failure when the language system breaks down, making communication with others difficult. Others attribute greater responsibility and burden to conversational partners and express frustration if the partner does not adjust communication appropriately. Harry speaks at length about the way others fail to accommodate his communication difficulties, attempting to provide guidance for those communicating with someone who has aphasia.

Simple things like talking too fast, not giving me time to process an idea and not making sure that their speed of speech is going faster. And that's a common problem with everybody, friends or therapists, of being unprofessional in not wait . . . pacing their speech to the speech that I need . . . it took me forever to find ways to tell people that I couldn't understand what they were saying and many times since my ability to speak and use affect of speech got in the way and people became angry or turned off by my interactions to them because I came across as angry and demanding. And I began to know that I was being demanding and inappropriate but I didn't know what to do about it. . . . I think I'm at the point now where I instead of saying "I had a stroke and you need to talk slower" to telling what I need in terms of volume. That's always a big issue. Even the doctors and therapists tend to get very loud when they're talking to me to the point that it's painful for my brain to have that much volume to . . . and it has to do directly with how many words a minute I can process. And the resistance that people have in meeting their needs as opposed to this person's stroke functioning. And I become very very aware of how selfish other people are in interrupting and disregarding the thought that I'm trying to make and their need to say what they want to say. [People] will assume that I'm trying to say a the rest of a sentence or a paragraph or a thought and the therapist interrupting to say they understand when they don't understand what I'm thinking . . . it throws my thoughts off like a railroad train switching tracks. So they don't seem to understand how hard it is for my attention to be distracted

with sounds any distraction. Someone else joining a conversation just throws me so far off track that I can't understand what the person just said because I can't process it because of the interruption and I can't understand the subject of that other person's thought.

For Harry, struggling with life with aphasia is in part the chronicle of the success or failure of his interactions with others. Early on, he was concerned about a perceived absence of friends and family, indicating: "I was confused as to why all of these many friends that I had were not calling or coming over." He immediately had prioritized the importance of relationships with others in the difficult task of reframing self interactionally.

Some stories of communicative "recovery" are tributes to the remarkable commitment of life partners, the determination to preserve and advance the viable self of the person with aphasia. In fact, some couples learn to share the communicative responsibility so seamlessly, others often forget the extent of the aphasic impairment. However, the negative impact of aphasia is also felt to a great extent in the interactional domain. As Harry indicates, "When I'm alone, I don't have aphasia." He goes on to say:

But I spend more and more time alone because when I'm at home I don't feel like I've had a stroke. I think I can hear and function much better than I really can.

Just as some couples with aphasia are success stories, others seem to be unable to get past the aphasic deficit. Some become entrenched in the communication patterns established during the early weeks post-stroke, as will be illustrated by the story of Phil and Nancy later in this chapter.

In order to understand the impact of aphasia on the narrative self for those with aphasia, we must have an understanding of how this condition affects quality of life. Quality of life and related constructs are discussed briefly in the following section.

Quality of Life

Fundamentally, all strokes are life-changing, creating seen and unseen changes in many forms, including the emotional consequences of depression, frustration, and others. The life consequences of aphasia have been described in many texts and journal articles, as well as on the Internet (information and organizational Web sites, support groups, or patient forums). These studies will not be reviewed here. A greater understanding of the impact of illness in general has helped expand perspectives on the life consequences of stroke and aphasia specifically.

“Quality of life” is a highly individualized construct (LaPointe, 1999; Sarno, 1997), dependent upon cultural and social definitions and factors, as well as the person’s mode of self-discovery and philosophy about life. Harry indicates:

I spent a lot of time wanting to die, because the quality of life went from very very good to zip. And I even strategized in a rehab hospital how does one go about killing oneself. I think about life and what’s important about that, and whether I would ever want to survive a stroke.

Quality of life and well-being are also linked to concepts such as a sense of self-worth or self-esteem. It is clear that interactional support for self-esteem is linked to feelings of agency, certainty, success, and a sense of belonging, all associated with

dimensions of self addressed in this text (Andersson & Fridlund, 2002). To understand a person’s sense of self-worth, one must also understand the yardsticks against which he measures success and failure. For many, narrative self can only move forward after the individual begins to accept those experiences that had previously been defined as failures and to choose new arenas in which to succeed. Through these choices, new tools for self-negotiation can be created. Harry hints at this in the following:

Sometimes I make failures with that, but I’ve also been able to give myself a lot of room to make mistakes and work on not feeling useless. And I do a lot of things around the house primarily to ease the burden for my wife but in the process it also allows me to feel that I’m contributing and being useful.

The concept of life impact of aphasia applies to all within the social world of the individual. The following poignant e-mail from a daughter living 200 miles away captures the essentially family nature of this problem:

My father had a stroke about six months ago. His ability to speak is terribly affected, and he is so angry and depressed, we don’t know what to do. Daddy has always been the heart of our family, and we aren’t really sure how to help him. My mother is frightened and overwhelmed. I think Daddy gets angry with her and she sort of freezes up. My husband and I are trying to help, but we don’t know how.

For this family, the only solution was to travel 400 miles round trip for 3 successive months to attend a stroke support group. From that group, and some family time with

the speech-language pathologist, the father eventually reached a point of acceptance and actually moved forward with life.

We turn next to consideration of the impact of aphasia upon the self and life stories.

Self and Life Stories

The central premise of this section is that language is a core tool in maintaining a sense of narrative self, and that aphasia consequently creates a kind of identity theft (Shadden, 2005). The result is what Swidler (1986) terms “unsettled lives” and what MacKay (2003) describes in terms of a past self (“Tell Them Who I Was”) that no longer bears resemblance to the post-stroke damaged person with aphasia. The experience can be described as a sense of disconnect between one’s internal experience and knowledge of self (in part, biographical) and the culturally-defined, role-specific interactive selves that are presented to others post-stroke. This impact of aphasia on self is not restricted to the person with aphasia but encompasses all who interact with that person, as will be described in greater detail later in this chapter. When one person’s language is impaired, this forces others to modify their language and interactive styles to accommodate the aphasia. The impact of aphasia occurs at the levels of everyday talk referred to previously as well as more overtly meaningful dialogues about needs, perceptions, and meanings.

Perceptions of self are hard to measure, so they are often probed indirectly through terms such as self-esteem, self-concept, and self-efficacy. We tend to make inferences about self through observed behaviors, interactions, and emotions. Another challenge in writing about the impact of aphasia on nar-

rative self is the uniqueness of each individual’s experiences of self, as illustrated in discussions with Harry. When he was first asked how his sense of self or identity had changed since his stroke, he appeared to struggle with this topic. In response to one probe, he described how his:

... feeling of being a child and an animal increased. One evening my psychiatrist was making his rounds and saw me in the cage, maybe crying with frustration that I couldn’t use the bottle. And I was soaking wet and he saw this happen and at that point things changed. I didn’t associate those changes at the time except that at one point I found a way to open the sides of the cage a little bit so I could sit up. And one of the nurses came in there and reprimanded me for doing that and I just felt hopeless at that point. I was being controlled without knowing why or what I’d done wrong.

At this stage, Harry remembers treatment as demeaning and infantilizing; it is clear that others are responsible. Later in the same interview, he indirectly addresses changes in self when he describes himself before the stroke, then focuses on how others treat him now. In all instances, his need to validate himself is clear.

On a separate occasion, over lunch in a restaurant, he began to discuss his constant battle for recognition from others, whether friends or strangers. For the first time, he explored the fact that he was still fighting against the aphasia, still demanding attention that validated the pre-stroke Harry, the biographic particulars that had made him “who I was.” He went on to say he was trying to reconcile two “histories—who I was and starting over with who I am.” Harry described the challenge of having to switch gears, as though there would always

be a disconnect between his past and present self. Yet narrative self is dependent upon linkages from past through present to future. His struggle in reconciling past and present self has consequences for his wife. Until he finds some continuity in his projection of self, it is difficult for her to provide those interactive responses needed to recognize and affirm that self.

Another example of the difficulties of discussing self can be found in the following e-mail from the wife of a stroke survivor, after the topic of self-esteem had been raised. She wrote:

And you are right about self esteem being a huge issue. One of the biggest things that I noticed with Jeff is having all the filters that he developed over the years to protect him and his identity stripped away leaving him vulnerable. I think he has done quite well under the circumstances, but some of his fears are too strong to get past sometimes. I have to give him credit for being willing to put up with me and at least trying different things. . . . He is not the most aware individual of his physical and mental cues. He tends to describe things in the most general of terms. As you can imagine, trying to get to the root of something can be difficult.

These comments are intriguing because the wife actually brought up identity issues when asked to reflect on self-esteem. It is also interesting to note that she refers to Jeff's premorbid style of self-reflection and communicating, highlighting the importance of understanding the person before the onset of aphasia if we are to understand her after.

Sometimes brief observations (in this case, offered spontaneously by a person with fluent aphasia) capture the global impact of aphasia. Dennis was introduced earlier

in Chapter 4 of this text. Over the course of several stroke support group meetings, he talked about his struggles with the total destruction of his life story as the result of a brain hemorrhage 3 years previously (when he was 39). He articulates his sense of loss of core self with remarkable and poignant clarity.

They keep telling me to let go of Bob—he's dead and gone—but I miss Bob.

I died 3 years ago—that's what the doctors said should have happened, and I do believe I should have died. Well, I did die . . . I went away.

I don't look at myself as a man anymore. I'm erased.

Although these quotes suggest that Dennis's primary "battle" is with a perceived loss of some core or essential self, his story contains elements of all four dimensions of self described in Chapter 3. The connectedness of aphasia with multiple dimensions of self is also seen in the following statement from Raskin (1992):

I now realize that my vocation in life has changed. Now I represent the one million Americans who cannot speak for themselves. My plight and theirs are one: to inform the public that those of us who have lost the ability to invent fluent phrases or sentences have not lost the ability to think. We retain the skill to communicate our thoughts and feelings, whether through writing, picture boards, pantomime or facial expression. We can still speak! We hope that you will listen with your ears, with your eyes and always with your heart.

In this quote, Raskin highlights his new sense of responsibility that goes beyond the work of reframing self *interactionally* to

consideration of self structurally (in new roles) and culturally (at the level of public awareness and policies). He pleads for awareness and understanding, reaffirming the fact that aphasia does not destroy the person or diminish the person's need for communication with others. Elsewhere in the same document, he provides his biographic particulars, including the fact that he is a person with aphasia.

In the following sections, aspects of self related to culture, role, interaction, and biography will be considered through the lives of persons living with aphasia. Often, these four dimensions are difficult to separate, and they are always interwoven with the life stories and illness narratives that people share.

Self and Culture

Persons with aphasia are often confronted with issues of self and identity at the cultural level. Successful presentation of self requires society's implicit or explicit assumptions of what characterizes successful individuals in any culture. In the American culture, for example, those attributes most valued are independence, power/strength, material affluence, and competence, among others. Thus at the level of cultural values, the person with aphasia has an uphill struggle for acceptance and validation, because she has few of these attributes (except possibly material affluence). Almost immediately, stroke survivors are also confronted with the loss of status associated with being a patient in a medical environment that defines ill persons as those who are dependent, incompetent, and without control. In understanding self construction at the cultural level, therefore, it is probably most important to recognize these cultural values related to illness and disability, as well as the associated stigma.

Issues of disability and identity or self were alluded to in Chapter 3 of this text. In recent years, there have been several studies exploring social/cultural values related to stroke, aphasia, and disability (cf. Clarke, 2003; Mold, McKeivitt, & Wolfe, 2003; Moss, Parr, Byng, & Petheram, 2004). In all studies, there is consistent evidence that public images of disability related to aphasia (and stroke) may interfere with access to services, sense of well-being, and negatively-framed identities carried forward in illness narratives.

One issue in reestablishing one's sense of personal agency relates to the stigma sometimes associated specifically with brain damage, particularly impairments of the less visible cognitive or linguistic skills that define us as persons. Kate Adamson is quoted by Moran (2006, p. 37) points out, "Everyone has a disability. Some of them are visible, some of them aren't. It's all about what we can do, not about what we can't." On-line posts often tackle this difficult issue of disability and stigma. As one person wrote, "Too often people are not given a chance—we just assume that this particular disability means that 'you can't' rather than looking at what YOU CAN do."

The idea of social/cultural stigma associated with stroke and aphasia also leads some to try to validate the disorder. In a presentation at the Speaking Out Conference, Harry Alter (2006) talks about the "country of aphasia," "aphasia people." Others try to develop images that capture their challenges in more familiar terms. For instance, Harry refers to "getting around the stumps ways of functioning in daily life at home or outside." But at the most basic level, Wulf, 1986, p. 13) asserts, "Every aphasic needs to know there is something he can do, even if it's watching birds."

Time and again, people living with aphasia and advocacy groups highlight the

fact that most people know little or nothing about aphasia (National Aphasia Association, n.d.). One on-line discussion group participant wrote: "No job after aphasia is common—because people don't know about it." Another pointed out, "There are more people with aphasia than Parkinson's, but we don't have a Michael J. Fox that stands up and talks about it." Lack of awareness about aphasia is one small component in the more overarching cultural challenges created by negative perceptions of illness and disability.

Another consequence of lack of public awareness of aphasia is the tendency for friends, family, and strangers to make inappropriate judgments about what the person with aphasia can do. A new member to a stroke support group expressed her fear of telling people she had had a stroke, because she would be seen as incompetent. This was a particular concern with respect to driving. Although she knew she was competent in her driving, she was afraid she would be blamed in an accident because of her stroke. Others apologize frequently for their difficulties. It is common to hear persons with aphasia say, with some embarrassment, "I used to be able to spell," or "I used to read all the time."

Some try to develop images that capture their challenges in more familiar terms. For example, for 10 years, Harry has been angered by the cultural misperceptions of his aphasia and by extension his competence. At one point he suggested, "They build ramps to buildings. Why can't they make the waiters study aphasia and change the way they are with people like me." Harry's pre-stroke perceptions of self were very strongly anchored in culturally validated domains. It was important to him to be important in the community, and he expected cultural validation. Thus it is not surprising that he struggles with self validation within the broader

community. Others also resist the cultural norms that suggest they should accept their dependence and role as incompetent.

For example, Doreen is a 75-year-old woman who experienced an extensive left hemisphere aneurysm rupture and who was profoundly impaired during the first months after the stroke. Her language recovery was relatively rapid, and she appeared to have little trouble dealing with the fact of her new life that included some degree of aphasia. In fact, her approach to treatment was systematic, thorough, and rigorous. She welcomed homework and independently began writing and reading on her own. During a therapy session about 5 months post-CVA, Doreen began to describe having a "sad day" accompanied by what she referred to as flashbacks to her time in a geriatric psychiatric unit. All of this monologue is transcribed below. Portions will be referred to throughout this chapter section.

... because I was saying I don't think it's because this happened because of you. I don't think it's because that you knew how I was feeling, what was going on with me. You didn't know about it. And that made him feel better. Except that I said, I just want you to make a promise that I will never have to stay in a place like that again ever. You get somebody to come to the house to take care of me whatever it is. because I don't need to be in a place like that to. I mean it doesn't makes me feel bad, it makes me feel terrible. Because xxx he would come in and maybe 20 minutes in the evening, and that was it. He never brought a dinner over so we could read together. and I'd say maybe they'd let me walk, you could ... take me for a walk around ... nearby or something like to let me know I'm a real ... really alive person. I just felt and you felt like you first every-

thing's locked up. and and all this like I'm in prison a real prison, you know, this is a real prison. and that's it. really made you feel bad. I wasn't the only one. this this this wasn't a happy time in any respect. Well it isn't like feeling in control. it's just that this is me my person. This is what I'm doing . . . and then eating real food and uh all this sort of things would just save your life. you have a life. you you just feel like you don't have a life. I felt like I was in prison. and when I get out of here I'm going to save things and run away someplace. So I because I knew Dave was not thinking I was real. but he still feels I was this person that would Pffff any place any time. And um that he had to watch, be careful, watch watch. If he just had come, brought a paper, read the paper to me rode. Well you're not supposed to be able to do anything. You're supposed to be just sitting there.

In the context of cultural self, Doreen's comments about her environment and her treatment in that environment are particularly relevant here. She felt she was in prison, treated as a nonperson, assumed to be incompetent and docile. Her comments also relate indirectly to self as structurally defined through roles, to which we turn next.

Self and Roles

For Doreen, the roles implied in the above transcript relate to being a wife, being a homemaker. In these roles, she would be accorded recognition for the person, the self that she is. Instead, she felt that her husband could no longer perceive her from these perspectives, and that absence is profoundly disturbing. Dennis also struggles with roles and self in his attempts to move

past his stroke and aphasia. Part of his projection of self pre-stroke was the role of competent, responsible, powerful professional in his job. In a support group, he referred repeatedly to all he had lost in the public persona he projected in his job. For him, the loss of these structural/role governed aspects of self leave a tremendous void in his narrative self, and he has not yet been able to determine how to fill that void. He has not yet been able to give up his pre-stroke structural self.

Harry has struggled constantly with alterations in life roles and their implications for his sense of self. Of particular interest has been the difficulty he has experienced with knowing how much or how little to talk in the stroke support group that he originally cofounded years before his own stroke.

. . . but there's been a long transition where the group needed for me to kind of back off and I was still trying to be a co-leader. That's created some communication problems within itself because the other members wanting to take more power or authority in running a conversation and me still trying to lecture or teach. And that's still a problem. I'm trying to back off with talking so much but I have a real problem in finding a way or seeing the signs that say I'm talking too much. And that's hard—I need to be able to talk . . . to help the group through my talking.

For many, work and family roles are those most altered by aphasia and thus those with greatest potential impact on self. For one couple, the husband's stroke occurred shortly after they moved to a new state and a new job as pastor of an area church. Roger found it difficult to acknowledge that his aphasia and other cognitive