



# Lessons From a Clinical Life in Aphasia

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# Lessons From a Clinical Life in Aphasia

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Not only do clinicians play a role in shaping the lives of their clients, but they are shaped by the individuals they work with. This article interweaves selected aspects from the stories of 12 aphasic individuals into a story about some of the things they have taught me about my clinical life. **Key words:** *aphasia, burnout, communication*

I think of my clinical career as a patchwork quilt. I am the one-color side that absorbs the stitches and holds the multicolor side together. This quilt is not stylized, nor does it have a traditional repetitive design; rather, it is a crazy quilt – an incredible array of varied pieces and design that still manages to be coherent and whole. The quilt is not finished, nor will it be until I stop seeing people with aphasia. It is growing with each new encounter I have with aphasic individuals and their families and loved ones, except for the first few years of my clinical life (when I was too totally self-absorbed and worried about whether what I was doing was right or wrong). I have looked back over every preceding 5 years or so and realized that I am a better clinician now than I was then (whenever the now and the then actually were). This does not embarrass me. The crazy quilt changes because I change, of course. But my changes, at least those growing out of my work, result from what people have shared with me and permitted me to learn from them. That is, my clinical changes largely come from their stories.

I fail to understand clinical burnout, because I have never experienced it. Concerning adults who have endured brain damage that results in communication impairment, the infinite variety of language manifestations itself never ceases to fascinate me. But more important, what keeps me from burning out is how people who find themselves aphasic, undergoing what is probably the most mystifying and devastating assault on one's interpersonal interaction and identity, somehow cope and deal with it. Because aphasia is bound to be shared by one's closest others, their adaptations also intrigue me. Then there is how interactions with strangers – store clerks, bank employees, people occupying the adjoining seats on buses – are managed. Clearly, the range and

degree of adaptation, accommodation, acceptance, acknowledgment, and moving forward are at least as infinite as the variety of language manifestations; but the fascinating part is that, in my experience, there is little relationship among the language impairments and the coping. Some people with mild aphasias, supportive families, and excellent and appropriate intervention remain devastated. Some people with much more severe aphasias, questionable or absent support, and minimal interventions manage to fit aphasia in and to some extent, overcome it. What goes on here? How can this not be a question to fuel one's fascination and avoid burnout?

What follows here will be bits and snippets from the stories of 12 individuals who have, to borrow from Robert Frost, "taken the road less traveled..." – those who have managed, despite this devastating disorder, to do more than survive. They have moved on. It would be easy for me to focus on the negative, but that story is well known and there are fewer lessons to be learned from it or guidelines to be found for living more fully. The 12 people described here will not be telling their own stories. Rather, this is my story about them (bits and pieces of my crazy quilt) and some of the lessons I have learned from them. I will first introduce readers to the group and then discuss what they have taught me, lesson by lesson.

## The Group

I had more candidates for this article than I will be talking about. I chose these 12 from the larger pool of potential individuals because I wanted to

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cover a range of severity from mild to severe, as well as a diverse set of aphasic syndromes. With the exception of Mike and Roger, who would insist on being themselves, I have given them all pseudonyms. I call them by their first names, because they are my friends not just individuals I have worked with. For the record, two had relatively mild aphasia (Mike and Martha); six had moderately severe aphasia (Harry, Alice, Isabel, Liam, Roger, Clyde); the remaining four had severe language problems (John, Dom, Sam, and Peter). In relationship to type of aphasia, two had conduction aphasia (Liam and Roger); six had Broca aphasia (Peter, John, Isabel, Clyde, Harry, Alice); two individuals had global aphasia (Dom, Sam); one of the final two had anomic aphasia (Martha); and one is unclassifiable (Mike). Readers will hear about each of them in the lessons that follow.

### The Lessons

Some of these individuals have become good friends and, over the course of years, have taught me a lot. I have had briefer relationships with others and subsequently have shared and learned less from them. I will concentrate here on five lessons that are general and more representative of the group as a whole, as follows:

1. Acknowledgment is the first step.
2. Hope is not mine to give nor dampen.
3. Resilience matters.
4. Getting ones' groove back is a good idea.
5. Looking outward counts.

#### Lesson 1: Acknowledgment is the first step

Until a person comes to grips with his or her aphasia, I think it is impossible to live fully with it. I am not quite sure what form this acknowledgment takes nor actually what it means. But acknowledgment of aphasia involves recognizing that the disorder is probably chronic, is not going to go away, and is likely to be an abiding presence. This does not appear to happen rapidly, nor should it. Some individuals actually do have full recoveries. (Hope will be discussed later.) Parr, Byng, Gilpin, and Ireland,<sup>1</sup> analyzing the extensive in-depth interviews they conducted with a large cohort of individuals with aphasia, acknowledge

that it takes almost 2 years of experiencing the disorder before it can be accepted. People who live well with the disorder have typically spent some time struggling with it and challenging it, and almost all have been active participants in rehabilitation, either formally or of their own or their family's devising.

Mike exemplifies this latter approach. Unsatisfied with traditional rehabilitation, and in many ways never fully apprised of what the recovery path was likely to be, he and his ever-supportive spouse Elaine essentially did it their way, commissioning a wide national search to further their understanding of aphasia and what could be done about it. At the other end of this continuum was John, who had incurred aphasia as a relatively young man and had consistently sought, received, and benefited from intervention, at least to his satisfaction, for the 30 or so years that followed its onset.

Acceptance does not mean giving in, walking away either from direct treatment or from psychosocial support such as might be provided by participation in group therapy experiences. Rather, it means making some sort of truce with aphasia or making peace with it. And this takes time. In fact, of these 12, I knew only Peter during the first 6 months following his stroke; the majority of these individuals had been aphasic for at least a year before I met them. Peter was depressed and difficult to work with initially, and it was not until well into the second year of his stroke that he came to acknowledge his aphasia. Clyde was 13 years post stroke at the time of our first encounters. He and his spouse sought out our group program not because they were suffering or devoid of friends, but because they felt it offered something new and different to them. But to a person, all 12 people of interest here chose to work on their problems within the context of their knowing that improvement might occur but nevertheless that their aphasia was here to stay.

I struggle to define what acknowledgment and acceptance might really mean, and I can think of no way that others can hurry the acknowledgment process along. It happens in its own time, influenced by overall health, motivation, and a host of other factors related to how one lived before the onset of the aphasia. Most of these things are often difficult for clinicians to accept

when they are confronted by an individual with a severe communication problem. Further, there is no value that I can see for a clinician to suggest that acknowledgment is inevitable and will come along in time. It isn't inevitable. Some folks never achieve it, and it is ethically questionable to suggest that it is important; for some individuals, such information can be devastating and impede their progress both to language improvement and even to moving them toward acknowledgment. Yet this elusive factor characterizes almost everyone who lives well despite aphasia.

## **Lesson 2. Hope is not mine to give nor dampen**

Early in the course of recovery from aphasia particularly, clinicians are likely to be asked to predict the course of recovery and what the long-term outcomes are likely to be. There are a few specific bits of information that we can and should share. These include some facts about the shape of the spontaneous recovery curve and, provided no unanticipated negative problems occur, the natural course toward improvement.

But this is seldom what we are truly being asked. Especially as the intensive rehabilitation process continues, and improvement gets harder and harder to see (much like watching hair grow), the answers we are asked to furnish become more sharply focused on the longer term. When will this be all over? When will I feel like myself again? When, when, when? As the questions become more urgent, most clinicians begin to feel trapped by their inability to provide answers.

I was once there myself, and I stayed there for a long time as I struggled through the research of others and conducted some of my own<sup>2,3</sup> to find answers to such questions. I felt trapped between the rock of what the available data led me to believe and the hard place of knowing the importance of a number of intangible factors such as motivation, prestroke coping and learning styles, and extent of family support.

I was also painfully aware that physician prognostication could range anywhere from what families and persons with aphasia understood to be "You will never talk again" to a dismissive "You will be just fine in a year" (or somewhere

between 6 months and 4 years, depending on the physician's proclivities). I was equally aware that for some individuals and families, their reactions to the physician's comments could range from being devastated to becoming supremely challenged to serve up the doctor's own words to him or her on a silver platter.

This was a game in which I wished to play no part whatsoever. So I became extremely skilled in a host of ways to say, "I don't know. It depends on many things I don't know about." But I struggled with hope and its evil twin, false hope. Over the years, I stopped believing in false hope. I truly do not know what it means, except at the extreme of cockeyed optimism. And I continued to hone my evasion skills.

Recently, at the National Aphasia Association's Speaking Out Conference, I was granted a reprieve by the spouse of an aphasic man who had been listening to a group of clinicians wrestle with the false hope issue. This woman stood up and said, "I have an idea for you clinicians. Why not just leave the hope issue to us families and people with aphasia?" I felt as though a weight had been lifted from my shoulders. I think this really is the essence – hope is not mine to give nor to take away. Honest appraisal to the best of my abilities, coupled with an attitude of support and faith that people really know what is best for them, is about as far down that road as I intend to go. I will of course continue to merge the data with my clinical experience in clear I-don't-know statements, but I have stopped worrying about instilling hope or taking it away. It is not mine to manage.

Every one of the 12 individuals who fed this writing had some kind of hope. In some instances, it was the result of a measured and realistic appraisal of what a good outcome might be. In others, it was faith in the higher power of their choosing. In a few, it was doggedness in the face of clinical reports documenting "unreal expectations" that had been explained as the reason for their dismissal from previous therapies. In some, it was picking up their lifelong habit of successful problem solving and applying it to this new challenge. In some, hope resulted from collaborative efforts with a strong support team. For some, it was simply a matter of having to get on with life in the absence of any support at all. And of course, there were

some combinations of all of this as well. But none of it was because physicians or clinicians knew when or how to play the hope card.

### Lesson 3. Resilience matters

There is a growing and healthy literature, nourished by positive psychology, strongly suggesting that resilience is a key to living fully.<sup>4-6</sup> Some that are particularly pertinent to aphasia are the findings that resilient people live longer,<sup>7</sup> recover more quickly from bypass surgery,<sup>8</sup> and are less likely to be depressed.<sup>9</sup> Resilience, that is, the ability to bounce back and get on with life after adversity, suffuses this group. It was most obvious in Isabel, who had four young children at home when she had her stroke and in a very short amount of time resumed her formidable home responsibilities with ingenuity, selflessness, and grace. Never complaining despite her extensive aphasia and its accompanying hemiplegia, she just picked up and went on. One of my enduring impressions of her occurred when I was videotaping her family at Sunday morning breakfast for a project I was working on. Isabel was laboriously slicing a bagel impaled on some prongs with one hand, while the kids and her husband obliviously joked and talked. Bagel slicing with two hands is hard enough, and I couldn't take it. I stepped out of my cameraperson role and said, "Hey you guys, will somebody help Isabel with the bagels?" The whole group, including Isabel, looked blankly at me, and she and her husband both said, "Why?" "My job," Isabel added. (Live and learn, Audrey!)

Dom was also a formidable example. Before his stroke and its resulting global aphasia, Dom owned and managed a successful restaurant. The stroke forced him to sell his business, but it did not force him to give up a career in the food industry. Dom had virtually no speech and was hemiplegic as well, but he managed to convince a fellow restaurant owner to hire him as a dishwasher on a trial basis. He worked in this much lesser capacity on a full-time basis thereafter; although he worked day shifts, he managed to come in on his lunch hour over the next year for his weekly therapy sessions. He remained severely impaired linguistically but without complaint and with great self-assurance.

An interesting and important fact about resilience and optimism is that, to some extent, both can be increased and learned. Indeed, it seems reasonable to suggest that activities and exercises can be adapted and used to help aphasic individuals and their families increase these traits.<sup>10</sup> But it is also worthwhile for clinicians who observe resilience and optimism in their clients to guide them in how they can apply these qualities to living well with aphasia.

### Lesson 4. Getting one's groove back is a good idea

Participating in one's community or society is clearly recognized as important by the World Health Organization's International Classification of Functioning, Disability and Health (ICF).<sup>11</sup> But the importance of social participation as a way of living well despite aphasia may be underestimated or overlooked because communication has such a major affect on one's role in society. That is, persons who don't understand the many facets of communication might easily assume that when language is compromised, participation is similarly compromised. My experience suggests that this is far from necessarily so.

Individuals with aphasia who can surmount the language problem with successful communication strategies, along with those who make significant recoveries, are still the best candidates for rejoining their former worlds. But this does not mean that people who have less success in language recovery or strategy deployment cannot make gains in getting back to their former lives or even establishing new and different ones. As Harry's wife Lois succinctly put it, "We're back to normal. It's just a different normal."

Alice incurred her stroke at the very beginning of her retirement, at about the time she and Miles, her husband, had finished making elaborate plans for traveling and developing a new life. Miles looked back a few years later on that time and noted, "We are not having that retirement, but this one is almost as good."

Some people among my 12 have gotten back to their old lives, if perhaps in slightly muted forms. In this regard, Peter seems to have been almost lucky. He was an interior designer whose life partner, Leslie, was also his partner in their joint

interior design business. Even before Peter's stroke, Leslie was responsible for most of the "people work" while Peter worked behind the scenes, busy with drawings and plans. This unique situation enabled Peter to resume his profession relatively easily despite severe aphasia, but with massive support from Leslie. Others, such as Clyde, an easygoing man who had successfully mastered retirement before his stroke, relatively quickly settled in to his prestroke patterns of church-related activities and family gatherings arranged by his supportive spouse Emma. This was also the pattern for Martha, but she was different from both Clyde and Peter in that she was a widow who lived independently, without constant support from a caregiver.

Other people in this group have gotten into a new groove instead. Isabel began to paint after her stroke and had a number of successful one-woman shows as the result of her new career. At one point following his wife's entry into the art scene, her spouse, Bernie, said, "I never knew who I married until she had her stroke." Harry got serious about physical exercise for the first time in his life, proving that being aphasic is not incompatible with being a gym rat. Sam, a goal-oriented, hard-working, and successful businessman and a widower, turned the business over to his sons, took his forced retirement seriously, and used his free time to travel extensively. He took advantage of the fact that he could easily afford the luxury of a paid travel companion, which made trips possible that could not have been managed alone.

Liam took the "opportunity" of his stroke and aphasia to retire and to get serious about his beloved golf game. His idea of a good outing post aphasia was to do well at a public course in a foursome with three strangers who did not realize that he had significant language problems. He would relate these experiences with relish at his clinic sessions. "Those other guys .... they never knew ... fooled 'em." He also took on new volunteer jobs, delivering Meals on Wheels to "old guys" and serving as a hospital volunteer to aid people in finding their way around the hospital. Given the severity of his language disorder, I once questioned him on how he did this. "I don't ... ya know ... speech ... I take 'em there."

Some individuals have given their talents to helping others with aphasia. Roger developed aphasia groups throughout Phoenix, where he lived, and tirelessly gave his time and support to activities designed to publicize the plight of people suffering from aphasia.\*<sup>1</sup> Mike in partnership with his wife Elaine, founded the Adler Aphasia Center, the crowning achievement in their long history of philanthropy.

The point of these examples is to suggest that there are various paths to getting back to life. When I consider how I would do it should I have an aphasia-producing stroke, I have no idea, but I certainly have role models. The aphasic individuals I have worked with have also armed me with examples that I use to illustrate to newcomers to the aphasia world (students, people with aphasia, families) the many ways they can get on with life despite aphasia. The important message is that it matters less how it is done than *that* it is done.

### Lesson 5. Looking outward counts

Perhaps obliquely, all of the above lessons are contained in this one. Individuals who look only inward have a harder time living well with aphasia. I suspect this is related to motivation and preaphasic coping styles, but there are few studies that support this contention. Looking outward has many facets. Probably foremost, it means recognizing that one is not the center of the universe. When one cannot look beyond one's own tragedy, making peace with it is difficult. In some instances, the looking beyond grows into volunteerism: Liam, Roger, and Mike all chose different paths to be of service, but in their cases, reaching out to help others also helped to normalize their lives.

Looking outward also involves humor. This is not to say that everyone who lives well with aphasia has a well-honed sense of humor. But it helps. Certainly, aphasia has its tragic aspects, but it does not preclude people from having a good laugh now and then, possibly even occasionally finding that aphasia itself causes some pretty funny moments. Many could laugh at their aphasic errors or marvel at some of their complicated linguistic

\*An inspirational videotape, "A Conversation with Roger Ross," is available through the Department of Speech Language and Hearing Sciences at the University of Arizona for a nominal fee used to support the department's aphasia clinic.

predicaments. I suspect one of the reasons that participation in aphasia groups plays such a powerful role in recovery from aphasia is that there is typically a lot of laughter happening there. With the exception of Sam, who almost never laughed, the other people highlighted in this article were able to see the light side of life at least occasionally. One of them, John, was probably the cheeriest person I have ever known – I see him as the ideal Wal-Mart greeter. The point is that life can continue to have a light side despite aphasia; and when that is recognized, it plays a major role in living well with the problem.

Much has been made of the importance of a strong family support system in recovery from aphasia. I do not dispute this, but I think it is really part of a larger picture involving the ability to have deep attachments to other people or institutions. Indeed, for some people who have substantial families, support is clearly missing, and for others who have no family ties, attachment is nonetheless obvious. Attachment occurs in many forms –from gregariousness to religious faith. In this sample of 12, all had attachments. Some had excellent conventional family support: Mike, Isabel, Peter, Sam, Clyde, Harry, and Alice. Conversely, for John and Liam, friends and clinicians were paramount. Roger's attachment was primarily to his cause – his aphasia groups; Dom's was his commitment to working again and being financially independent; Martha's was her abiding religious faith. I have learned that, in addition to family support, I needed to be alert to the larger issues of attachment – friendships and other relationships that add to living a meaningful and outward-looking life. They all count in important ways.

## Final thoughts

I am very aware of the number of times I have voiced my uncertainty or lack of knowledge and prescience in this article. In some ways, it was hard to give myself permission to do it; but this is my story, and lack of certainty has always been a part of it. I also think my lack of certainty plays a role in my having avoided burnout; it keeps me curious, for one thing.

I wrote the bulk of this article while I was in Australia, and it has become an interesting metaphor for my clinical crazy quilt of a life. Australia is a foreign country to me – just like aphasia is a foreign country. And its people are foreign too, just like people with aphasia. But this is not a totally foreign country for an American – we almost share a language, as well many values. This too is just like aphasia – it is not totally foreign in language or values. I love exploring Australia and its people and being continually thrilled by what I find – the similarities to what I am so comfortable with at home, packaged in surprises to unravel and new things to find out about. For me, that's the way it is with aphasia and people who have aphasia, too.

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