7 Learning from Roger Ross: A clinical journey

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Roger Ross was a big man, in almost all ways larger than life. We learned an incredible amount from him over the course of the six years we worked with him, collectively and individually. Roger Ross had incurred a stroke at the age of 62, 3 years before I[1] met him in 1994. Although he had exhausted his benefits for reimbursed services, he continued to seek help. Ruona Bertaccini, of Martha Taylor Sarno's staff, referred him to me when he moved from New Jersey to Scottsdale Arizona, 120 miles from Tucson. A few months later, he began coming to our clinic weekly, to participate in our aphasia groups, and to continue individual treatment. He was a linchpin in our programme until September 1999, when he suffered a second stroke that left him unable to drive the 250-mile weekly round trip. This second stroke seemed to "move about the wiring in my head" (to quote him) so that his speech, if not slightly better, was certainly no worse. I remained in frequent contact with him until his untimely death resulting from complications of a fall, in October 2000. I last saw Roger Ross in late August of that year. We will always miss him as our friend and teacher. He was our partner on a 5-year journey we took to unravel his aphasia and what could be done about it.

We want to talk about that journey, emphasizing what we did, and what we both learned from it. We begin by describing Roger's aphasia and the clinical interventions that were attempted; what worked and what failed to work, and why. Then we will describe attitudes and beliefs, and conclude by discussing what have become very dominant themes in our work. Some of these beliefs he simply reinforced; others he helped us to develop.

ROGER ROSS' APHASIA

A volumetric reconstruction of Roger's brain revealed extensive left hemisphere damage lesion with virtual destruction of Broadmann's areas 22, 39, and 40. He had no residual motor impairment, although he reported that his voice felt tight and lacked its pre-stroke vocal range. The reconstruction also

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[1] The use of singular personal pronouns in this chapter refers to ALH, its first author, or when appropriate, to Roger Ross himself. AER will be used to refer to the chapter's second author.

shows a very healthy right hemisphere, as well as the areas surrounding the infarct. This healthy tissue appears to be partly responsible for his capacity for change and learning following the stroke.

Rather than test scores, which have been described in a previous publication (Holland, 1998), we summarize these findings with an impression of Roger Ross' language. The most striking initial observation was how easily Roger wrote the words he could not say. He carried small pads of paper on which he wrote troublesome words for his hearers to read as he continued on. All of us, even his fellow aphasic group members improved our ability to read upside down as a result of frequent talking to Roger. This writing strategy, supplementing his laboured speech, made him a skilled communicator. His word retrieval was limited, and he overused his few words with impunity. For example, a spectrum of good things was typically described as "interesting" or "terrific" depending on his degree of enthusiasm. Bad things were "terrible". If he could not say the word he searched for, he correctly and effortlessly wrote it on one of the many small pads of paper he always carried, trusted his listeners to read the word (from any angle) and just continued to talk—about a wide range of topics. He made very few spelling or perseverative errors in his writing, and the errors he did make were often correctly chosen and spelled words in Portuguese, a language he spoke fluently before his stroke. Proper names were particularly pesky. Paraphasic errors almost never occurred, and long silences often occurred, seemingly in their stead. He could almost never read aloud the single words he wrote correctly. He spoke slowly, with false starts, revisions, and pauses. He did not write phrases or sentences spontaneously (and still did not at the time of his death). As hinted earlier by his inability to read aloud the single words he wrote, he could not read text aloud. However, his silent reading comprehension was excellent, and he reported it to be "almost back to normal". He read daily for at least an hour with a discipline and motivation that were his hallmarks. Finally, his comprehension of single words, when they were spoken in isolation with little or no context, was poor. But his ability to understand spoken discourse, jokes and puns, conversation, theatre and so forth was as good as ours.

Thus, this puzzling man could: (1) retrieve the written form of single words when he could not say them BUT then could not read them aloud; (2) comprehend difficult text when read silently BUT failed totally to read text aloud; (3) speak in laboured, complex sentences BUT could not repeat or say the alphabet; and (4) follow normal conversation BUT had difficulty understanding single spoken words and proper names.

Extensive testing, with a variety of instruments—The Western Aphasia Battery (WAB), reading, writing, and semantic subtests of the Psycholinguistic Assessments of Language Processing in Aphasia (PALPA), written and spoken tasks designed and described by Berndt and colleagues (Berndt, Mitchum, Haendiges, & Sandson, 1997; Raymer & Berndt, 1996)—extensive observation, and interaction, all coalesced into a pattern suggesting that, although Roger could be classified as having conduction aphasia, he suffered

Table 7.1 Roger Ross' strengths and weaknesses from tests and observations

	Evidence	*Interpretation*
Strengths		
Excellent comprehension for discourse and text reading	WAB, conversational skills, ability to read advanced fiction, nonfiction, newspapers and magazines	Context enhances linguistic performance
Spontaneous single word writing	WAB, Berndt tests, conversation	Semantic system largely intact
Lexical decision	PALPA	Phonologic/graphemic input largely intact
Weaknesses		
Cannot reliably access semantic from minimal acoustic cues	Observation, WAB	Questionable single-word auditory comprehension skills
Poor phonological memory	WAB, PALPA, repetition tasks	Acoustic to phonological conversion fails when three syllable span is exceeded
Poor grapheme/ phoneme conversion	WAB, PALPA, conversation	Cannot write nonwords to dictation, minimal ability with real words while talking
Cannot rhyme	PALPA	Minimal internal sound patterns

from a severe phonological access impairment. We believe in looking at both strengths and weaknesses and how they balance in linguistic and personal terms. The language strengths and weaknesses listed in Table 7.1 come from both formal testing and observation. Also listed here are sources from which the strengths and weaknesses were derived along with their effects on Roger's communication.

Roger described his own problems as: "I have no sound patterns in my head." His description reminds us that professionals can sometimes save a lot of time by listening to what our aphasic friends tell us is wrong. Indeed, it is a clearer, less jargonistic description than the professional version, which might be something like: "Difficulty in accessing the phonological lexicon."

ROGER ROSS, THE PERSON

In addition to language strengths and weaknesses, personal characteristics and coping styles must be considered if one wishes to describe an individual's particular aphasia comprehensively. Personality and character play a role, not only in treatment planning, but also in living with aphasia. Here are some of Roger's characteristics that were influential.

Roger Ross could be described by vibrant adjectives—intelligent, courtly, difficult, self-disciplined, loyal, motivated, funny, for starters. His careers, as an international book publisher and consultant, as the mayor of the town in which he lived, and as a foreign affairs expert, spanned three continents over 30 years. In addition to English and Portuguese, he also spoke Spanish and French fluently. He was avid about food, theatre, dance, history, sports, and politics. He read the *New York Times* daily, and consistently shared its op-ed articles concerning the brain with his aphasia group. He also read Camus and Garcia Marquez and other difficult authors. One of my responsibilities to him ultimately turned out to be keeping up with him in worldly matters and serving as his discussant and sounding board.

Long before Worrall coined the term "Participating in Choice" (2000) Roger Ross was insisting on it. He was an object lesson in clinical decision making: clinicians who decided to "work on something" without consulting him about his desires and goals were simply rejected. So were clinicians who were unaware of their own limitations. (Remember that he was paying for his therapy.) For example, he undertook some private therapy closer to his home, and quit following a session in which he used the word "pert" and his clinician informed him "there was no such word". He apparently attempted to disagree with her, and she did not honour his challenge. He reported that he went home upset, looked up "pert" in his dictionary, and called to terminate treatment. "She made me doubt myself," he told me. "I don't need it."

No description of Roger Ross could be complete without noting his passionate belief in the power of aphasia groups. He disdained what he called "cake and coffee" groups, but worked throughout his post-stroke life to develop and participate in groups focused on coping with aphasia. When I met him, he had formed and had run at least two aphasia groups, and continued to do so for the rest of his life. His style was to get a group up and running, then move on to develop another. In all, he probably initiated six or eight aphasia groups. He wrote and published, with the help of his fellow aphasic group members or his clinicians, two articles on the group experience (Holland and Ross, 1999; Ross, 1996). In one of these articles he states, "I did not begin to get over aphasia until I became part of a group" (Holland & Ross, 1999, p. 116).

THE INTERVENTION

What did we work on? In retrospect, I feel lucky in that, for some time, I have been committed to the notion that ideally the clinician should facilitate working on what the person with aphasia wants to work on. When this is not possible, then it is mandatory to explain as clearly as possible, and to provide some counselling concerning why such treatment is not likely to be helpful, for instance, when clinical experience dictates that the aphasic person's chosen goal is probably unachievable. A relevant example might be that of an individual with severe apraxia of speech who insists on working on speech rather than on compensatory strategies that have some likelihood of success.

We also believe aphasia treatment should be designed to maximize strengths. This is in contradistinction to approaches that pinpoint and attack where in the processing schema things break down, as in many standard cognitive neuropsychological approaches to treatment. Thus my preferences would have been to keep the writing strategy foremost, make it even stronger, and complement this single-word writing ability with more extensive emphasis on writing longer units, or possibly to teach Roger to use computers more effectively, given the silent reading skills he so obviously possessed.

But Roger wanted to be able to access words in spoken speech more easily. He did not want to work on writing connected discourse, nor pursue computers. My choices bored him, and he decided that neither avenue was interesting or likely to be worthwhile to him. He wanted to substitute speech for his single-word writing strategy.

Of all eight cases who resembled Roger Ross, and who have been described in the literature (Shelton & Weinrich, 1997) not one clinician had even considered trying to improve spoken word retrieval. Nonetheless we undertook treatment aimed at efficient spoken word retrieval. (This is called *Fools Rush In*.) And I had to choose another strength to focus on if we were to make any noticeable inroads on spoken word retrieval. I tried to bolster Roger's phonological weakness by using a technique that potentially could work with an individual whose strengths were essentially personal, not linguistic. In this case, the strengths were his motivation, his fascination with being challenged, and his obvious intelligence.

The first approach was Autocue, first described in relation to writing by Marie-Pierre de Partz (de Partz, 1986), and then more fully explicated for word retrieval by Nickels (1992). Essentially as a phonological self-cueing procedure, Autocue seemed a very sound tactical approach. The goal was to use phonemic self-cueing first in an obvious, out-loud, up-front way until it became firmly established. Then the next step would be to instruct Roger to internalize the steps, to visualize the word "in his head" so to speak, and apply the cue silently, and then say the word without the necessity of writing it on paper.

Because the Autocue procedure has been well described in the above references, as have its modifications for Roger (Holland, 1998), it is only briefly summarized here. The clinician (in our case, in consultation with Roger) finds a key word for each letter of the alphabet that the aphasic subject can access consistently. For example, because Roger could consistently access "terrific", he was taught that if the word he was attempting to access through his writing strategy, say “tarantula” began with /t/, he was to whisper “terrific”, /t/, /t/ . . . “tarantula”. Thus, the /t/ in “terrific” became the bridge whereby he could cue himself to access and orally produce the word “tarantula”. Eventually, Roger was able to access /t/ without use of the bridge word.

We taught each alphabet letter this way, beginning with consonants and working with four or five letters and sounds at a time. We adapted the cue cards from Hooked on Phonics for this purpose. Some of his bridge words included Pat, enter, and bell. At one point during training, Roger noted that he could not produce oral form of the word “p-r-a-y-i-n-g” by commenting “I haven’t learned the (gestured praying, wrote /p/) thing yet.” It took approximately 50 one-hour training sessions in which Autocue and dependent activities were featured, to master his bridge words and phonemic cues. That is, once learned, his therapy focused on each cue to reading word lists and naming pictures in confrontation tasks, with relatively good success. As he progressed with phonemic self-cueing, the contingencies were tightened, and Roger was expected to visualize (“inside his forehead”) the way the word was written, apply the phonemic cue, and say the word without writing it. This was not easy, but with effort and time he could do it fairly well. Each session ended with a conversation, geared to promote this internalized use of Autocues spontaneously.

However, there was minimal generalization to conversation, probably because the Autocue procedure competed poorly with his already effective writing strategy. Even at its most successful the cueing was quite slow. Further, practice with confrontation naming and with oral reading of word lists was very different from on-line retrieval of words Roger wanted to use in conversation. (Lesser, 1989, noted that retrieval of the words in confrontation naming tasks was very different from the self-selection involved in conversational word retrieval. This was the problem we were encountering.) Thus, at the end of each session, when we moved to spontaneous conversation, bridges and autocues were abandoned in favour of the more efficient and worldly writing strategy.

The Autocue procedure is laborious and challenging to any but the most dedicated of aphasic persons. Roger was one of these. He truly enjoyed the intellectual nature of the activity, and we decided to confront the generalization chasm directly. An important and relevant observation was that not only Roger, but also listeners like me, inadvertently played into his writing strategy by failing to *require* him to say the words he wrote. In effect, the writing strategy seduced us all.

To approximate conversational word retrieval more closely, we moved from confrontation naming and word lists to categorical naming. An even more critical feature was that both Roger and I made a mutual commitment to apply the Autocue strategy in our conversations. He would not write until he had tried to say the word via his Autocue training, and if he initially wrote the word, I would refuse to read it. This was at least as difficult for me as it was for Roger—perhaps even more so, since I quite liked and was intrigued by his writing strategy to begin with. The writing was comparatively fast and effective—and along with most of his listeners, I was content to say the words he wrote for him. It was *Roger* (and the trees that he killed with his endless consumption of writing pads) who was dissatisfied.

Each of the 11 treatment sessions that followed had five phases, detailed in Table 7.2. They were designed to illustrate to Roger (and to me), the effectiveness of the phonemic cueing and to provide extensive practice in using it for self-selected words.

I took responsibility for the categories for the naming tasks. They were deliberately selected to be difficult, and thus to have potential to evoke proper names, as well as to challenge Roger intellectually: they are also included in Table 7.2.

Table 7.2 Phases of treatment

Phase 1	Pre-test "Say words you can think of that have something to do specifically with the Renaissance" (5 minutes). Start and end times, words generated, and total words documented and reported to RR.
Phase 2	Demonstration "This time I want you to write and then say words relating to the Renaissance" (5 minutes). Time recorded, words generated, and total words documented and reported to RR.
Phase 3	Practice "Now we are going to practise writing and saying. You are going to use a new category. This time come up with words that relate to drama and dance. I will help, but we will not go to a new word until you have said the one you wrote" (25 minutes). Data gathered and reported to RR.
Phase 4	Post-test "Its time to go back to Renaissance words. Remember that a pen is available. Use it if you need to. But try to SAY these words" (5 minutes). Data gathered and reported to RR.
Phase 5	Conversation "Let's talk about __________. Your pen is there to help if you need it." Substantive words generated were tallied and reported to RR.

TOPICS FOR CATEGORY NAMING

Three topics for each session Phases 1, 2, 3, 4, Homework

(1) Medical terms, Religion, Wild West; (2) Latin America, Russia, Movie Titles; (3) Buildings and Monuments, Natural Sites, World Holidays; (4) Music, Printing/Publishing, Politicians; (5) Renaissance, Drama and Dance, Break—no homework; (6) WWI, Weather, Famous Animals; (7) Cleaning terms, Cooking, Herbs and Spices; (8) Sports, Travel, Time and Space; (9) Media, Television, Insects; (10) Tools and Utensils, Emotions, Water; (11) Vehicles, Body Parts, Games.

Table 7.3 Crib sheet

- Do not hold your breath
- Speak on exhalation
- Breathe out
- Get the first sound under control before talking
- Give yourself permission to
    - Be flexible. If you can't say the word you want, let go and think of an alternative
    - Relax
    - Take a chance. Paraphasias are at least in the ballpark

Table 7.4 Comparison of pre- and post-test phases and conversation

Session #	*Pre*	*Post*	*Conversation*
1	5	7	6
2	6	13	11
3	6	8	6
4	4	5	10
5	4	6	7
6	8	8	9
7	2	9	13
8	9	10	not tested
9	5	10	14
10	5	10	14
11	6	14	not tested

Roger also had homework to do daily, alone. This is a consistent feature of much of the work done in our clinic, where a general goal is to have aphasic individuals develop a sense of responsibility and ownership, not only of their problems, but also of solutions to them. (Roger always did his homework avidly, provided it appeared to him to be sensible.)

Finally, Roger also had a crib sheet, illustrated in Table 7.3 for use with his homework, as well during sessions, and presumably whenever he chose to use it. (He almost always had it with him, in his briefcase, or in the form of a wallet card.) It included reminders for maximizing speech production.

We formally evaluated our treatment approach by comparing Phase I (Pre-test) and Phase 4 (Post-test) for each session. The data appear in Table 7.4. It can be seen that consistently higher performance was generated in the post treatment phase of each session. Pre treatment phases were variable—the dip in Session 7 was probably due to Roger's insistence on naming cleaning products, rather than words related to cleaning (that is, for example, to say "Boraxo" instead of "soap powder" or "broom"). He relaxed this self-imposed criterion during that session's post-test. I should note that typically, only about half of the words generated in Phases 1 and 2 showed up in the post-test, indicating that he was generating words from a much larger semantic pool that he could access at any one time.

Because this was a fairly rigorous experiment—done that way because this was part of a federally funded research project—I have more extensive reliability data, as well as data from conversation that showed Roger using increasing numbers of words. These data have also been described elsewhere (Holland, 1998). Here, because we are describing a clinical process, we emphasize some observations that began with this treatment and became part of Roger's consistent strategies.

First, he was increasingly skilled at saying the words he wrote, and less reliant on his listeners to say them. Second, he began to permit himself to make paraphasic errors. This suggests that he was beginning to become more tolerant of his errors, or that he was actually getting closer, somehow, to his phonological lexicon. In either case, paraphasias gave listeners more clues than did silence, so they facilitated conversation. Throughout the course of his previous treatment, I urged him to take chances with paraphasias. It was to no avail until after these generalization sessions, when he could see their advantage directly. This represents a lesson in the power and importance of person-relevant explication and demonstration. A third change was that, with increasing frequency, Roger could use a *single written letter* to cue oral word retrieval. In some instances, simply moving his pencil towards paper was sufficient.

Although Roger continued until he died to use writing both as a phonemic self-cue and as a substitute for oral word retrieval, we all believed he had increased his ability to communicate orally. Why did it work? One reason had to be our mutually increased discipline in trying to use phonemic cueing to facilitate oral word retrieval in our therapy. Another reason was related to incorporating conversation into every session as a trial balloon right after the treatment. (Roger and I were never able to deny ourselves conversation, usually going on and on before and after our more formal exchanges. But here, building it in directly after cueing was required proved to be advantageous.)

Following Autocue, we changed focus to developing and carrying out specific training on scenarios and bits of real-life interactions that gave Roger particular and consistent difficulty. In our research we have recently been exploring the effects of what is referred to as "context" building on the work of Hinckley, Carr, and Patterson (2001). Context-based training can be contrasted to more traditional training in which components of bigger behavioural units are systematically taught, and expected to generalize to a wide number of behaviours in context. This is referred to in the skill acquisition literature as "part task training". For example, when we practise word retrieval skills, we often target words (for example, family names) that we expect the person will use in many settings. In contrast, the procedures of context-based approaches specifically target the content words and grammatical structures that might be appropriate for a single scenario, such as making a toast at a wedding, and drill the explicit scenario.

This concept can be used to characterize contemporary approaches to second language acquisition, where the focus has shifted away from learning vocabulary and sentence types and grammatical rules, to approaching dialogues appropriate to specific contexts, such as finding out where the post office is, or ordering your favourite meal in a restaurant.

We approach context-based training by first conducting an interview, designed loosely in consonance with Linda Worrall's procedures for her functional communication therapy planner (1999). The goal of this interview is to choose some specific scenarios and scripts as stimulus material for the training. Examples include such things as buying a specific gift at a store, ordering in a restaurant, telling a joke, using a photo album to cue self-disclosure, talking to a travel agent, and many other short transactions, interactions, or monologues. The clinician writes the scenario, and modifies it as a result of consultation with the aphasic person who intends to use it.

Next, the scenario is practised intensively, with the goal of making it automatic. In Roger's case, he chose some explicit scenarios that gave him particular trouble. They were giving directions to his house over the phone, and instructing a bartender or friend to make Roger's idea of a perfect Martini. We wrote the scripts with Roger's input. He approved or modified them as he saw fit and we changed the explicit language to accommodate his aphasia. Then we practised and practised and practised them, with Amy and me, with other people we could collar into listening, in aphasia groups, and, in the real test case, the real world. And of course, Roger practised daily at home with a tape recorder to check his own work.

He was extremely successful with his scenarios, and we were preparing to continue with more of them when the second stroke occurred and he was forced to terminate formal therapy.

Roger Ross has substantiated our beliefs in some basic principles of intervention with people who have aphasia. These include the following:

1 To the fullest extent possible, make the focus of treatment a joint decision, of the aphasic person, his or her family and only lastly, you.
2 Therapy is a collaborative undertaking, and a collaborative commitment.
3 Ensure that your rationales are clear, not only to you, but to the aphasic person. That is, if you can't explain what you are doing to the aphasic person's satisfaction, you probably shouldn't be doing it.
4 Provide demonstrations of effectiveness of what you are doing, in addition to rationales.
5 Challenge, encourage personal responsibility and ownership, and lighten up.
6 Attend to strengths before weaknesses.
7 Be flexible. When something doesn't work, try something else.
8 Remember that it is never too late to change.

Roger Ross also taught us other things, but they were about us, not therapy, and not Roger. Here are two of them:

1 We are not experts in anyone's aphasia. We may bring collective information, gleaned from many aphasic individuals with whom we have worked, but the true expert in one's own aphasia is oneself.
2 Often, in clinical interactions with aphasic persons, the behaviour that needs to be changed is our own.

Finally, Roger Ross was largely responsible for helping us to recognize and understand that acceptance of a problem, fitting aphasia into one's life, and recognizing aphasia as a player and as a reality, are crucial aspects to learning to live both with, and around, aphasia. This is an evolving process, which probably takes some amount of time to grow into.

In a stunning interview near the end of his life, Roger Ross basically said that he doesn't think about aphasia anymore. He is just who he is, doing what he has to do. More than just aphasia, acceptance is an essential feature in surviving any of the many tragedies that life can, and often does, deal to any or all of us.

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