

Living with Aphasia: The Insight Story

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Introduction

One of the first things Chris Ireland told me when we met in 1991 was that she wanted to tell the insight story about language disability. Though Chris sometimes devoices final consonants, insight seemed much more appropriate: the story would be about how she saw and experienced her language disability; it would give her own insights and thus bring language disability in sight. For someone with aphasia, describing and explaining her disability is difficult enough, but if she does so publicly in writing what she writes is usually 'corrected', edited and changed to such an extent that the disability becomes invisible. We are told that the insight and inside story cannot be one and the same.

We decided to pool resources and join voices to tell Chris' story. What follows are extracts from the book we are working on. We have not altered what Chris said or wrote, though we have made small additions, consistent with her psycholinguistic system, in a few places where the meaning would not otherwise have been clear. We have not edited out any of the ambiguities or 'errors' where what she produced was phonologically and semantically related to a 'target'. Indeed, in many cases, there was not a single 'target' and what she produced seemed more expressive since it conveyed the multiplicity of meanings she intended. For instance, we have kept the verb '*permanete*' which Chris uses often to express both the meaning of *permeate* and *permanent*.

I have a language problem, not a communication problem. Part of brain is dead but with a loss also a gain if work to build inner insight and strength. I think I am better communicator than before the stroke. I don't listen to flannel. I can't flannel now. My language is closer to my feelings. But it could be more difficult people to hear it cause people need flannel particularly to receive a critical issue, something challenging. People need some cushioning at times. I don't prepare people anymore.

Everyday is not a joy. Daily demands. Travelling difficult, noise and nausea. I can very aware of the noise. External noise interview . . . interferes me to listen. I can't concentrate with it. I can't screen it out. I so want to be involved with life, which I did before, but there is a little bit of me which is still difficult accepting my limits. Pain permanetes in my life. Try pain-killers, acupuncture, massage, yoga, relaxation. Often anger about it. I will to live active and enjoyable life. So hard to find out better to do about it.

It does take me more time to cotton what is going on. I am a bit slow to take it in but deeper perhaps. I lose something on the surface but I gain something else. But practically you need surface. My thoughts and emotions are so bigger and quicker than my language tools. I cannot compete clever with words. I need an intellectual role for myself as well: I am still clever, still reflective.

Many roles: professional as counsellor; language activist to educate people and build support network re people with aphasia; and disabled with insights, learning, limitations and needs. Working on pacing and adaptation. Hard. Each day I do not how I will feel. Unable to predict so feel out of control.

In June 1988 I had a stroke. First thing in the morning I tried to get up and fell on the floor. I tried to call out - my parents stay the weekend. When my mother came to me, I tried to tell her what had happened. Only strange sounds came from me. I see her mouth to move but I did not understand her. It felt like a veil in front of me, a speed up film. I tried to walk and it felt like very bad cramp. I did not feel my right arm. I felt so frustrated, confused and anger creeped with me.

My inner thoughts were felt so very alone. My family and friends reach to me to try ways to communicate. I picked up that they felt helpless and mixtures of feelings - worry, bewildered and anger too. My friend told me by writing down that I was saying only 'miff'. I did not monitor my language at all.

Later, lots of questions for me. Why I could not follow talking? Why I could follow rhythms but not words of songs on the radio? Why I knew to speak only short words? Why not able to read newspapers and books? Why I draw but not write sentences? Why to print and not to use my handwriting? I had to fight this ordeal with truth.

I explore within and try to communicate with others. I tried to keep be in touch: caring, social concerns, being creative, painting, nature, good food and music. So enjoy classical music now, more than before the stroke. Listen more attentive re rhythms and sounds.

I had speech therapy for about 2 and half years. Crucial for me but I couldn't do any more for the moment. Maybe later. It slows right down because first on I got leaps. We break up this and then this and crack a word. I remember 'banana', it took me ages to practise it. Then one day I thought, 'I can say "banana".' It was a wonderful feeling. That was very clear, concrete, successful but later it was more complex.

I understand more about my problems with language now. I enjoy talking perhaps even more than I did before. I have more pause and, if I don't, I have more errors. I haven't lose my excitement in me and if I get excited I make more errors. It doesn't worry me but it is embarass to other people at times. It depends on who they are with me. I do get fed up a few people make jokes of language to me. I irritated for people to take it up. It is difficult. Sometimes I want to laugh with them at my errors and sometimes I am not in the mood. And they do understand what we are going to talk about, there is enough information and communication. Why do they have to pick it up? If a person is with somebody with aphasia that person should say if they don't understand, like you would anyone else. That's respect. But people who correct you in the middle of you speaking, they make furious. They shut you up. If people knew what I am trying to say well enough to correct, why bother? What are they doing putting on a model perfect standard language? None of us use grammatic correct all the time. People do not talk like that, so why correct people with aphasia? For my friends I don't worry at all but with the public way, like when I have to write letters, I am very aware of my limits.

My language has changed but not how I use it. Like before, I use it to match my feelings, to analyse. I go for meanings, understanding. Language like tools. People like to be with me to chat out their feelings. But many people use language to convey what happened. Description. I have not been a concrete person. Maybe that is the hardest bit for me now, to concrete descriptions, to look it, the concrete. How things working, practical stuff. I find it hard to plan. Harder now but I don't think I have changed for language.

I usually get news from TV now. I don't buy papers. Only sometimes flick through them. Reading is still hard and less pleasure than before. So frustrating: means me cut off to learn knowledge. Belong in my private word, . . . world. Miss reading novels. Catch expression and inner feelings, more like poetry. A big loss. Last evening I tried to read again *Lord of the Rings* but I cannot read in the evening. I so weary and ache. I can't follow poetry, understand puns and symbolism. I complain I lost poetry. My friends say I tapped on some new poetry, my own poetry.

When tried to read what I had written, I found it so hard with my raw errors. Same when I tried to read my first draft of essay or chapter. I could read second 'correct' versions not too bad. This makes me think reading and writing processes separate within the brain. Part of my brain - my memory - knows the rules of reading and barks at errors.

I have feeling that I want to write. So difficult the mechanics re writing: translate thoughts to words, put together with grammar, forgetting the right spellings, haltering to express the right climate. Haltering words and hearing out aloud to write down - then I forgot the thought!

Now allow me to write more flowly, direct with errors and feel more freer. Have a space, a challenge, to communicate the deep issues. With speech therapist, more rules and practice, focus on my grammatical structure and spelling. I need that way too and attend my resistances to learn again. Without my therapist's persistence, her humour, her gentle and strong demands I would not able to write enough to communicate my thoughts now. I have always find writing helpful to sort thoughts, reflect, put to perspective. So glad I can able writing enough to communicate. Unable to write would be powerless and more lonely. Yes, mine not good grammar but alive. What the phrase, more effective at the pen and not the sword . . . ?

Aphasia research is a big issue. I believe research back to people. Good to communicate sharing issues with others. Feel less vulnerable somebody wants to hear the difficulties and learn together. Gave me feedback, insight and debate. But some research I not sure how help and educate 'patient'. Partly they don't know and partly is complex. If not sharing to the 'subject', perhaps not real good education and learning. To emphasize on my errors perhaps to miss on my real communication skills. Who to say if learning or not?