

WEBWORDS 18

Aphasia

Caroline Bowen

Purring along

Are you brainy? I expect so. Communicative? Of course you are. Do you know why you can read this? Correct: the language centres in the left hemisphere of your brain are purring along nicely. Truthfully now, do you think you could write a better intro than this? I see, good self-esteem then. Any signs of depression? What, none? And you enjoy playing with words, don't you? Yes. Right handed? Same.

What happens if we brainy, knowledgeable, confident, critical thinkers, communicative, literate, opinionated, optimistic right-handers have a stroke¹, a bad hit on the head, a tumour, a gunshot wound, or some other trauma to the left side of the brain, and the injury damages our language centres? Nearly all of us will get aphasia², that's what. And about half of all left-handers will too.

Wham!

The incidence of stroke, which can of course happen at any age, increases as we get older. The risk doubles each decade after 55, with about 72 per cent of strokes occurring after you turn 65. Makes you think. Just as you're reviewing your life achievements and settling happily – or perhaps under protest – into the big retirement plans, WHAM!

If it happens to us, we will still be a brainy lot, still have opinions, knowledge, attitudes and preferences. But our capacity for communication through speaking, listening, reading and writing will be impaired, the probability that we will experience depression³ will increase dramatically, and our lives and how we and others view them, and our perceptions of ourselves, will have changed. A lot. We might want to, *if we could*, write about our experiences.

What would he say if he could speak?

The Internet abounds with first-hand accounts⁴ of stroke survival⁵ by people with both left⁶ and right⁷ hemisphere lesions. Those that focus specifically on aphasia⁸ promote a range of reactions. Sheer outrage is the immediate response to stories that betray a heavy, patronising or exploitative editorial presence.

Bev's poetry⁹ and Bil's story¹⁰ have an authentic ring to them, but elsewhere on the web there is sometimes a sense that a poem, story or quotation is being imposed on the purported "author" by someone with superior writing skills, or by someone with a condescending air of, "What would he say if he could speak?" As well, one is frequently left with the feeling that something has been posted to the net without the person behind it really understanding what that means in terms of personal disclosure.

It's definitely not all bad news, however, and some of the best material on the net is home grown in client advocate and support groups in South Australia¹¹ and Queensland¹².

Australian stories

Devoid of literary device, and somehow the more powerful for it, are the simply expressed stories of David, Bunt, Betty,

and others of the Talkback Association for Aphasia in South Australia, and Gordon and his associates from the University of Queensland Aphasia Groups.

By contrast, the adjectives flow in author Penelope Nelson's personal and eloquent memoir¹³ of her father, wordsmith and journalistic legend David McNicholl, and his experience of aphasia.



Family

In keeping with contemporary thinking about life participation approaches¹⁴ to aphasia therapy, identity-based therapies¹⁵, and person-centered practices¹⁶ both the Queensland and the SA sites, and the Nelson article, are as much about family¹⁷ members as they are about the people with aphasia. Clive's story, for example, is illustrated by him and written by his wife, Carol. Without falling into the trap of hijacking his identity, she writes, "Dreams are something that for the past 10 years both Clive and I have worked so hard towards. They are imperative to our survival!"

Aphasia-friendly

What is so impressive about the SA and the Queensland websites is their serious, and largely successful dedication to making the web experience for their visitors aphasia-friendly. The Queensland site provides a free Internet training package for people with a communication or literacy disability, listing the four main features of an aphasia-friendly website, which

are: to write in simple words, using big print; to use lots of white space; to use pictures to help explain the words; and, to allow more time to read.

Simple? Not really. Guidelines such as these pose very real hurdles for web developers who still have to produce attractive looking, high quality, well-designed pages that will engage visitors' attention, look good in any browser, and at the same time incorporate an effective and intuitive navigation structure. No mean feat.

Resources for clients and families

At a local level in the UK the [Interact Reading Service](#)¹⁸, whose patrons are Sir Alan Ayckbourn, Alan Bleasdale and Richard Briers, provides a live and interactive reading service, provided by over 120 professional actors, for people in Britain who have had strokes. More internationally, many people with aphasia participate in the listservs <http://groups.yahoo.com/group/Aphasia/> and <http://health.groups.yahoo.com/group/strokesurvivors/>.

Resources for students and clinicians

According to Sally Byng¹⁹, "clinicians are often left to deal as best they may with complex, distressing, interdependent, and sometimes impenetrable effects of aphasia." So it's good to know that the Internet has much to offer practitioners looking for [books](#)²⁰, [software](#)²¹, [historical](#)²² and [up-to-date](#)²³ information about [clinical aphasiology](#)²⁴, the latest aphasia [research](#)²⁵, practical guidance such as the paradoxically titled [how I run an aphasia self-help group](#)²⁶, as well as the abundance of journal articles, online discussions, listservs and networking opportunities available to [ASHA](#)²⁷ members and affiliates.

Congratulations

Speechwoman's Site of the Month for June 2004 is the [Talkback Association for Aphasia Inc](#)¹¹. Congratulations Clive and Carol, David, Bunt, Grant, Betty, Marilyn and friends.

A CONSUMER SPEAKS

"Sam"

"Sam" is a pseudonym. Sam first came into contact with speech pathologists in 1999, after a left parietal stroke, resulting in mild expressive aphasia. Unfortunately, Sam had another stroke in 2002, causing a moderate receptive and expressive aphasia. Sam shares his experience following his second stroke. Sam was contacted by Jane Arnold, speech pathologist at the Gold Coast Hospital.

My second stroke was strange because I woke up and my talking was all muddled. At first I was very scared and upset that I could not communicate. When I looked around at the other guys in the ward, I saw strokes did different things. I could move my arms and legs and even today my walking is alright. I did find some things easy – like washing my hands, brushing my teeth and combing my hair. These were things I normally could do.

When I was in Gold Coast Hospital, I had speech therapy every day. Slowly, my words started to come back. This was a huge relief.

Links

1. <http://www.asha.org/public/speech/disorders/Stroke.htm>
2. <http://www.nidcd.nih.gov/health/voice/aphasia.asp>
3. <http://www.clinicaltrials.gov/ct/show/NCT00071643?order=23>
4. <http://www.ukconnect.org/com-dis/index.html?stories>
5. <http://www.strokesurvivor.org/>
6. <http://www.ralphrobertmoore.com/strokeinformation.html>
7. http://www.asha.org/public/speech/disorders/right_brain.htm
8. http://www.asha.org/public/speech/disorders/Aphasia_info.htm
9. <http://www.bbryant.com/poetry.html>
10. <http://www.tbihome.org/members/bil/index.html>
11. <http://www.aphasia.asn.au/aphasiafriendly/index.htm>
12. <http://www.shrs.uq.edu.au/cdaru/aphasiagroups/index.html>
13. <http://www.abc.net.au/rn/talks/lm/stories/s746690.htm>
14. <http://www.asha.org/public/speech/disorders/Life+Participation+Approach+to+Aphasia.htm>
15. http://www.acsu.buffalo.edu/~duchan/identity_based_therapies.html
16. <http://www.reachoflouisville.com/person-centered/person.htm>
17. <http://www.asha.org/public/speech/disorders/Family-Adjustment-to-Aphasia.htm>
18. <http://www.interactreading.co.uk/>
19. <http://www.afasie.nl/conference/byng2/>
20. <http://topics.practical.org/031546/031624>
21. <http://www.propeller.net/react/>
22. <http://www.afasie.nl/conference/ronprins/>
23. <http://www.afasie.nl/conference/>
24. <http://www.clinicalaphasiology.org/>
25. <http://www.nidcd.nih.gov/health/voice/adultaphasia.asp>
26. <http://www.speechmag.com/archives/shelp.html>
27. <http://www.asha.org/default.htm>

When I went home, I had to come back to see the speech therapists. I still had problems with my talking. I knew what people were saying but I couldn't get the words out even though I knew what was what. I still have problems with writing. I can spell small words but bigger words are hard. Sometimes my talking is quite good and then other days, it's all ... wrong. The stroke also affected my brain so I can't read music anymore. You miss it when you can't do it.

After the second stroke, I had four therapists and each one seemed to have a different way of tackling the problem. Speech therapy is a lot of hard work and I had a lot of homework to practise. It has helped me and when I think about the early days [before the stroke] there's no comparison.

I still find speaking with confidence very difficult. When there are one or two people that's alright but when it's a bigger group, I don't say much – I listen to what they say.

I am very grateful for the speech therapy I have had at Gold Coast Hospital. I know it has been a big help to me. Thank you.