

Aphasia Insights!

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“However, it is essentially to support the involvement of people with aphasia in this work from a position of equality with *meaningful* rather than tokenistic involvement (Pound, 2013; McMenamin, Tierney & MacFarlane, 2015; McMenamin & Pound, 2019). Researchers and co-researchers with aphasia should work collaboratively to co-design and co-evaluate aphasia awareness campaigns that will positively impact the lives of people living with aphasia around the world (pp. 464).”

Beyond the statistics: a research agenda in aphasia awareness. Simmons-Mackie Nina, Worrall L, Shiggins C, Isaksen J, McMenamin R, Rose T, Guo Y, Wallace S. *Aphasiology*, 34:4, 458-471 (2020).

Aphasia Nation, Inc. is committed to educating the wider public about stroke and aphasia and the “*Aim High for Aphasia!*” international Aphasia Awareness campaign.

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Raising Aphasia Awareness: We Can't Keep Preaching Just to the Choir!

By Tom Broussard, Ph.D.

It is an interesting conundrum and difficult to describe. Although every hospital staff knows what aphasia is, the problem is that most staff (unless you are a speech therapist) don't use the word *aphasia* when talking with a person *with* aphasia or their family.

I had my stroke in 2011 and stayed at the hospital for six days. I was admitted on a Monday and “woke up” on a Wednesday without knowing why I was there. I didn't know what was wrong with me and just wanted to go home.

The nurses told me that I would go home eventually but needed to rest first. But I was told that I could walk around the floor as much as I wanted, and I did. As I looked at other patients on the floor and saw their deficits (unconscious, trauma from car accidents, wheel chairs, and crutches), I wondered why was I still there? After looking at the other patients, I studied my arms,

legs, and face looking for any problems that had kept me there.

The only thing I could think of was that something must be wrong with my brain. I started looking out the windows at clouds, cars, people, planes, and buildings, and started talking to myself. I knew what I saw but was having trouble finding the words I was seeing. I realized that something must be wrong with me.

I saw the staff speech language pathologist on Thursday that week,

not that I remembered it but because my wife told me later that I had met her. I saved the notes from that



Preaching *new* messages
to *new* choirs

conversation and read it a year later. The notes indicated that I was having problems communicating with this thing called aphasia.

I was discharged with a one-page description of a list of “typical problems” that included aphasia, cognitive-linguistic disorders, dysphagia, language, dysarthria, verbal apraxia, and voice disorders. I went home with nothing about aphasia (other than that one page) until my first speech therapy session a month later.

It was only later when I realized that many hospitals' staff *do*

discuss stroke but *don't* discuss aphasia although 25-40% of their stroke patients *have* aphasia. It takes a long time for the brain to “settle down” after a stroke and begin the process of recovery. The problem is that while waiting for speech therapy to begin, neither the person with aphasia nor the family are provided with any information about aphasia, in my case, at their discharge.

My daughter came to see me a week before my formal speech therapy started. She created a variety of language and memory tools of letters, numbers, flashcards, cartoons and toys. I worked with them for a week before starting therapy and brought my tools with me. It turned out that some of my “tools” were almost identical to the materials that the therapist provided.

I was lucky to have a daughter (a PhD researcher) who used the “waiting” time to our advantage. But absent that serendipitous occurrence, families need to be provided with a stroke/aphasia primer from the beginning, long before any formal therapy starts.

I talked with my PCP (primary care physician) recently on a TeleMed call. He asked me what I have been doing. I told him that I donated a half dozen copies of my fourth book, *The ABCs of Aphasia: A Stroke Primer* to his hospital and explained the problem about the dearth of aphasia awareness in the country and especially in the healthcare and hospital communities.

I told him about his hospital (he is also a board member) that there is *no* information in the hospital's website about aphasia. If you enter “aphasia” in the search, you get, “No results”.

Working with stroke and aphasia survivors, doctors and nurses will often refer to them as having “communication problems” with no mention about aphasia. The language (and lexicon) of aphasia includes a lot more than just problems talking!

When my doctor heard about the missing information about ‘aphasia’ in his hospital's website, he was appalled and wanted to know why. I told him it is a public and healthcare education issue, among other things.

It took years for the healthcare community to develop the HIV/AIDS lexicon that was needed to educate the population about the issues and linkage between HIV and AIDS.

The missing educational linkage between stroke and aphasia have the same siloed problem. We can't keep preaching just to the choir. We must enlist new voices and preach to new choirs with a new message!

In an analogous way, most of the public knows a lot about stroke today. They have been educated about the prevention, causes and risks of stroke. Yet few know much about aphasia.

Sadly, many healthcare providers including large, well-informed hospitals do not provide *any* information about aphasia *even at certified comprehensive stroke centers!*

The leadership, staff, nurses and doctors at every healthcare provider and hospitals are the new choir and need to be educating *about* aphasia from the perspective of a person *with* aphasia doing the preaching.

Signed: *The Johnny Appleseed of Aphasia Awareness*

Citations:

Beyond the statistics: a research agenda in aphasia awareness. Simmons-Mackie Nina, Worrall L, Shiggins C, Isaksen J, McMenamin R, Rose T, Guo Y, Wallace S. *Aphasiology*, 34:4, 458-471 (2020).