

Aphasia Insights!

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“We are culturally programmed to view the world from our own ... perspective. This makes us blind to our own culture.

Just as fish can't see water, leadership teams from the same nation as the company ... may struggle to see when a potentially derailing cultural dynamic is at play.”

Fish Can't See Water, Kai Hammerich & Richard D. Lewis, John Wiley & Sons. Ltd, 2013. United Kingdom.

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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Aphasia Awareness: *Fish Can't See Water and Hospitals Can't See Aphasia.*

By Tom Broussard, Ph.D.

I had an ischemic stroke and was lucky enough to get the clot buster drug within the three-hour limit on September 26, 2011. I was discharged to home six days later from a Level 1, Comprehensive Stroke Centered Hospital and was assessed as having aphasia.

But most people with a stroke/aphasia don't know what they don't know, and I certainly didn't know anything about aphasia.

It took me a couple of years to really *see* aphasia myself and began to notice that many hospitals can't *see* aphasia either. Stroke centered hospitals need to educate aphasic patients and their families about aphasia *while still at the hospital!*

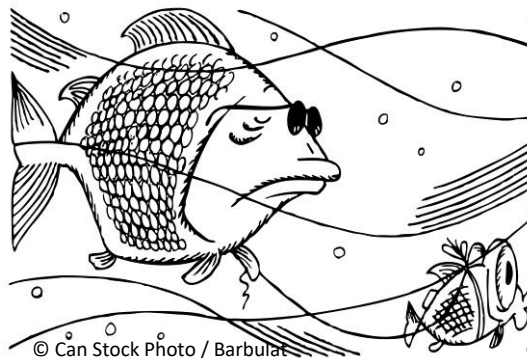
Why?

Because stroke centered hospitals only treat the *physical* injuries of a stroke. Once the stroke patients are medically stabilized, they are discharged as quickly and safely as possible with about a third of stroke patients discharged to inpatient specialized facilities and the other two thirds discharged to home (Shipley et al, 2019). This leads to two connected problems.

First, since stroke centered hospitals assume that people with aphasia will be treated somewhere else, the hospital staff won't *talk* about aphasia with a person *with* aphasia, although they still have those very same patients under their care.

Second, after a patient is discharged to home pending rehab, it can take months before being admitted to an outpatient facility. A person with aphasia will wait without yet knowing that she/he actually *does* have aphasia. If the hospital's staff can't tell me (or more importantly, my family) about aphasia *before* I am discharged, who can?

One problem exacerbates the other. The fact that 25-40% of a hospital's own stroke patients have aphasia and aren't told about it, is a



travesty. That is not to say that they weren't told about it, but once isn't enough. Repetition is key, and starting therapy early is paramount to aphasia recovery.

I had just one "conversation" about aphasia the entire time I was at the hospital and that was with the speech-language pathologist (SLP) who did my assessment.

Thank goodness I saved everything from my hospital room when I left and that included two sheets of scrap paper. There were a number of words in my own handwriting that were scratched out, lined out, and misspelled. Among other words were "BRANDEIS" and "REBECCA." (The name of the SLP was "Rebecca." She left her business card on the table.)

But other than seeing the SLP, there was no mention of the word "aphasia" by the staff, nurses or doctors while I was there, and certainly there were no materials about aphasia to be provided to me or my family.

I still had no idea of what was happening to me. After walking around the floor, I could see there were other patients whose injuries appeared to be more severe (accidents, strokes, falls,) than mine.

I kept looking at my arms, legs and my face in the mirror searching for an indication of any problems that I *could* see. After a couple of days, I figured that whatever was wrong with me had to have been something wrong

with my brain, something that I *couldn't* see.

It was much later when I came to understand that I couldn't read, write, or speak well. I just wish I had been told that from the start.

Hospital nurses and doctors should talk to us *every day* about aphasia as well as provide aphasia materials. Aphasia is a family affair that starts with the loved ones at the very start of healing and recovery.

Hospitals are incredibly good at what they do, and their staff are the healthcare heroes that we all know and admire.

The members of Aphasia Nation aren't asking for any drastic changes as much as sharing with the healthcare community the difficulties we are having months before therapy starts.

If we do that, it should provide a new perspective about aphasia to the staff with a new way of seeing things.

As people with aphasia go through the process of recovery, we can see the gaps in the continuity of care of aphasia. As a result, we can explain the needs of future aphasia survivors to the hospital staff and take aim at a target that didn't exist before.

Recently, the public has heard about aphasia through Gabby Giffords' (gunshot), Bruce Willis' (primary progressive aphasia) and John Fetterman's (expressive aphasia) language difficulties but

their types of aphasia and recovery are completely different from each other. Aphasia is so much more than just having "trouble speaking" to the millions of people with aphasia.

The hospital community (SLPs & PWAs too!) is needed to help clear the water.

They can educate the wider public about aphasia by 1) updating their websites to include all types of aphasia, 2) educating their staff, patients, family and the community about aphasia, and 3) providing materials about aphasia (e.g., *The ABCs of Aphasia: A Stroke Primer*) to the patients and family *before being discharged*.

If not, aphasia will remain blind to the needs of millions of people with aphasia as well as the wider public who can't see it either until it happens to them.

Signed: *Johnny Appleseed of Aphasia Awareness*

Shipley J, Luker J, Thijs V, Bernhardt J (2020). How can stroke care be improved for younger service users? A qualitative study on the unmet needs of younger adults in inpatient and outpatient stroke care in Australia. *Disability and Rehabilitation*, 42:12, 1697-1704.

The author is a three-time stroke survivor and aphasia. He could not read, write or speak well which took him years to recover.

He is Founder and President, Aphasia Nation, Inc., a non-profit organization whose mission is educating the wider public, national and international, about aphasia and plasticity, the foundation of all learning.

