

Aphasia Insights!

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“The majority of participants also had to wait three to six months for an outpatient clinic appointment with a physician, if they received any follow up at all.

During this time, they were left with marked uncertainty about managing post-stroke life and related the need for much earlier follow up.” pp.1700.

Shipley J, Luker J, Thijs V, Bernhardt J.

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.

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: *Updated Survey of 429 418 Stroke-Centered Hospitals.*

By Tom Broussard, Ph.D.

Aphasia Nation, Inc. has continued to update the survey and database of all stroke-centered hospitals in the US and will regularly report the scope of the problem. We have inventoried 418 hospitals so far, cataloging the stroke-centered hospital’s name, address, website, stroke certification (where possible) and whether the hospital provides any information about aphasia on their website.

Our updated results of aphasia info of the website of 418 *stroke-centered* hospitals (28 states) to date:

- 153 hospitals (37%) provide **NO** info.
- 141 hospitals (34%) provide **ONE MENTION** info.
- 92 hospitals (21%) provide **VERY LITTLE** info.
- 17 hospitals (4%) provide **SOME** info.
- 15 hospitals (4%) provide **GOOD** info.
- 0 hospitals (0%) provide **COMPLETE** info.

In summary, 386 hospitals (92%) provide little to no information about aphasia while 32 (8%) hospitals provide decent/good information about aphasia. Examples of aphasia information at hospitals surveyed in each category:

NO info: These hospitals do not use of the word “aphasia” anywhere in their website although they provide stroke treatment and include rehab and speech language

pathologists are part of treatment. Most hospitals are certified as stroke center although it can be difficult to discover their stroke

designation. It is also possible to find that the “mother” organization which can give the appearance that all the “child” hospitals are “certified” in their purview. It can take time to “drill down” on the website to find plenty of info about stroke but not a word of aphasia and no links to the National Aphasia Association (www.aphasia.org), Aphasia Nation, Inc., (www.AphasiaNation.org) or any other aphasia-related organization.



ONE MENTION info: There are often 1-5 (or more) search “hits” with mentions of news articles of rehab, speech therapy, opening new office that includes aphasia but no mention of explanations of aphasia, no direct pages in the hospitals’ website about aphasia, same article listed three times, 20 hits of doctors with no professional link to aphasia, and no links to the National Aphasia Association, Aphasia Nation or any other aphasia related organization.

VERY LITTLE info: We found many mentions of aphasia in these hospitals but only listed in the location of therapy, or news of rehab therapy including aphasia, or an intensive program but no email or call for more info or links to AHA, ASA, NAA, or no direct pages in the hospitals’ website about aphasia, or aphasia listed in other affiliated organizations but not listed hospital’s pages. There were some links to some affiliated rehab organizations and find more info about aphasia by “drilling down.”

SOME info: We have found that there are some with more info about aphasia with full sentences about aphasia or a full (but still basic) page but still without explanations, causes, symptoms, diagnoses, treatment, and recovery about aphasia. These searches can lead to wellness, rehab, physical rehab, sports rehab citations that can connect minimally to the word aphasia, and some with links but few. In all the hospitals surveyed to date, we have found out just two or

three citations and hyperlinks to NAA.

GOOD info: We have found a few hospitals variously with info and links to an Aphasia Clinic, a health library about aphasia, a community page with aphasia groups, stories, articles about aphasia, a page “What is Aphasia?” that provides explanations, causes, symptoms, diagnoses, treatment, and recovery about aphasia. One hospital provides a stroke booklet with some info about aphasia with the links AHA, ASA, and the National Aphasia Association (NAA*) plus a discharge checklist. A couple of hospitals provide stroke focused info at discharge but include very little or no info about aphasia in the materials.

COMPLETE info. There are no hospitals classified as Compete Info. It would require updating their websites to include every type of aphasia plus educating their staff, patients, family and the community about aphasia, and providing materials about aphasia (e.g., *The ABCs of Aphasia: A Stroke Primer*) to the patients and family before being discharged as well as provide Aphasia codes to be used and saved in the database/Electronic Health Records for survivor/family needs and research purposes.

Aphasia Nation, Inc. will issue a Proclamation to one hospital which excels in terms of aphasia awareness in their website and materials at discharge. It will be issued to the president of the hospital, the press, and social

media on the first day of June for Aphasia Awareness Month 2023.

Speech Language Pathologists (SLPs) and People with Aphasia (PWA) need to team up with the stroke-centered hospital’s Stroke Coordinators (SC) to help break down the barriers to aphasia awareness and educate the hospitals, healthcare providers, and the wider public about this thing called aphasia, *that few people have ever heard of!*

Signed: *Johnny Appleseed of Aphasia Awareness*

*As far as we can tell from the survey, only 3 hospitals (out of the 418) include the hyperlink to the NAA in their website. <...sigh...>

Shiple 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 that 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.

