



National Aphasia Awareness Survey

2016 Results and Findings

Presented by the National Aphasia Association



The National Aphasia Association (NAA) is a non-profit organization founded in 1987 as the first organization dedicated to advocating for persons with aphasia and their families.

Executive Summary

This “National Aphasia Awareness Survey” is the first major survey to determine the level of familiarity and understanding of aphasia in the United States. People with aphasia and their caregivers consistently report to the NAA that they confront not only a lack of awareness of aphasia, but also a lack of understanding of the condition. This anecdotal evidence was confirmed by the survey with a strikingly low aphasia awareness number: only 8.8% of respondents had heard of the term aphasia and correctly identified it as a language disorder. These are the respondents that we have identified as “aphasia aware”.

A large number of people do not encounter the term aphasia until they, or someone they know, is diagnosed with it. Of those respondents who were “aphasia aware”, 34.7% either knew someone who had aphasia or had the condition themselves.

Closing this “aphasia awareness gap” is one of the goals of the NAA. Along with affiliate partners, the NAA will continue to raise awareness and educate the public about the signs, symptoms and impact of aphasia.

Another result from this survey was that 30% of respondents did not disagree with the following statement: “If a person has difficulties with speech, they also have intellectual deficiencies.” The prevalence of this idea can make interactions between people who have aphasia and those who are not aphasia aware particularly challenging.

The NAA and its affiliates have been working hard to increase awareness of aphasia. These results show that there is still a lot of work to be done in educating the public about this often misunderstood condition. The people hurt most by the lack of awareness are the people with aphasia and those who care for them.

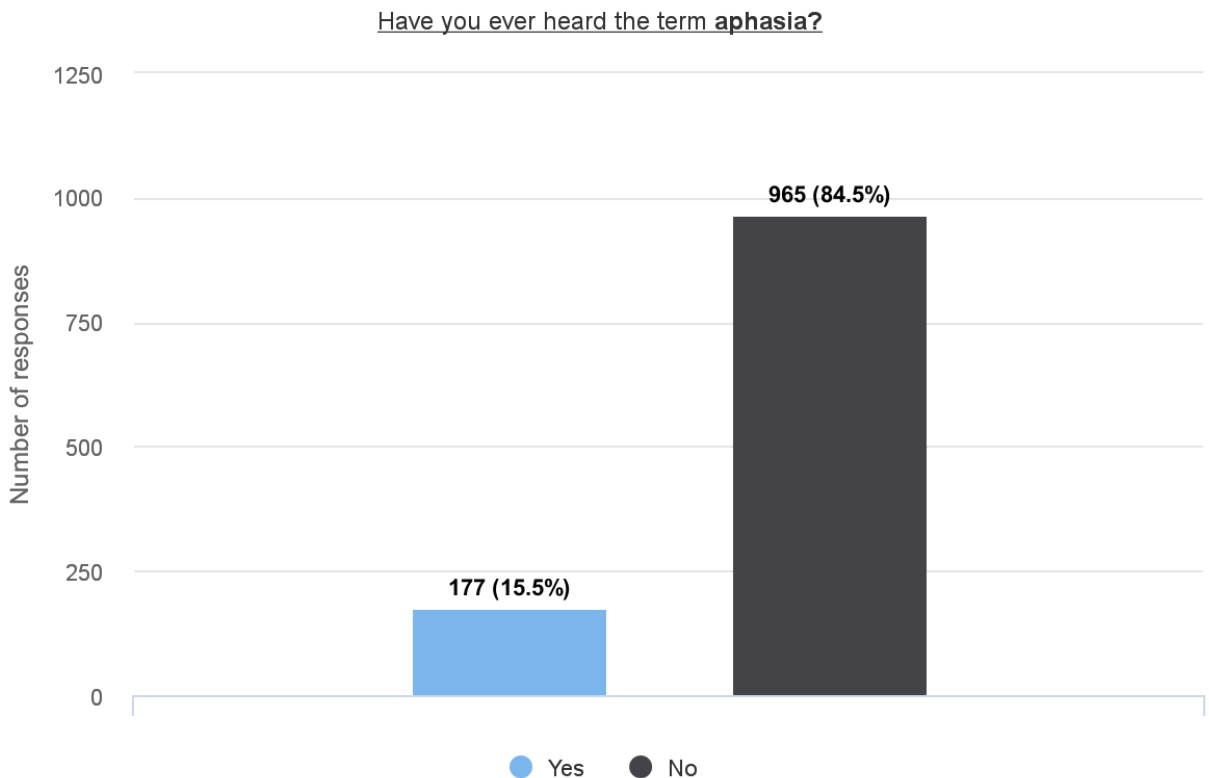
Methodology

This survey was commissioned and designed by the NAA and conducted by Survata, an independent research firm in San Francisco. Survata surveyed 1142 online respondents between October 18, 2016 and October 19, 2016. Respondents were reached across the Survata publisher network, where they take a survey to unlock premium content, like articles and ebooks. Respondents received no cash compensation for their participation. More information on Survata's methodology can be found at survata.com/methodology.

The data from this survey is meant to be representative of the U.S. population ages 25 and over with a 3.1% margin of error. The raw data for this survey is available for download at aphasia.org/survey. The data is free to use and share with attribution to the "National Aphasia Association 2016 Aphasia Awareness Survey".

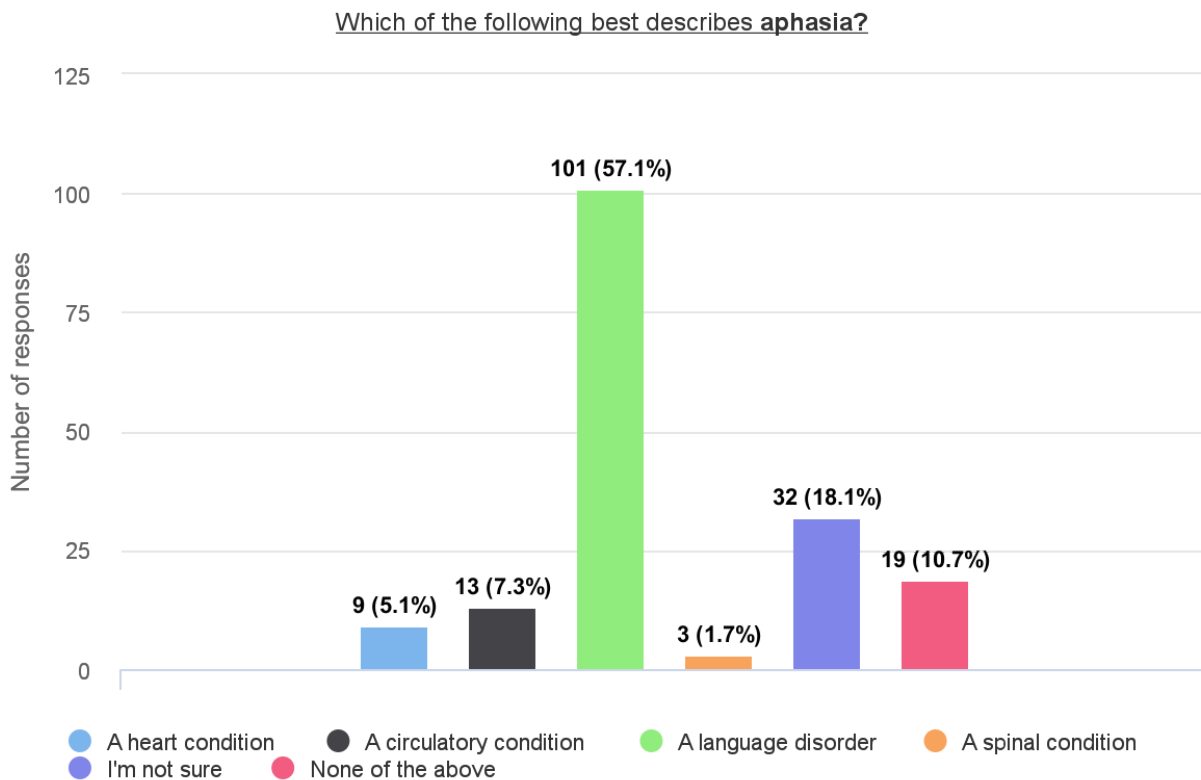
Key Findings

84.5% of respondents have never heard the term "aphasia"



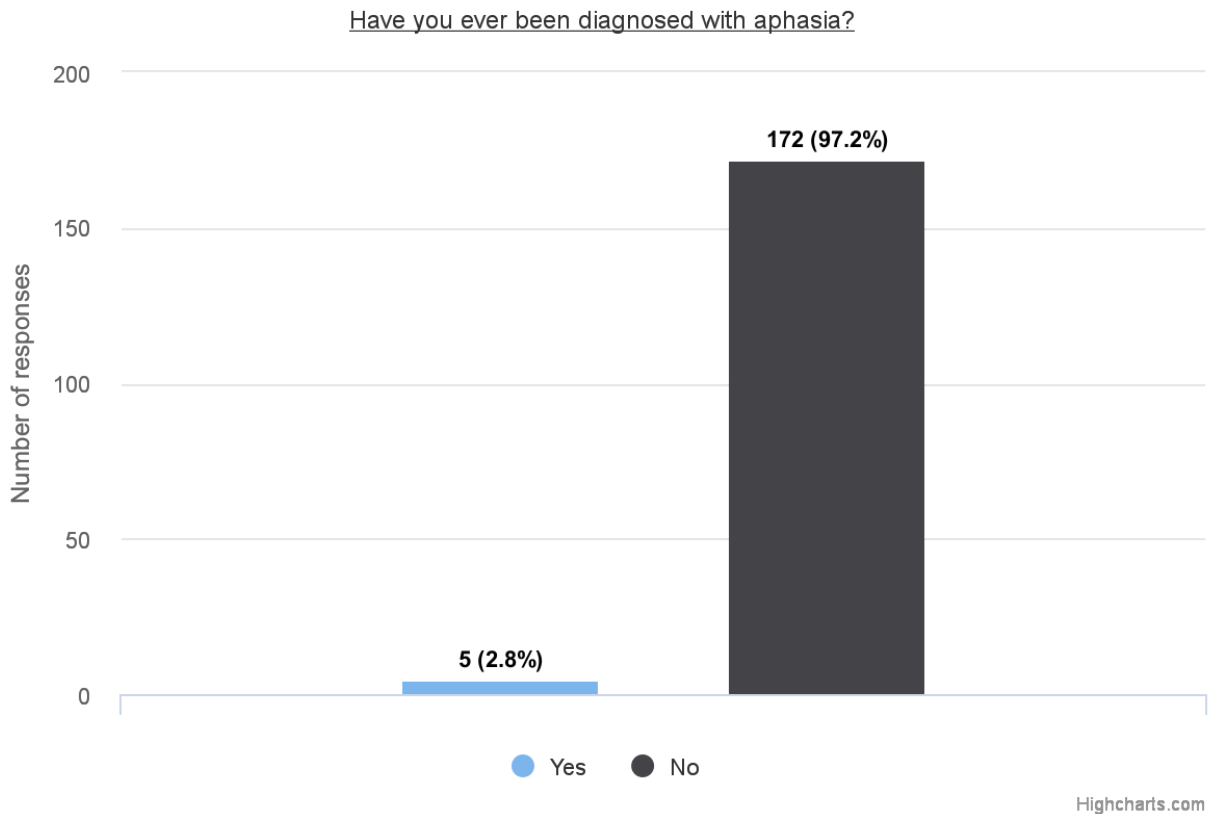
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The 15.5% of respondents who had indicated that they had heard the term aphasia, were then directed to answer another question to qualify their response. The goal of this follow up question was to make sure that we are not just measuring familiarity with the term *aphasia*, but awareness of the condition. The following question asked respondents to pick a choice that best describes aphasia.

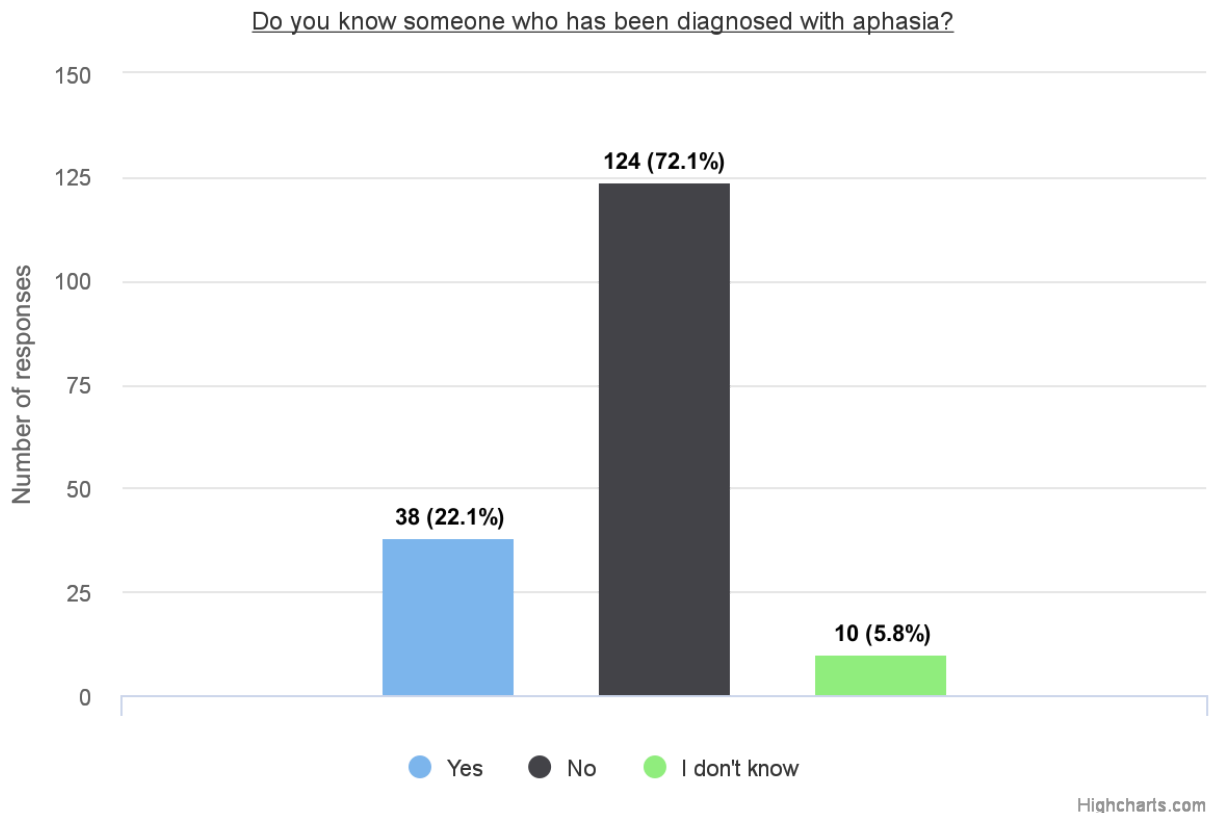


The portion of the 15.5% of respondents who further correctly selected aphasia as a language disorder are those that we are considering “aphasia aware”. 101 respondents, or 8.8% of the total 1142 respondents, made the correct selection.

2.2% of respondents self identified with having been diagnosed with aphasia.

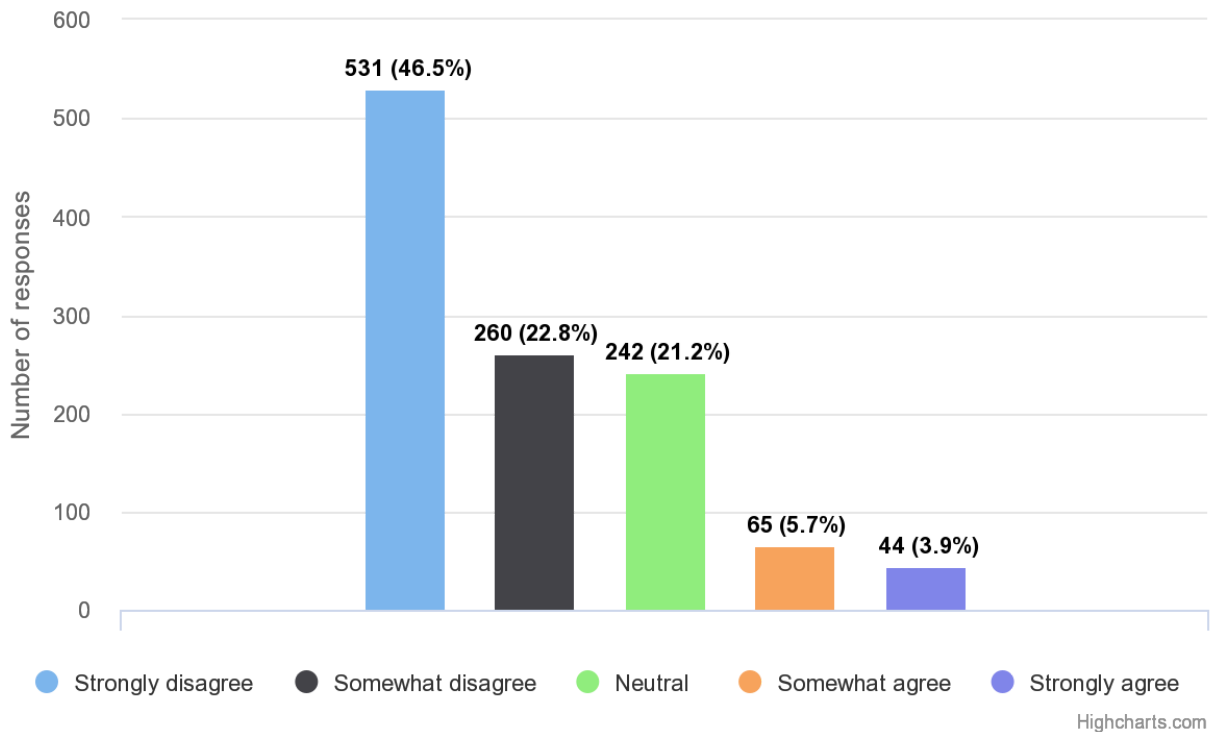


The graph above is slightly misleading, because one of our respondents identified as having aphasia, but incorrectly identified it as a heart condition. Removing that response, we see that 2.2% of our respondents reliably self-identified with having been diagnosed with aphasia.



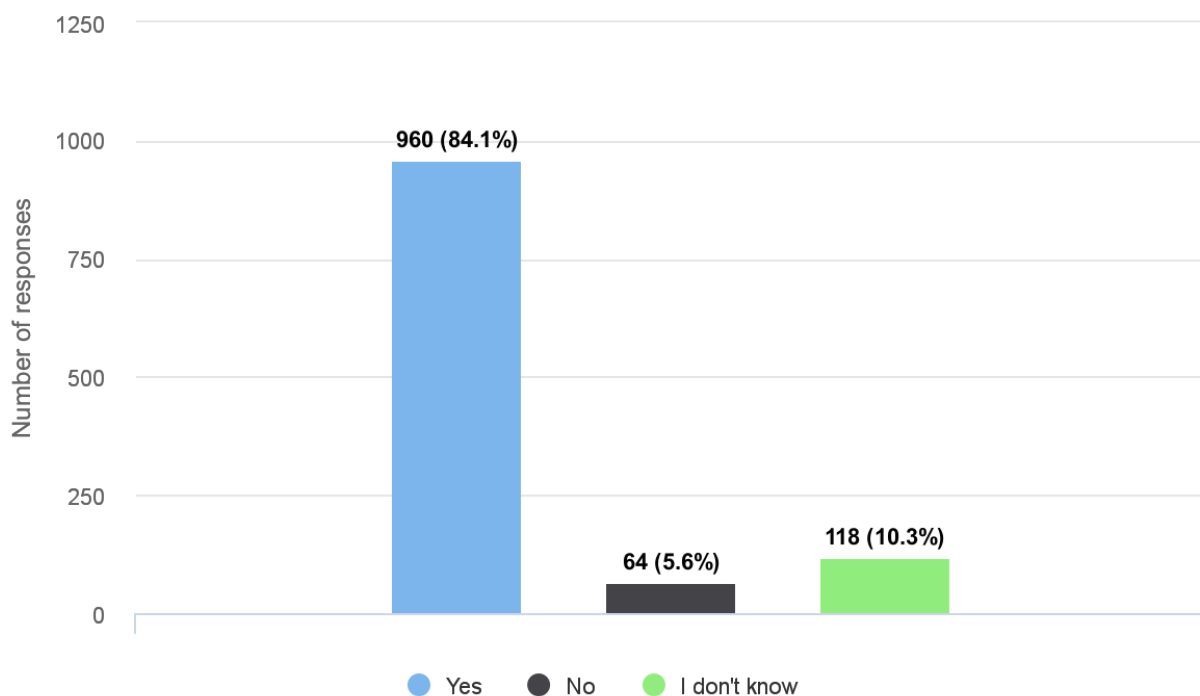
The 38 people who replied yes to this question, together with the 5 who identified as having aphasia, resulted in 43 of our respondents who were familiar with the term aphasia due to a personal experience of it. After cross tabulating the data to eliminate people who did not correctly identify aphasia as a language disorder, that number was reduced to 31 for this question and 4 for those who said they were personally diagnosed with aphasia. 35 people is a 34.7% of the 101 “aphasia aware” respondents had aphasia or knew someone who did. Clearly, a very large number of people who are aphasia aware are hearing about it from direct personal experience.

To what extent do you agree with the following statement?
If a person has difficulty with speech, it means they also have intellectual deficiencies.



Approximately 31% of respondents agreed or gave a neutral response to the statement: "If a person has difficulties with speech, it means they also have intellectual deficiencies". A significant number of people strongly correlate intellectual capacity with speech ability. It is heartening to note that a large majority - 79.3% - of our respondents disagreed (46.5% strongly) with this statement. There is a large chunk of the population that can separate speech ability from intellectual capability.

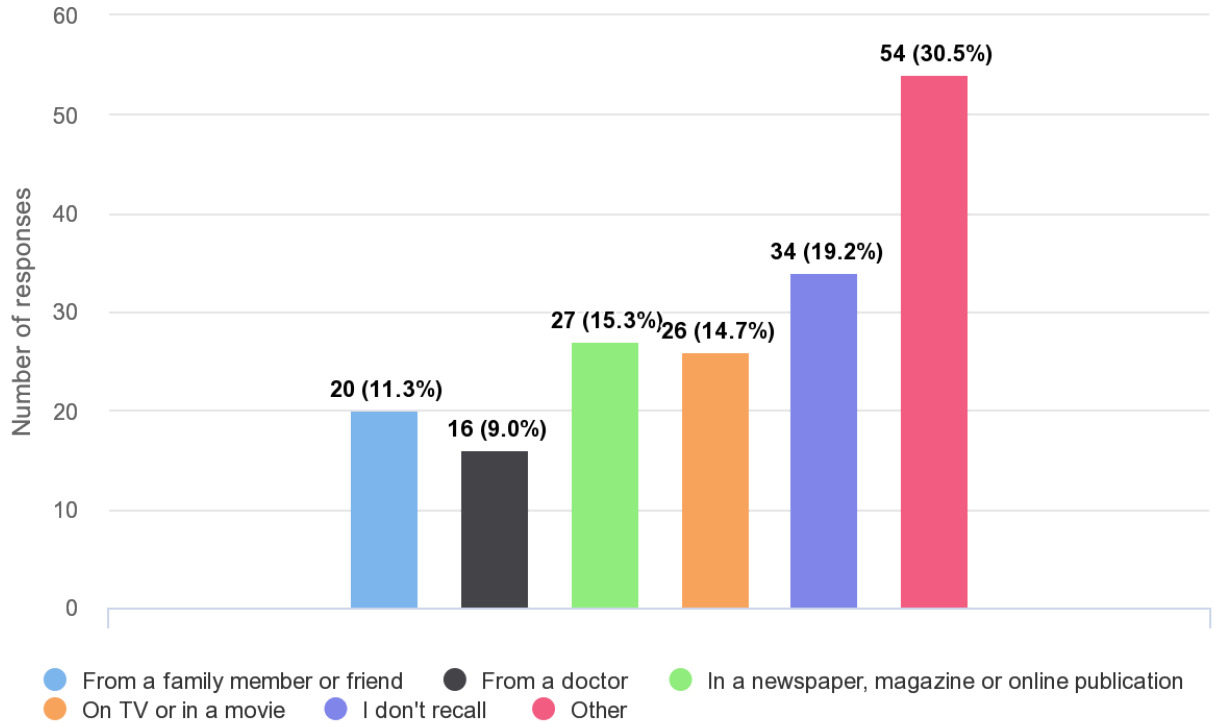
Is it common for a person who has had a **stroke or brain injury** to have difficulties with speech and communication?



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84.1% of respondents made a connection between stroke and brain injury, and difficulties with communication. But, as we saw in earlier questions, the overwhelming majority of respondents (91.2%) does not properly connect problems with speech to the term “aphasia”. This can be interpreted as an indication that there is awareness of speech issues that are connected with brain injury and stroke, even though the respondent is not capable of defining it as aphasia.

If you can recall, **where** do you think you first heard about aphasia?

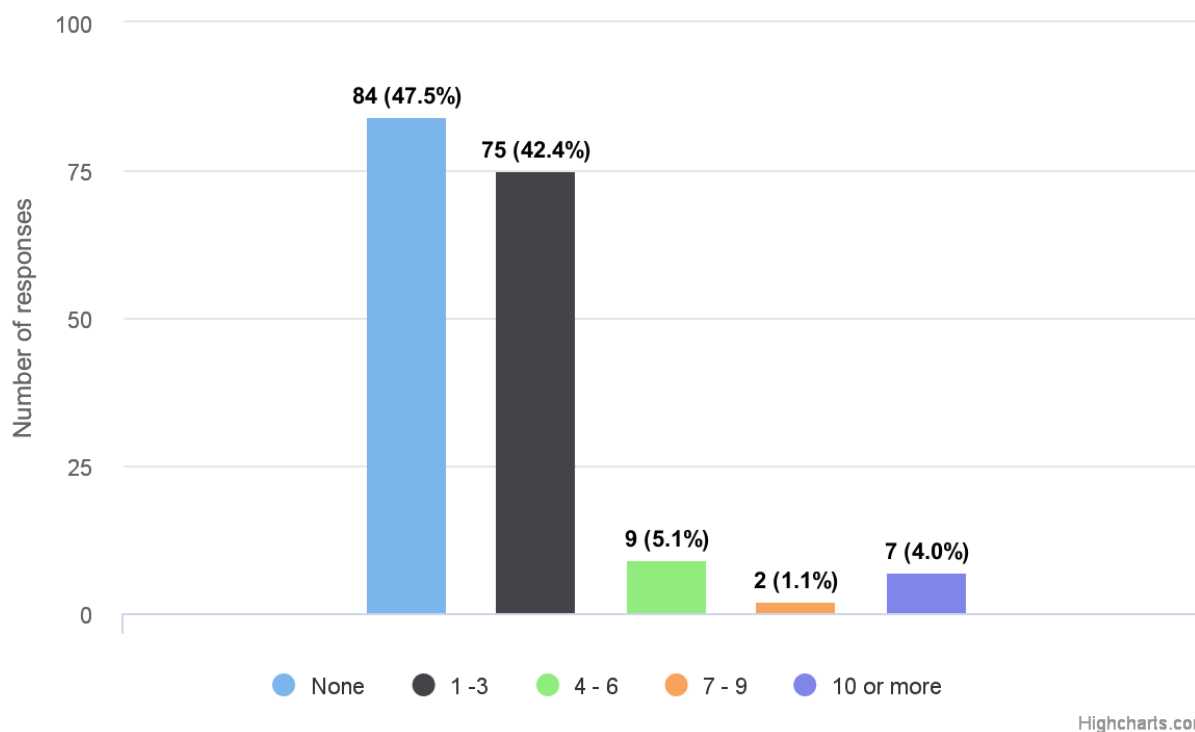


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Newspapers, magazines or online publications were listed as one of the most common ways that people remembered first hearing about aphasia. Outreach to traditional media outlets as well as digital media with accurate information are very important for raising aphasia awareness. This was closely followed by television or movies.

On the next page is a word cloud that depicts responses as well as the frequency (the larger, the more common) written into the "other" category.

In the past year, how many times have you seen or heard mention of aphasia in a newspaper or magazine (paper or online), on TV, or on the radio?



In the past year, 93 of the respondents who had heard the term aphasia recall seeing or hearing mention of aphasia in a newspaper, magazine(paper or online), on TV or on the radio at least once. That's 52.5% of the 177 who had identified as having heard of aphasia.

Conclusion

This first reported aphasia awareness level of 8.8% is low. We hope that these results will help galvanize people to become aphasia awareness advocates and to reach out to their communities and their networks to help spread the word and educate more people about this condition.

What can you do?

- Share this survey - or highlight infographics - with your friends and across your social networks
- Talk about aphasia with those who don't understand it
- Get involved with your local aphasia group - or start one if there isn't one in your area
- Run a race! #aphasia
- If you are a speech professional, become an NAA affiliate and get a listing in our national directory of services at aphasia.org/affiliate
- Reach out to your local media (newspapers, magazines, TV channels) with potential stories and news about aphasia, especially during the aphasia awareness month of June
- Stay updated on aphasia news and current events by signing up for the NAA's newsletter via our website at aphasia.org and share with others via your social media channels
- Donate to the NAA at aphasia.org/donate or to your local aphasia center

We have a number of resources for people with aphasia, caretakers or professionals who work with people with aphasia on our website at aphasia.org. Please feel free to share these resources far and wide.

If you'd like the raw data set, you can download it on the survey report website at aphasia.org/survey.

If you have any questions about this survey, please reach out to us at naa@aphasia.org.

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