



THE 2020
**Aphasia
Caregiver
Report**



An aphasia diagnosis can be one of the most devastating things to happen to someone who survives a stroke or traumatic brain injury. In an instant a person can lose their ability to comprehend and use language.

Though varying, the impact of aphasia on these individuals is well documented. Social isolation, anxiety, anger, loss of identity, deterioration of interpersonal relationships, and depression are common.

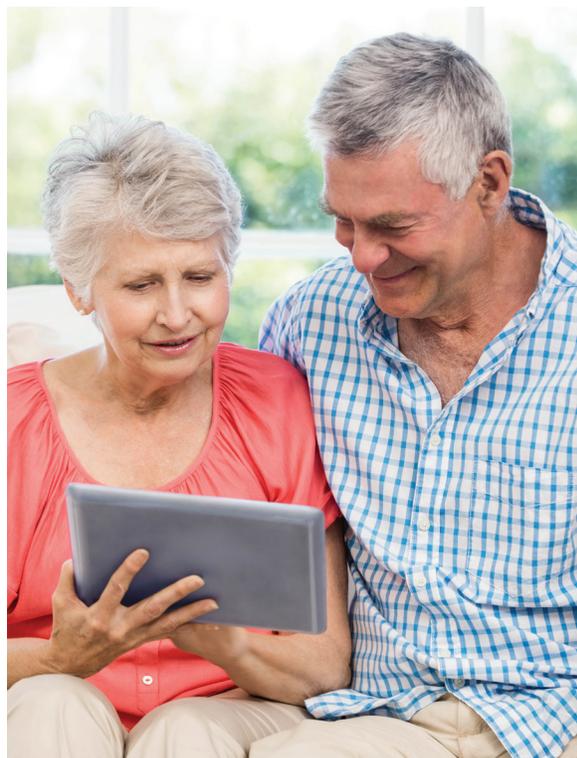
What is less understood is the impact of aphasia on caregivers.

REPORT OVERVIEW

The 2020 Aphasia Caregiver Report provides a never-before-seen look at the individuals who care for someone with aphasia. The survey that underlies this report was conducted across three weeks in September of 2019 and elicited responses from a total of 733 caregivers of people with aphasia. We believe it is the largest contemporary survey in circulation.

These individuals go by several names and titles: caregiver, care partner, communication partner, co-survivor, wife, husband, child, sibling, and so on. They come from all different walks of life, reside in different geographic regions, and have diverse backgrounds. Yet, they are all bound together by this common thread: their lives were irreversibly changed when someone close to them acquired aphasia.

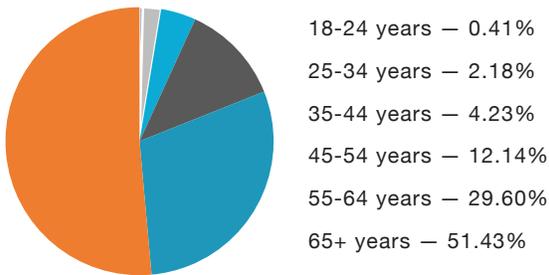
This report highlights mental, emotional, and physical changes they've experienced, how their relationships with others have changed, and the biggest challenges that they face. We also learn how much of their daily lives are spent caregiving, their most common support activities, and their biggest motivations for being caregivers. Finally, we highlight key resources that we believe will be beneficial for all caregivers of people with aphasia.



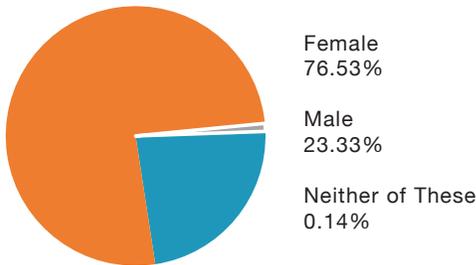
KEY DEMOGRAPHICS

Below is basic demographic information about the 733 caregivers of people with aphasia who responded to the survey.

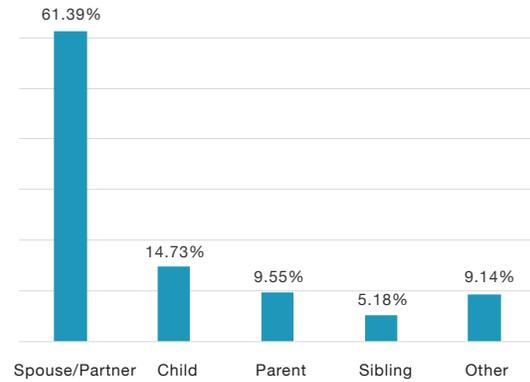
What is your age?



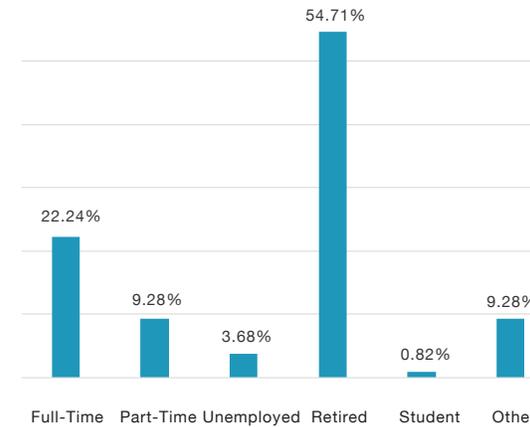
What is your gender?



What is your relation to the person with aphasia?



What is your work situation?



BY THE NUMBERS: A Closer Look at Caregivers

65+

Caregivers of people with aphasia tend to be older adults. Over half of all respondents indicated they were 65 years of age or older. Additionally, close to 82% are age 55 or older.



Perhaps this is not surprising given that the most common cause of aphasia is stroke. According to the CDC, **nearly two-thirds of strokes occur in adults 65 years of age or older.**¹



Over 60% of caregivers are the spouse of the person with aphasia, and that over 56% report that they are retired. Additionally, close to 58% say they have known the person for over 40 years.

Other Interesting Findings:



Over 77% of caregivers are female. Over 85% of caregivers reported their ethnicity as Caucasian, followed by Hispanic or Latino at just over 5%, Black or African American at close to 4.5%, and Asian or Pacific Islander at over 2.5%.



Within the US, **over 31% of caregivers reside in the South** followed by those in the Northeast at just over 27%. Those in the Midwest account for nearly 23% of respondents, while those in the West number the fewest at just under 19% of all caregivers.



Over 27% of caregivers have a bachelor's degree, and close to 26% have a high school diploma. The remaining respondents report having earned certifications and associate degrees, as well as advanced degrees in roughly equal numbers.

¹Stroke Facts. (2017, September 6). Retrieved from <https://www.cdc.gov/stroke/facts.htm>.

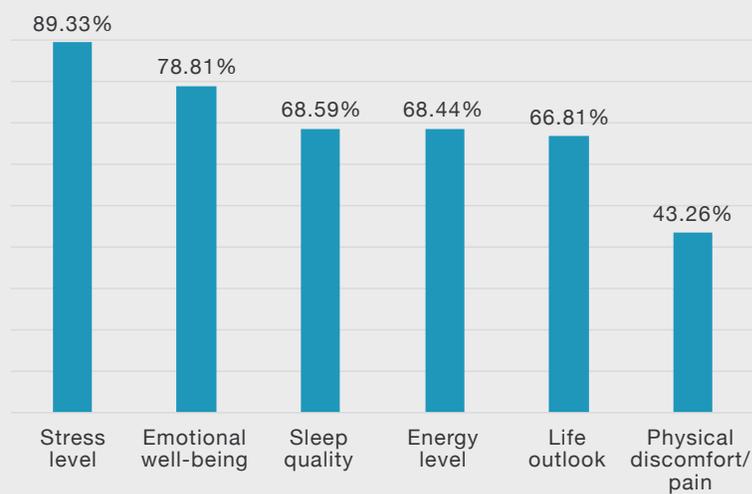
The Mental, Emotional, and Physical Impact of Aphasia on Caregivers

Over 89% of all caregivers feel that their stress level has worsened and 79% report a decline in their emotional well-being. Respondents ranked sleep quality, energy level, and life outlook as the next highest traits to have suffered as a result of becoming a caregiver.

The results suggest the need for resources and strategies than can help caregivers to better cope with the physical and emotional demands of caring for someone with aphasia. For example, caregivers may benefit from:

- Better time management skills, including making time for self-care, leisure, and relaxation
- Relaxation exercises like breathing, meditation, walking, and stretching
- Eating a healthy and balanced diet, and avoiding drugs and alcohol
- Practicing good sleep hygiene and avoiding caffeine later in the day
- Connecting with friends, family, support groups, or counselors for emotional support

Percent Who Report Worsening:
(check all that apply)



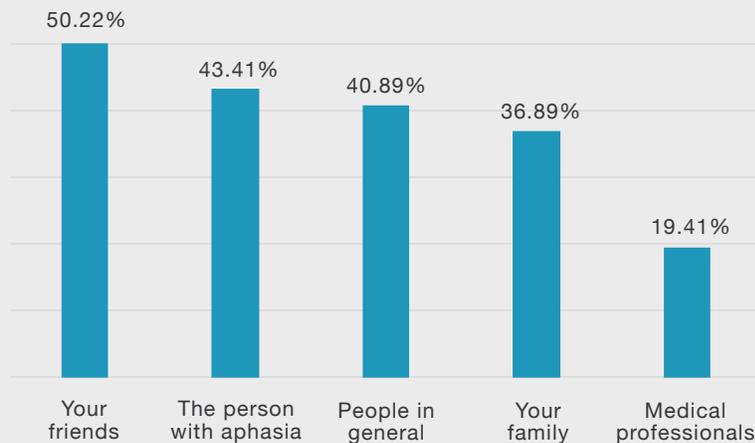
Caregivers Experience Worsening Relationships

More than half of caregivers say that their relationships with friends have worsened. It is next most common for caregivers to report that their relationship with the person who has aphasia has deteriorated, followed by people in general. Over a third of caregivers say that their relationship with family has worsened.

Although it is difficult to determine exactly why these relationships deteriorate, we have spoken to members of Lingraphica’s Aphasia Support Group in the past who note instances of:

- Friends not being able to come to terms with the illness
- Disagreements among family over how best to provide care
- Difficulty communicating with the person who has aphasia
- The general lack of awareness around aphasia most people have
- Stress and depression making it difficult to interact with others

Percent Who Report These Relationships Worsening Since Person Acquired Aphasia
(check all that apply)

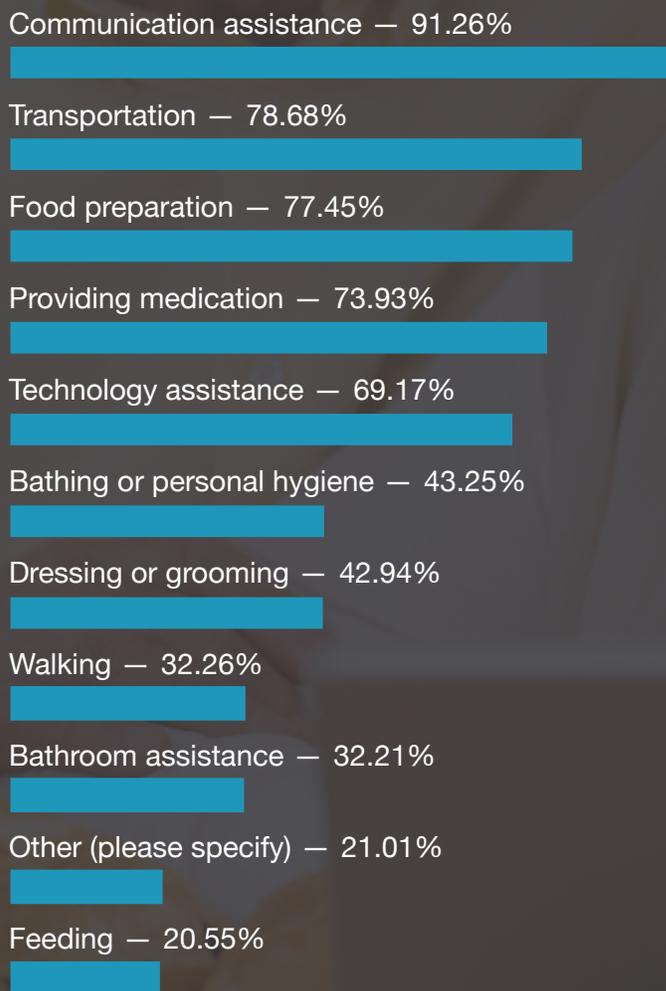


Most Common Activities Aphasia Caregivers Help With

Not surprisingly, of all the activities aphasia caregivers help with, the most common is communication assistance. The next most common activities include transportation, food preparation, providing medication, and technology assistance.

I help the person with aphasia with the following:

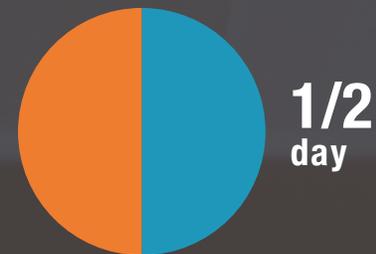
(check all that apply)



So how much time do caregivers spend engaging in these activities?



Over 63% spend as much as 1/3 of their waking day providing care to someone with aphasia.



Close to 45% spend as much as 1/2 of their waking day providing care to someone with aphasia.

The Biggest Challenges Caregivers Face

Of all of the challenges aphasia caregivers face, the most common is the inability to communicate or converse with the person with aphasia. The second highest is adjusting to the person with aphasia's dependence on them. This is followed by motivating the person with aphasia and finding time for self-care and personal activities.

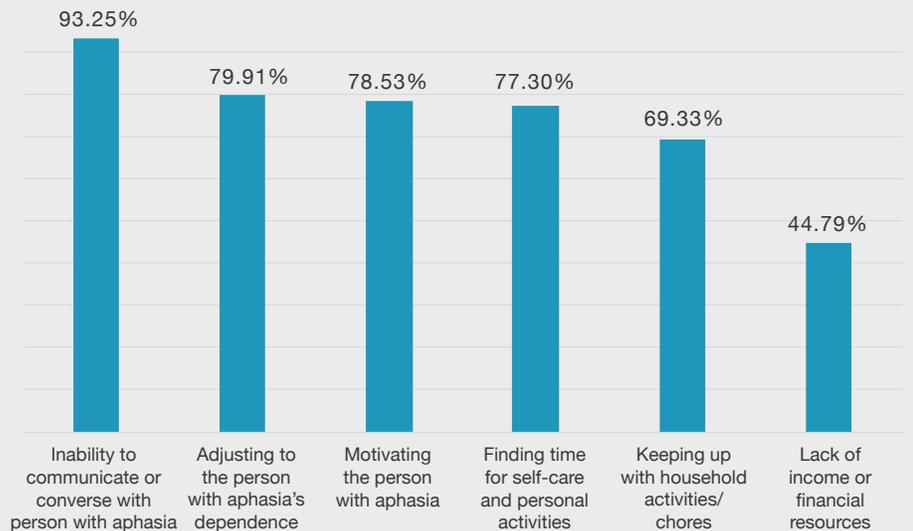
As we saw earlier, the majority of caregivers spend time providing communication assistance. Here we see that their inability to communicate with the person is generally the biggest challenge. So, one might wonder if caregivers have received communication training to make this less of a challenge. Communication aids can also help facilitate conversations between caregivers and people with aphasia.

Unfortunately, caregivers noted that

58%

of the time their loved one did NOT have a communication aid.

The Biggest Challenges Caregivers Face: (check all that apply)

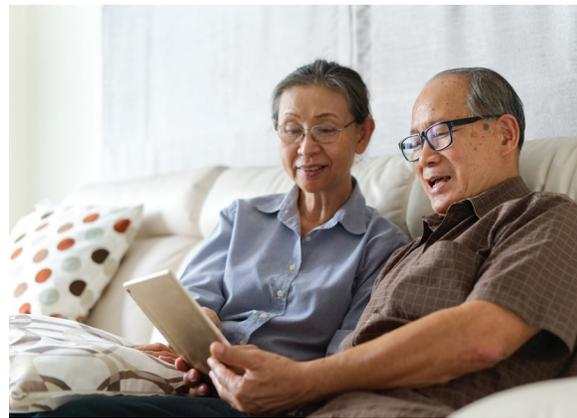


What Motivates Aphasia Caregivers to Do What They Do?

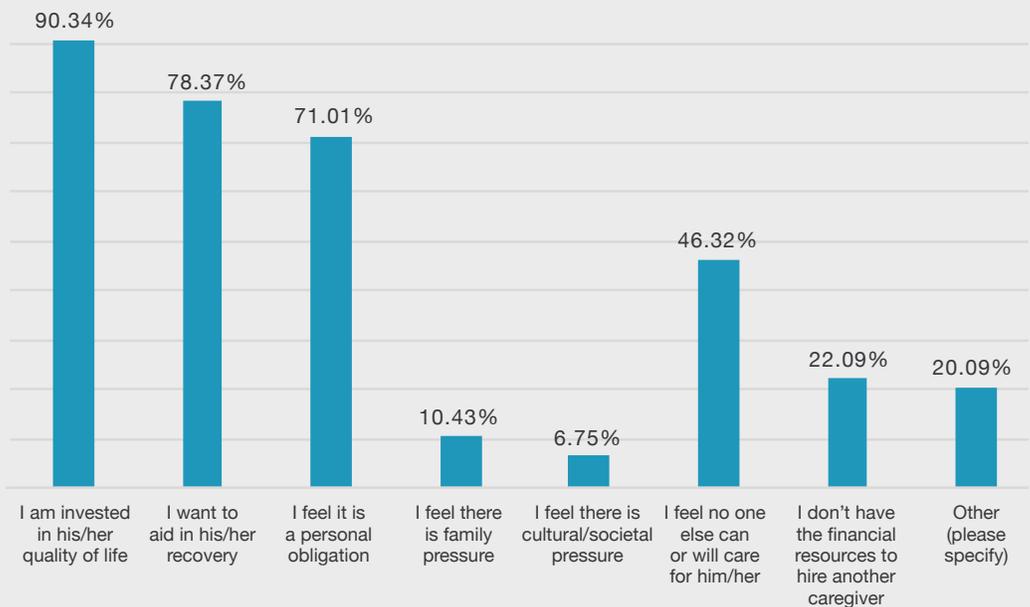
Despite all of the challenges and the way they can negatively influence mental, emotional, and physical wellbeing, as well as their relationships with others, caregivers have largely altruistic intentions.

Over 90% of caregivers say that they take care of the person with aphasia because they are invested in his or her quality of life. Over 78% note that they want to aid in his or her recovery.

However, some note they also feel that it is a personal obligation (71%) and that no one else can or will take care of them if they don't (46%).



I take care of the person because:
(check all that apply)





Knowing what we now know
about aphasia caregivers,
the question becomes:

**How can we help caregivers
get the support that they need?**

Getting Aphasia Caregivers the Support They Need

While aphasia caregivers face a variety of challenges, the single most common challenge—shared by over 93% of caregivers—is their inability to communicate or converse with the person with aphasia.

Communication assistance is also the most common activity caregivers assist with. Yet, it is unclear whether caregivers have received any communication training whatsoever, and the vast majority say that their loved one does not have a communication aid.

Although aphasia varies in both type and severity, which influences how best to communicate with someone with aphasia, we recommend the following foundational resources that support communication and provide other valuable information.

NO.1

Aphasia Communication Tips

Learn fundamental principles you can use for everyday communication whether you are a new or experienced caregiver.

www.aphasia.com/communication-tips/

NO.2

Life with Aphasia Blog

Insights around everyday communication, as well as advice on health & wellness and staying motivated.

www.aphasia.com/aphasia-blog

NO.3

Find a Speech Therapist

Speech therapists can help both you and your loved one to improve your communication to support life goals and activities of daily living.

www.aphasia.com/find-a-speech-therapist



Lingraphica Can Help

Finally, Lingraphica offers free one-on-one consultations for caregivers who want to improve communication with their loved ones and help to aid their recovery but aren't entirely sure where to start. To learn how Lingraphica can help, schedule a free, no-strings-attached one-on-one consultation at:

www.aphasia.com/improve-communication

About Lingraphica

Lingraphica is the only company dedicated to helping adults with aphasia improve their communication and quality of life through devices, applications and resources developed by speech-language pathologists and leading researchers.

We understand the challenges people with aphasia and their families face. We know how critical communication is in aiding recovery and helping those affected live fulfilling lives.

To learn more, watch our 2-minute video at
www.aphasia.com/caregiver

