

Caring for Those Without Words: A Perspective on Aphasia

John A. Liechty, Justin B. Heinzkehr

Abstract: A technical grasp of a medical condition does not always give a person a sense of the emotions behind the disease. Medical professionals, of course, cannot afford to be emotionally invested in every illness they see. Some amount of distance is needed for them to maintain their own emotional health and to give good care to patients. However, emotional or psychological struggles are a large component of a patient's suffering. If these realities are ignored, a medical professional will be much less effective on any level.

My condition is aphasia. I have trouble communicating in words. Aphasia is not an objective condition for me, but a daily challenge that tests my emotional strength. Medical professionals must be able to understand the subjective reality if they are to interact helpfully with people who have aphasia.

This became clear to me one day as I was talking to a social worker at the psychiatric hospital where I work. She asked me what I did for a living. "I'm a housekeeper," I said. "I have aphasia." She interrupted, "Oh, you mean you had a stroke."

Her reply frustrated me because it denied the continual struggles I face due to my inhibited ability to communicate. While technically accurate, the social worker's reply deemphasized the pain that aphasia causes by focusing on a past event. The stroke happened once; aphasia is an ongoing condition.

My story illustrates the ongoing nature of this condition and the frustration that it causes. I had just received a master's degree in social work and was starting a new job in Cincinnati. I was looking forward to applying my knowledge to a practice setting in a family cancer center, but this dream was shattered. I suddenly had a severe headache. I don't remember much about that day; I went back to my apartment and then to the hospital, where I was diagnosed with a ruptured aneurysm, which resulted in aphasia. I could no longer communicate with my friends. To say even one word required extreme effort.

The injury I suffered had caused damage to the language area of my brain, leading to an inhibited ability to communicate. More than 1 million Americans suffer from this same condition (National Institute on Deafness and Other Communication Disorders, 2007). Some people who suffer from aphasia have trouble putting their thoughts into words (expressive aphasia), while others find it difficult to understand words spoken to them (receptive aphasia). For some people, both of these statements are true. For people with expressive aphasia, it seems as if their thoughts are on the tip of their tongue, but they cannot find the words to express themselves. For those with receptive aphasia, it may seem as though others are speaking in a foreign language. The common characteristic of all people with aphasia is the limited ability to communicate in words.

For me, like many others, aphasia was devastating. Lack of communication often leaves people feeling isolated, depressed, and angry. Aphasia erodes the social bonds that give life meaning. Everyday interactions with family, friends, and coworkers take tremendous energy. Some people with aphasia succumb to depression or consider suicide when they find their condition unbearable.

The unfortunate reality is that few people understand the emotions behind this condition. A friend with aphasia was approached in church by a member of the congregation who asked her if she could still do housework. She was hurt because she felt that housework was one of the few things that she *could* do just as well as before her stroke. She wanted to explain that aphasia does not affect a person's intellectual or physical abilities, but only one's ability to communicate with words. Often friends will simply avoid a person with aphasia because it takes so much effort to make him or her understand what they are saying, which only contributes to the isolation that troubles many people with aphasia.

Questions or comments about this article may be directed to John A. Liechty, MSW, at jltechty@verizon.net. He has been a volunteer advisory board member with National Aphasia Association. He also works as a housekeeper at Oaklawn Psychiatric Hospital, Goshen, IN.

Justin B. Heinzkehr is a recent graduate of Goshen College, where he studied religion. He is a staff person at the Center for Intercultural Teaching and Learning at Goshen College, Goshen, IN.

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How can caregivers be more sensitive to people with aphasia? How can they reach out to those who are isolated by their condition? There are five things to remember when interacting with people with aphasia.

1. *Music and visual arts are often positive ways to break through the communication barrier raised by aphasia.* For example, in the time immediately after my stroke, I struggled to relearn how to speak. I was working with a speech therapist but making slow progress. Even a short phrase like “I’m thirsty” was difficult to articulate. My therapist advised me to try singing this phrase. Suddenly the words came to me! It was a very exciting moment. From then on, I made much better progress.

Music can help people with aphasia reconnect with their community as well. At church, for instance, I found that I could not understand the sermon. There were too many words to process in a short time. However, I could still understand the music in the service. I began to attend church choir practices, at first simply listening, but then participating. I found that music helped me to reclaim my spirituality in a way that I could no longer do through words. I could sing the old hymns quite easily. Although the lyrics to new songs sometimes escaped me, I had no trouble singing a melody.

2. *Take time to talk with people with aphasia.* It will take more energy and time to converse when a person has to sort through every word that is spoken. It is easy to become impatient at times. Caregivers must fight the urge to interrupt or to become irritated and instead allow time for interaction. Edith, a friend of mine, has aphasia. Like many others, she was initially depressed when people avoided speaking to her. One day, however, she was coming out of a bookstore and was greeted by an Amish woman. Although this woman did not have any technical knowledge of Edith’s condition, she waited for Edith to fumble for words in response. Unlike many others, the Amish woman did not interrupt or try to finish Edith’s sentence for her. Instead, she simply exhibited patience. Once Edith had responded to her greeting, the Amish woman asked another question and again waited for Edith to respond. When Edith got home, she told her husband about this interaction with tears of joy in her eyes.

Caregivers might apply this lesson when talking to a patient with aphasia by talking in an unhurried manner and being supportive while the patient takes time to construct a response. If there are family members with the patient, it can often be tempting to talk to the family members instead. However, this leaves the person feeling as if the healthcare provider is talking *about* them rather than *to* them.

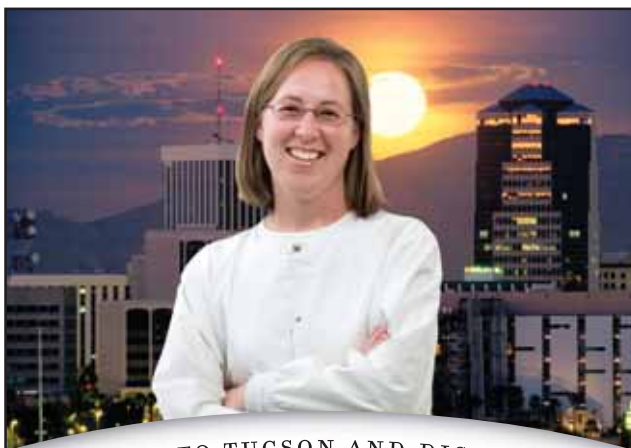
3. *Help people with aphasia realize their own limitations.* The truth is that very few people with aphasia will ever fully regain their ability to communicate. However, with therapy, they can make significant progress. For instance, after 28 years I have moved from a beginning vocabulary of 10 words to being able to speak at public events, but I still have trouble with verbs and sometimes mix up prepositions or pronouns. In addition, I cannot follow the sermon at church.

Some people with aphasia may wish to ignore their condition. In a family setting, a person with aphasia may try to fill the role they played before the onset of their condition. In one such case, the matriarch of a family had a stroke that caused aphasia. Even when it was hard for her to communicate, she tried to take control in planning family gatherings and in communicating these plans to the rest of the family. This ended up frustrating family members because she would either wrongly hear or wrongly communicate the information. It is important for a family to respect a member with aphasia and to keep him or her engaged in family life, but it is also true that people with aphasia must recognize their limitations and the necessity of a different way of living.

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4. *Connect people with aphasia to available resources.* Support groups and other resources are essential to a holistic treatment of aphasia. In a society where people do not understand or accept an inability to communicate, it is a relief to gather with people who share a common struggle. In my city, there is an aphasia support group that meets once a month at the hospital. We share our experiences, our frustrations, and our triumphs. We enjoy the company of friends who understand when we cannot find the right words. Isolation may be a symptom of aphasia, but the support group provides a time of empathy and connection—good medicine indeed.

Although doctors and nurses do not need to be directly involved in such support groups, they might help to locate a support group in the area and encourage a patient with aphasia to attend. It would therefore be helpful if medical caregivers were aware of such support groups. One way to locate support groups is to visit the National Aphasia Association’s (NAA) Web site (www.aphasia.org). The NAA provides a list of support groups in the United States



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5. *Treat people with aphasia as individuals.* It is often easier to see people with aphasia only in terms of their condition. This is especially true since people with aphasia cannot express themselves easily. It is sometimes hard for them to convey their personality. However, all advice on how to treat people with aphasia must be tempered by the caution to treat each case individually. Some people with aphasia will not be interested in singing in a choir. Some people with aphasia are more introverted than others and may not appreciate as much conversation. To treat any person with dignity is to treat him or her as an individual. One must be especially vigilant in observing this when dealing with a person with aphasia.

Aphasia is an emotional as well as physical condition. It is isolating and frustrating, but it can be softened by medical professionals who care for patients' mental health. Caregivers must seek to assuage the pain of solitude by helping patients to be incorporated back into their communities. They must exhibit patience and a willingness to relate to these individuals. For people with aphasia, these practices can transform medical care from one more isolating experience to the beginning of emotional healing.

Reference

National Institute on Deafness and Other Communication Disorders. (2007). *Aphasia*. Retrieved August 9, 2007, from www.nidcd.nih.gov/health/voice/aphasia.htm.