

On the Tip of My Tongue

LIVING WITH APHASIA

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BY JOHN A. LIECHTY

I have aphasia. Twenty-eight years ago, a week after I had earned my master's degree in social work, I suffered a ruptured brain aneurysm. After my operation, I could not speak or communicate.

There are two types of aphasia: expressive and receptive. Receptive aphasia affects the receiving of language. This can make persons with

aphasia feel as though everyone else is speaking a foreign language, and everything they read is gibberish. In fact, recovery is more difficult because the person with aphasia often must relearn the meaning of symbols before beginning to relearn language.

Expressive aphasia affects the production of language. A mild version of this is when someone experiences the *tip-of-the-tongue* phenomenon. You know what you want to say, can describe it, maybe even draw it, but cannot think of the word or phrase. For persons with aphasia, many or all words are *on the tip of the tongue*. Because their cognitive skills are more advanced than their language skills, aphasics often are frustrated by having much to say and no way to communicate.

It is hard for someone who has

never experienced aphasia to understand what aphasics live with. When I began speech therapy after my stroke, the therapist started with just ten words—“house,” “hammer,” “fork,” etc. It took a long time and much energy to hear and say those words properly. When the occupational therapist handed me a bar of soap, I put it into my mouth—without words, I didn't know what to do with it.

Gradually, speech came back. But even today, 28 years later, speaking is difficult. Sometimes the right word won't come, or I get my tenses wrong. I have greater difficulty with receptive aphasia—understanding what other people say. People who speak rapidly leave me totally lost. Complicated conversations leave me clueless. Recently I had lunch with my sister and her hus-



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Photo: Cemstock

band who were hosting friends. They were talking about their travels around the U.S., and I couldn't follow what they were saying because I couldn't keep track of the states—it was all jumbled. Once in a while, I try to read *USA Today*. I can read and comprehend the state-by-state summary paragraphs, but a front-page article is a struggle. For e-mail, I use a text-to-speech converter, and this helps with my comprehension. I also use voice recognition software to dictate my e-mail replies and other documents. These tools have helped to open my world.

A MUSICAL BREAK-THROUGH

After my aneurysm surgery, the impact of the language barrier was so severe I became isolated and lonely. Then a speech pathologist suggested trying music therapy. She said, "Try to sing, 'I'm thirsty.'" The words flowed out! This breakthrough was enormously gratifying! Upon returning to church, I found that aphasia affected my ability to understand the sermon. I had difficulty identifying and interacting with the sacred, and again I felt isolated. However, I found that listening to the choir allowed me to reconnect spiritually. My father, a good tenor, suggested we attend the adult choir rehearsals and sing in the Sunday morning worship. Although I had difficulty understanding sharps and flats, I found that I could still sing well. As I struggled through understanding scales and attempting to sing "Do, Re, Mi, . . ." choir practice became a means of salvation—a holy and sacred time for worship.

One proud moment came when I sang in the choir's performance of composer Alice Parker's *Martyr's Mirror*, a difficult cantata to sing due to the dissonant music. Over time, and with practice, I was able to sing the magnificent piece with the choir, with the

composer directing. This again became a way to connect with the spiritual part of my being.

In music I also have found a way to connect with God. Music brought language and meaning back to my life. Singing is possible because of the areas of the brain where music is interpreted and formed. The damage in my brain was on the right side, but music is developed on the left side. Now when I sit in church, I find that old familiar songs are my favorites; new songs are challenges waiting to be met. Either can be a path to the Savior.

Music in any form or style can be therapeutic for someone needing to connect with others, him- or herself or God. Studies have shown that some patients with Alzheimer's can remember musical pieces from their childhood. Nurses, singing for or with a patient can build a significant bond and help them recapture meaning and expression. Consider quietly singing to patients who are confused, lonely, afraid or demented.

SIGNIFICANT LOSSES

What have I lost because of aphasia? I am a trained social worker, but I work as a housekeeper. After I had gone through some rehabilitation therapy, I went back to the social service department in the hospital where I had worked before my stroke. Sadly, that job lasted only a week. It was too difficult to handle. I yearn for the possibility of in-depth discussions with fellow professionals. At the psychiatric hospital where I work, many of the staff know about my condition. We talk with each other, but because it takes time for me to comprehend what someone says and then respond, it is difficult to carry on a conversation with busy professionals.

I was going through a divorce

when I had my stroke, and I remain single. I would like to pursue a relationship with a woman, but it is hard to find things in common or build relationships when there are such great communication barriers. This applies to all of my relationships, not just with women. Although my family has been supportive, I find I need more than my brother, sister and mother can provide.

This story illustrates my final point. Early in my treatment, I was auditioning to sing in Handel's *Messiah*. I had difficulty communicating directly, so we focused only on music in the audition. The director expressed concern about my ability when he instructed me to sing down the scale. With aphasia, I found it impossible. Due to his lack of understanding of aphasia, I was not permitted to sing, even though I had sung Handel's *Messiah* every year in my church since I was fifteen.

The point? People with aphasia need other people in their lives, who are involved in helping them communicate. Had someone been with me at the audition to help explain my condition and advocate for me, things might have turned out differently. From the deep understanding and strength shown by my friends in the Goshen Aphasic Support Group, to a friend's encouraging smile, without the support of others I would not be where I am today. My friend Don spends an hour or so each week as my resource person. He helps me solve computer problems, edits the draft articles that I have dictated and helps me shape my proposals for presentations at conventions. Currently I am a member of the board of advisors for the National Aphasic Association (NAA). I regularly make presentations at national and regional health-related conventions, educating individuals in health care on helpful techniques for working with individuals who have aphasia. ■JCN