When my husband and I stepped out of the hospital following his stroke at the age of 44, I recall the feelings that washed over me as the doors closed behind us. He had survived the stroke, and the worst of the physical problems were solved in the hospital. But, as I stood outside the hospital, I had no idea where to turn or even who to ask about the problem the neurologist called "aphasia." My husband seemed to be trapped in his body without the ability to communicate, and we were both uncertain of the eventual outcome. I slowly realized that much of my desperation was the result of my lack of knowledge about the condition. Many months later, I came to understand that we were not the only ones who had to live through that terrible period of not knowing. Spouses and persons with aphasia from all over the country call the 800 number for the National Aphasia Association (NAA), and I am the person who responds to their all-too-familiar need none of that when my husband and I began our adjustment to living with aphasia.

For the first year, we were absorbed in a balancing act of learning more about the new demands my husband's mind and body placed on him, then adjusting our life to meet them. There was no satisfactory explanation for why the stroke had occurred, and that lent a "walking on eggshells" quality to every aspect of our life. Added to that was the roadblock that the aphasia presented to my husband. He had salesmanship skills that could hypnotize an audience before his stroke. After the stroke, he not only experienced extreme frustration in trying to communicate with others, but also his own ability to understand the nature of his impairment was limited by the aphasia.

The first priority was to simplify. My husband needed rest and plenty of it. There was not time for the busy lifestyle we had maintained before the stroke. Contact with my husband's business became minimal, and the circle of our friends drew closer as the less essential people moved further out of our daily orbit. Gradually, as we understood more about the aphasia, we began to select and control our environment to accommodate his needs. Rather than arrive at our daughter's school a half hour early in order to socialize with the other parents, we timed our arrival with the beginning of the event so he could spend his limited reserve of concentration on our daughter's performance. In restaurants or any public setting, seating was chosen carefully to minimize distractions. We avoided blaring speakers, and, when possible, my husband chose to sit with his back to a wall. This allowed him to eliminate distractions from behind and to focus all his attention on the scene in front of him.

While these external adjustments were going on, we also had internal hurdles to overcome. Shock, of course, numbed us both at first, but I grew to appreciate the "cushioning" it provided us from the fear we both experienced. It was a natural and healthy way to deal with a painful situation, and it allowed us the time to develop other defenses.

We did our share of questioning and bargaining with God, with the doctors, with ourselves. "Why didn't I see this coming? How could God and/or the doctors let this happen to my loved one? Why me?" And later, I tried bargaining, "If only you help my loved one get better, I promise to . . . !" My whole world seemed to be falling apart. I felt overwhelmed by the situation and depressed. In addition to all the changes that were taking place, we both had to
deal with fear, anger, depression, and isolation. We slowly grew into a different family than we had been, and life took on a new shape. It required a firm commitment, time, patience, and a sense of humor, along with the acknowledgment that there are no short-cuts to recovery with aphasia.

As the days went by, we began to sort out the many questions that had to be answered about an uncertain future. My own initial response was to feel total doubt about my ability to handle the changes that had occurred so suddenly. During that early period, I recall my husband asking, "How can I raise three young children, manage my life, marriage, and a business with severely impaired communication skills?" We were forced to confront a lot of issues as a couple. Would he be able to participate as an active family member again, with the children, relatives, and friends? Will we as a couple ever be able to have an intimate relationship again? Will he ever be able to work again and support the family, or will I be solely responsible for the income?

I will always be thankful for the people in our lives who were there to listen: people from our church, neighbors, our family physician, my husband's speech pathologist, and relatives. From my point of view, we needed to be able to express our frustration in order to relieve our anguish. Our support system needed to be there to listen.

My husband worked with a speech-language pathologist daily for the first 6 months, then continued twice a week after the insurance ran out. We made his recovery a priority, and the whole family pitched in. At the speech pathologist's urging, we teamed up to draw every bit of language we could from my husband. When it was easier and faster for us to produce the words he was so clearly struggling to create, we forced ourselves to wait patiently. Mealtimes became a game where we would only prepare those foods that my husband could name. I give my husband a lot of credit for his daily efforts to keep things upbeat and optimistic. It helped sustain us all.

Slowly, over a long period of time, our family acquired a degree of acceptance of aphasia as a disability. However, this acceptance should not be confused with or mistaken for happiness. Neither my husband nor I would ever be happy that his ability to carry on personal communication had been compromised. But a degree of acceptance provided a step toward rebuilding our lives.

Two years after the initial stroke, another unexplainable stroke occurred. This time, the impact on communication was minimal, and there were practically no external signs. The major impact was the occurrence of a deep depression. Our family physician, who among all the doctors we visited during those years kept the clearest image of my husband's mental and emotional health, recommended that we seek professional counseling. It was a disaster. The highly qualified psychiatrist we visited had no experience with persons with aphasia, and the bid to help boomeranged into a deeper depression. Fortunately, we discovered that the speech pathologist who had worked with my husband for so many months also had training as a counselor…a rare and precious combination! She began counseling my husband and gradually the depression lifted. We were able to see the man who kept the motto, "make things happen" front and center on his desk reemerge.
As I answer the 800 number for the NAA these days, spouses often ask me how I coped. A support system, as I mentioned earlier, is essential. It was perhaps a year after my husband's first stroke before we learned of any community groups for stroke survivors. Fortunately, there were persons with aphasia in both of the groups who eventually became a regular part of our lives. Although we found these groups several months after the aphasia first occurred, there was still so much to learn from the group members. Talking to members who were 10 and 15 years post-stroke, we gathered some sense for what could be expected in different circumstances. There were those who failed to progress, and they, too, had their value in instructing us. Talking to new stroke survivors and their families, we could appreciate how far we had come.

I also had to develop some emotional survival skills. Dealing with aphasia 24 hours a day can leave one emotionally exhausted. Caregivers need several kinds of "time": time to be alone, time to be with others who will listen when we talk, time to find out who we are again after a painful readjustment. Maybe a hot bath, a nap, or a shopping trip is all that is necessary to make it through a low period, but it is difficult to be there for your spouse when you are not feeling like a whole person yourself.

There are also economic issues that must be addressed. The spouse may be forced to reduce or find help for financial stresses, which may mean finding employment. Getting back into a routine can also go a long way toward helping one feel organized to some degree. Seeking out hope has to become a priority, and support groups, such as an aphasia community group made up of people who have had similar experiences, is a good place to begin. Caregivers, especially, need to allow themselves to accept expressions of caring and helping from others.

Finally, as soon as the strength is developed, the spouse as well as the person with aphasia may want to set some goals. Goals give people something to look forward to - an important factor in getting on with life. It could be something as small as going out to see a movie, or as large as planning a trip. Whatever works toward a future that can be shaped is worthy of some goal setting.

My husband and I chose to become involved in helping others with aphasia through the NAA. We created a distribution center for educational materials and installed an 800 number in our home. Every day, the NAA toll-free line brings stories of frustration, fear, and desperation. We get involved for a short time in these people’s lives trying to educate, encourage, and empower them to help themselves with their personal journey in the world of aphasia. For those callers who are adjusting to a recently acquired aphasia, there are basic factual information and local contacts who can discuss area resources. The NAA keeps a roster of all aphasia community groups that are known in the United States. For those callers who would like to begin their own group or enrich an existing one, the NAA has compiled the experiences of successful groups from across the United States and made them available in the form of the Aphasia Community Group Manual. Young people who acquire aphasia in their teens and 20s have a special set of problems, and we make an effort to connect their families in a Young People's Network. Twice a year, the NAA publishes a newsletter that shares ideas and resources for groups and individuals.
Each June, we distribute posters, press kits, and educational materials to support groups and individuals in their efforts to educate their communities about aphasia and its impact during National Aphasia Awareness Week. Throughout the year, we distribute on request speeches and articles that share expertise and encouragement. Perhaps most important of all, I can assure callers that they are not alone. Sometimes, as many as 70 people call our distribution center in a week. Health professionals who are seeking resources for their clients and persons with aphasia and their families call, and each person who requests that I contact them receives a return call.

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Managing the NAA Distribution Center has been an educational process. That experience, along with the encouragement from our speech pathologist and personal research, helped us defy the 6-month limit on regaining communication skills that we heard so often. In our situation, it was encouraging to see significant gains at 12 and 18 months post-stroke. It is my hope that persons adjusting to life with aphasia will continue to strive for fuller communication and not give up hope after 6 months.

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