

MY APHASIA
By Chuck Hofvander
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I woke in Milwaukee and thought "I wonder how I got here?" I was confused and not in Milwaukee at all. Over several days, I came to realize that I had had a stroke.

When I regained my senses, I accepted the fact that I could not walk or use my right arm, but I was confused because no one could understand my speech. That puzzled me. In the past, I had prided myself on my ability to communicate, but now no one could understand me.

Before the stroke, I had been a senior project manager at Xerox for 6 years. I had also been a senior project manager at Zurich Insurance, and for 21 years, I was employed by CNA in various positions. I had a wife, two kids, and a house in the suburbs. I rode a bike an average of 2,500 miles per year. I was happy. To my knowledge, I didn't have an enemy in the entire world. To paraphrase a line from the "Wizard of Oz," "it's not how you love, but by how much you are loved by others." Well that fit me to a tee, but it took the stroke for me to realize it. I received hundreds of letters, cards and e-mails expressing support. They are still coming and it's been almost two years.

Over time, I learned I had a brain disorder called "aphasia" (a language disturbance) and that it had no known cure. I just had to learn to live with it. Well, for me the news was devastating. Now, I was locked inside this big body and I was unable to communicate.

Through hard work and perseverance, I have improved a great deal. Yet, I'm not nearly back to the way I was and that is quite frustrating. I can "think it" but cannot "say it" or "read it" or "write it." My mind has a will of its own. Aphasia does not affect intellect and that is what is so frustrating about this disorder. Because individuals with aphasia speak haltingly or not at all, people often assume they are mentally ill or mentally challenged. It is one of the most heartbreaking and devastating of disabilities. I know because I have difficulty communicating with my two young sons.

But my aphasia has a bright side. Since becoming aphasic, I have made several friends that I would not have made otherwise. Len, Mary Lou, Barry, Dick, Janet, and Mike are just a few and others too many to mention in this short essay. I truly value their friendship. My relationship with my "new friends" is substantially altered from the "friends" I made before I had aphasia in that they understand what it is like to have this disability. I am somewhat uncomfortable with someone who does not have aphasia because they do not know what it is like to struggle with every word you speak. With those who share the same disorder, I feel as

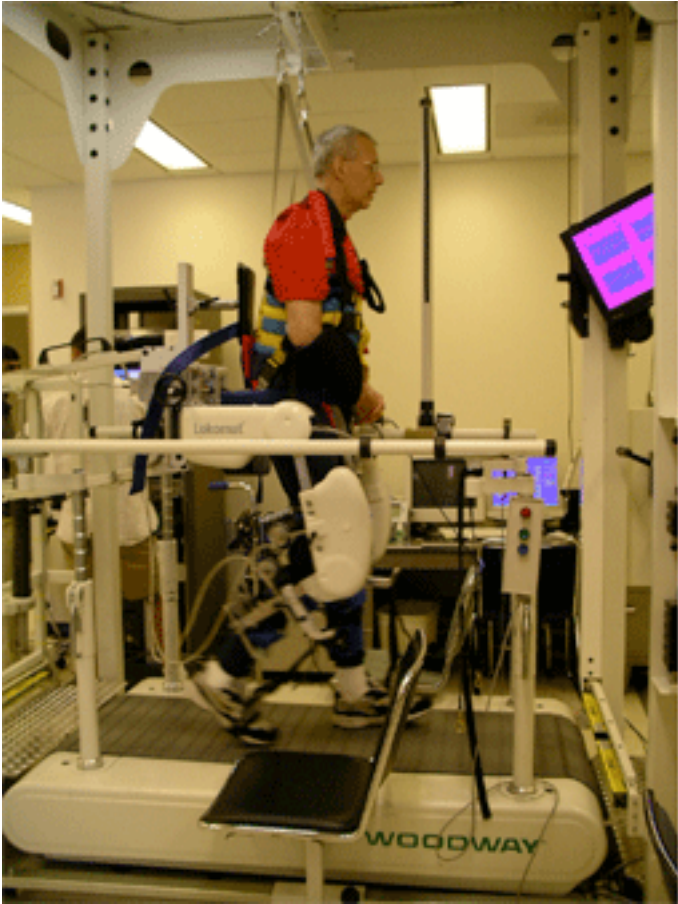
though there is a common bond between us. I share a ride with Len coming downtown, and we often joke that each of us are prone to lose our concentration at times.

As I mentioned previously, my aphasia has improved with time. Now, along with my wife, I am participating in a project sponsored by Northwestern University. It is called the Midwest Regional Aphasia Conference. I am also volunteering my services to many studies at the Rehabilitation Institute of Chicago (RIC) that include the Lokomat (see picture attached), a study to restore movement in my right arm, and in several writing exercises and conversation groups.

As I mentioned earlier, I was into bicycle riding in a big way. Well, my cycling buddies bought me a high performance tricycle (see picture attached). During the summer of 2005, I rode over 1,000 miles, and I plan to do more this coming year. I feel like I did not have a stroke at all when I am riding. I feel free!!!!

I am learning to live with my aphasia, but I am frustrated by it nonetheless. I'm learning to accept that I will never get back to the way I was. I have to realize that I am stuck with aphasia, but I cannot let my disability get me down or give up. I now realize that in a way the stroke was a blessing. I have made new friends, reaffirmed some old ones, gotten closer to my wife and children, and gotten more introspective in my way of thinking.

My stroke and aphasia has taught me several things. First, it has taught me not to worry about the little things. I used to worry about the littlest details. Nothing was too small for me to worry about. The second thing it has taught me is to not fear death anymore. Now that I was near death, it does not scare me. And third, I have learned to enjoy life. It is precious.



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