

STUTTERING: A CHALLENGE TO THE SPIRIT

By Hank Stupi

Unitarian Universalist Fellowship of the Rappahannock

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Can anybody guess what I have in common with James Earl Jones, John Stossel of 20/20, Marilyn Monroe, and Winston Churchill, just to name a few? We all stuttered from childhood and never completely outgrew it. I began to stutter in the first grade. Like the celebrities above, I never grew out of it and struggle with it to this day.

Over 3 million Americans stutter or approximately 1 percent of the population. Stuttering affects four times as many males as females. About 60 percent of those with the disorder have a family member who also stutters. Some 20 percent of all children go through a stage of development during which they encounter disfluencies severe enough to be a concern to their parents. Approximately 5 percent of all children go through a period of stuttering that lasts six months or more. Three-quarters of those will recover by late childhood, leaving about 1% with a long-term problem. This and much more information about stuttering is available at The Stuttering Foundation (www.stutteringhelp.org).

Interestingly, just last month CNN reported on a new study that brings researchers one step closer to unraveling a medical mystery that has perplexed scientists for thousands of years: What causes people to stutter? Research appearing in the *New England Journal of Medicine* reveals three genetic mutations in the brain cells of people who stutter. The cells are located in the part of the brain that controls speech, which suggests that genes could play a big role in the disorder. "People have looked for a cause of stuttering for 5,000 years," said Dennis Drayna, a researcher at the National Institute on Deafness and Other Communication Disorders, and a co-author of the study. "Many, many things have been suggested as a cause of stuttering. None of them have turned out to be true. For the first time today, we know one of the causes of this disorder." Drayna pointed out, "Just knowing a disorder is genetic doesn't really help us understand that disorder at a level that, for instance, doctors would like to know." He went on to emphasize that finding the genes for stuttering does not automatically mean a cure, but that better treatment and diagnosis is on the horizon. In an editorial appearing in the journal, Simon E. Fisher, an investigator into molecular mechanisms underlying speech and language, said, "As with other neurodevelopmental disorders that affect speech, the task of connecting the dots between genes and stuttering is just beginning."

I have no idea why I began to stutter. No one in my family did. Frankly I'm not sure what difference it would make if I did know the cause. Frederick P. Murray, Ph.D. Director, Division of Speech Pathology, Eastern Michigan University said, "Many stutterers have mistakenly believed that if only the 'cause' could be found, a fast cure would result."

I recently read an article likening speaking to such activities as typing, playing a musical instrument, etc. I can relate speaking to playing my guitar. When I'm first learning a new tune, it goes slowly, I have to think about each note and how to finger it, and there are

lots of starts and stops, like a child learning to speak. After a while, with practice, I get to the point where the tune is "in my fingers", and I can play it effortlessly without thinking too much about it. In fact, my online guitar teacher generally suggests that you practice a pattern until you can play it while watching TV. I've gotten to that point many times. Now, if I stop and "think" about playing something that I've learned everything goes awry. I suddenly stumble and fumble over notes that I was previously playing effortlessly. The only way to play it is to turn my mind off a bit and let my fingers take over most of the work. I also know how to type, but ask me where a particular letter is on the keyboard, and I'll have to visualize my fingers typing something that has that letter for me to tell you where that letter is. For me, even the simple unconscious act of breathing has similarities – I breathe effortlessly without thinking about it. Whenever I've concentrated on the act of breathing, I find myself struggling to breathe until I forget about it. I think that's what happened with speaking for me as a child – I got too hung up thinking about speaking and started struggling with something that most people do effortlessly without thinking. Then a vicious cycle started in that the more I stuttered, the more I thought about it so the problem didn't go away.

Stuttering seemed to consume much of my childhood, adolescence, and young adult life. I woke up thinking about what speaking situations I might encounter during the day. Whenever I did speak during the day I guarded against the stuttering and actually learned some tricks to "hide" the problem. I often pretended to be thinking when I encountered words that gave me difficulty. I also became good at substituting words I could say for words that I knew would give me trouble. I went to bed at night thinking about what speaking situations I might encounter tomorrow. The problem upset me tremendously, but I hid it, refusing to talk about it to anyone, even my parents. During that first half of my life it was one of the greatest challenges to my spirit and sense of self-worth.

I went through a few different unsuccessful therapies growing up. The earliest was a clinical trial at Johns Hopkins to test the effect on tranquilizers on stuttering. Then there were the useless speech therapy groups in elementary school where I was in with kids primarily with enunciation difficulties. I could enunciate fine... I just had trouble getting those clearly enunciated words to come out of my mouth. I even wasted money on 10 sessions with a hypnotist during my college years.

In college, I decide to become an accountant, partially because accountants don't have to talk, they just work with financial records... WRONG. After graduation, I quickly learned that communication skills are equally important as accounting skill to succeed in an accounting career. So in my late 20's, I had to communicate more and more and found it overwhelmingly difficult to deal with.

At that point I saw a psychologist, Dr. Stanley Berlinsky, who specialized in speech therapy. I wanted to be fixed right away, but was told that this could take years. I didn't know what else to do so I began weekly sessions with Dr. Berlinsky. I thought we'd mostly be talking about and working on speech issues, but that wasn't the case. One of Dr. Berlinsky's earliest questions was whether I considered myself to be an emotionally "open" person. I answered that I was, I had no problem expressing my joys and my

angers. Well, it didn't take long to find out that I was dead wrong in my initial assessment, particularly when it came to dealing with feelings of hurt, pain, embarrassment, etc.

So, that's when the hard work began, exploring and dealing with the hurtful things in my life, which I had learned to hide so well. Stuttering was just one of many. I spent about two years in psychotherapy and was committed to doing the hard work. With respect to stuttering, I began to be open about it. I had a long, tear-filled talk with my Mom and Dad making them aware of how much pain this problem had caused me in my life... they had no idea, but then I had hid it so well. I began to tell people that I had a stuttering problem, which had the positive effect of making me not have to hide it, and somehow made speaking easier. I stopped using tricks and word substitutions as much as I could and forced myself to say what I wanted even though I might end up stuttering more.

After two years, I left Dr. Berlinsky, not cured of stuttering, but more acceptant of my problem and more comfortable dealing with it. I got involved in the Washington, D.C. Council of Adult Stutterers and even became president of that organization for a year. A few years later, I mustered up the courage to apply for a job as an accounting professor at a community college. During the interview I openly addressed the fact that I stuttered, but despite that fact, I viewed myself as a good communicator. I ended up getting the teaching job (never in my early years did I think teaching was a possibility for me – my cousin, a former English literature professor told me that it was likely the fact that I had been successful at openly dealing with my stuttering that separated me from the rest of the applicants). For much of my teaching career, I always announced on the first day of class that I stuttered. I did this so that when those "blocks" and "repetitions" did occur during the semester the students would know what was going on. Doing this made it easier for me concentrate more on the subject matter and less on the speaking. I resonate with the words of Margaret Rainey, Ph.D., Director Speech Pathology, Shorewood Public Schools, Wisconsin, "When you begin to really accept yourself as the stutterer you are, you are on your way to much easier speech and most certainly to greater peace of mind"

I still am a stutterer and I also resonate with the quote in the bulletin that "I call myself a stutterer because I still have small interruptions in my speech now and then. But, there's another more important reason why I call myself a stutterer. I'm not trying to hide the fact anymore!"

So at this point in my life I no longer look at my stuttering as I did as a young adult - a horrible curse – a living hell. Had it not been for the stuttering, I doubt that I would have ever entered therapy where I learned the importance of being in touch with my feelings, both positive and negative and the importance of dealing openly and honestly with hurt and pain rather than hiding it and holding it inside. This is a lifelong process for me. I've been blessed that I have a wife who has often been able to tell when something was bothering me and has always encouraged me to talk about things that troubled me. The person that I am today to a large extent has been shaped by learning to deal with stuttering and becoming acceptant of this difficulty that life has handed me.