

The Grieving Process and Acceptance of Spasmodic Dysphonia by Iris Miller Stetson

In June of 1999, I lost my father and, unable to cope well, I sought the help of a grief counselor. By December, as I began to feel more like myself, I was diagnosed with spasmodic dysphonia (SD). I should have been ecstatic because I had struggled to speak since childhood and had spent decades searching for a diagnosis. Yet, when my doctor said, "You are severely speech-disabled with a classic case of SD," I fell apart. There was a sense of relief to finally have a name for my problem but I was overcome with fear that nothing could ever help me and in shock and denial that the words, severely disabled, were being used to describe me. I found myself mourning again, experiencing the first stage of grief.

For any of us diagnosed with SD, our lives and the way we see ourselves can easily change. Although there is no right or wrong way to respond, I believe that many of us suddenly find ourselves on a new path. I was on it, lost and trying to find my way, looking for acceptance and peace. Initially, I became overly anxious about work and other activities that I feared might be in jeopardy. What I thought or felt may not even have been based in reality but the feelings were real for me so I took them seriously. I waded through a sea of emotions with the understanding that, though painful, my discomfort was a normal part of grieving — a process that would help me to heal.

From grief counseling, I knew that one of the best things I could do was reach out to others and learn all I could about SD. Since it is hard for many of us with SD to speak, we may withdraw and become isolated but we can stay connected by getting professional help, joining a support group, chatting online through the NSDA Bulletin Board, and/or turning to a spiritual advisor, caring friend or family member. Additionally, the NSDA and many online sites can help us learn about SD. Once I began sharing my grief with others and became better educated, I gained momentum. Feeling more grounded, I began to move on.

The Elizabeth Kübler-Ross book, *On Death and Dying*, established the five stages of grief — denial, anger, bargaining, depression and acceptance. Though written in 1969, these stages are still considered the norm for anyone dealing with a terminal illness, the death of a loved one, or any serious loss. However, for an acquired life-changing disability like SD, I learned that the stage of acceptance is different. Many medical professionals call it "the restructuring phase," the time when we rebuild our identity.

Most people diagnosed with SD have a formed identity. To change how we see ourselves or to reconsider altering our work or lifestyle can be scary. However, change can be an empowering experience when we see it as a time to re-establish ourselves and grow.



This viewpoint helped me to face my feelings of inadequacy and build up my confidence. Looking at my reaction to the words *severely disabled* and the anxiety around my prognosis, I realized that two words did not define me and, instead of dwelling on my inability to speak, I needed to focus on my abilities.

In this effort, I became more objective. I started to see myself more clearly as I imagined someone else in my situation. Listening to their challenges and thinking of ways to help them gently pushed me to see new possibilities, become more creative and gain a healthier perspective. I felt a sense of control when I recognized that SD might affect certain things in my life but not everything. I might never have the perfect job but I could still work, read, listen to music, cook, write, be with loved ones, and smell the flowers along the way. Knowing that I may never again have the voice I once had, I began to accept that, whether or not I had SD, I was strong and capable.

Though having SD is challenging for many of us, one silver lining is that it puts us on a road of self-discovery. We find that our capability is not represented by the nature of our speaking voice but by our inner strength and determination, the qualities that make it easier to deal with any of life's hardships. I believe that having SD almost forces us to reflect on who we were, who we are, and who we want to be. As we gain a deeper understanding of ourselves, we learn that acceptance is not an act of surrender; it is coming to terms with our struggles. Ultimately, accepting that I have SD not only gave me peace but gratitude and hope — gifts that come when we not only see how much we have but how much we have to give.

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