

My Journey with Spasmodic Dysphonia

Finding support, and in turn working together to help others

My name is Andrea C. Butteworth. I am a 42-year-old woman with a happy life, and wow, now I am part of a group of people finding their voice. Here is my story and how I hope to contribute to helping others.

I would say I've always had a voice issue. I was teased in school on occasion, sometimes when at work, and in interviews I would always sound nervous. But that was just my voice, I didn't care, I love to talk. I suffered depression for so many years and with successful treatment I began to love myself, and started giving to others, offering empathy, and just meeting and talking to all sorts of people. I also love animals.

So, when I landed a job as a receptionist at a non-profit organization that offers low cost spay, neuter and vaccines I was ecstatic. For nearly two and a half years I was helping animals while educating clients, talking cheerfully about flea prevention, making appointments, and thinking I will retire here in the chair at this clinic.

It wasn't until my third year that people started noticing I sounded out of breath. First it was just my husband, and occasionally someone would say I had laryngitis. The breathiness continued so much and became so frequent that my husband was concerned I had breathing problems, and everybody always thought I was sick. I knew I wasn't out of breath no matter how bad it sounded. So I began my Google search. Thankfully I found results about Spasmodic Dysphonia. Finally, finally, all the breathiness, interruptions and breaks in speech, the trailing off in the middle of a sentence, having to constantly repeat myself and restart a sentence all the while explaining I'm not sick and I don't have laryngitis turned out to be something that had a name and a reason. And other people had it too!

Then I began to realize not many doctors have heard of it, getting diagnosis wasn't easy, and options for treatment were few. I went to three different ENT's and a Speech Therapist. Yet none of them definitely diagnosed me (although my chart stated I had spasmodic dysphonia-like interruptions) and so I was asked to try speech therapy before Botox[®] injections were considered.

I joined a spasmodic dysphonia support group on Facebook because I was becoming increasingly frustrated. Being able to connect with people who understood the emotional issues that come with this voice disorder has been more helpful than I could have ever imagined. No matter how much people who live and work with you say they understand they simply don't. More than the vocal interruptions, more than feeling self-conscious about our voices, more than disappointment and flat-out grief over losing certain abilities to perform tasks at work involving interaction with clientele and using the phone, there is the extreme exhaustion that comes with repeating oneself all day. The speaking to family members who are not focusing when you desperately need them to. The annoyance no matter how you tell people over and over it is a permanent medical condition they still say "I hope you feel better soon."

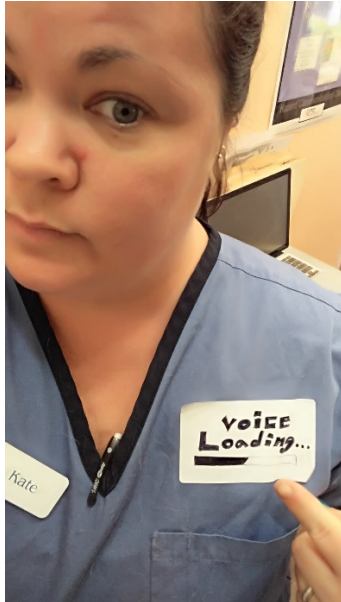
All of us in the group have wished there was a card, a sign, something that we could wear or hand out that said in essence, please look at me and be patient, I am not sick, not incompetent, drunk, or mentally incapable. Please give me the same respect you would give someone with a visible disability. Don't interrupt constantly.

We felt if we had something to wear, it would give us confidence, and allow people to recognize it is a disability that we have no control over, no matter how hard we try. I went for it and shared my ideas with the Group, and received so much positive feedback I decided to order some magnetic name tags.

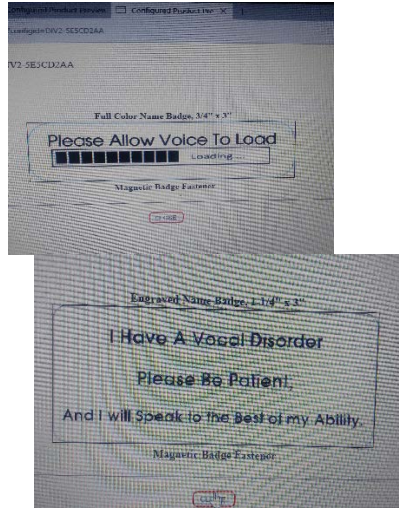
With the common ideas, support, and working with the NSDA, I hope that these buttons help many feel more confident and open the door for conversations about our unique vocal disability.

Here is evolution of our ideas, together with the NSDA's help:

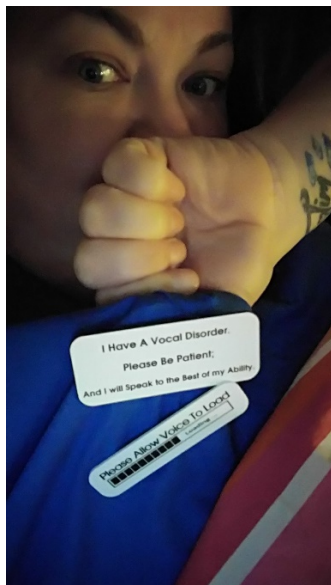
First version:



Online Order:



Nametag:



NSDA Button:

available at www.dysphonia.org

