Professor Manuel Pastor ‘speaks out’ on his experiences with spasmodic dysphonia

Many people may be surprised to learn that even seasoned public speakers like Prof. Pastor can struggle daily with a voice condition.

In this piece, PERE/CSII Director, Manuel Pastor explains what spasmodic dysphonia is, how it impacts his life, and the strategies to help manage it so he can continue "speaking out" for inclusion and justice.

Spasmodic Dysphonia and Me
by Professor Manuel Pastor

I have spasmodic dysphonia. Basically, it’s a neurological reaction where the muscles sort of twitch and tighten around your vocal chords – you can laugh, sing and shout (that all sounds joyful) but your regular speaking voice “breaks” a lot and sounds strained/hoarse. The “strangled voice” can get worse and worse and some folks just kinda stop speaking. The onset can be triggered by a sinus infection or stress but it’s neurological – so it’s really just lingering in you waiting for the trigger.

I could describe it more but you can also just read about it at these links; it kind of describes my symptoms perfectly.

- [http://rarediseases.about.com/od/rarediseaseass/a/spasdysphonia.htm](http://rarediseases.about.com/od/rarediseaseass/a/spasdysphonia.htm)

The Wikipedia entry is surprisingly complete but the second has some additional insights.

And for those who are really medical, try this Medscape.com article, [http://emedicine.medscape.com/article/864079-overview](http://emedicine.medscape.com/article/864079-overview)

There is no cure and the most prescribed treatment is regular injections of Botox in your throat: that essentially paralyzes the muscles so they stop responding to the neurological signals. In short, your brain is twitching but your neck doesn’t know it. If it works (and it does in my case), your voice initially becomes “breathy,” then it finds a new equilibrium, then sort of deteriorates till the next shot.

The shots are, well, not exactly fun (it’s a series of four accompanied by a camera running through your nose – kinda the opposite of fun). So most folks like to do the shots infrequently, like every three to six months. It’s not like I like to do them but I do shots once a month. That allows for a lower dose per shot and thus shorter breathy periods or end periods with a “breaking” voice. Still, I never quite know what my voice will sound like – although after years of doing this, I have a sense of the range. And phone conversations can be a particular challenge, partly because you can’t supplement your voice with visual cues.

Sounds like a bummer but on the other hand, as my daughter commented when I was first diagnosed, with a constant stream of Botox shots, I now have a young, beautiful and very fashionable throat.
There is also a surgical procedure that some folks swear by called Selective Laryngeal Adductor Denervation-Rennervation (SLAD-R). It essentially involves cutting the current nerve to your vocal chords and connecting up a different nerve — and hoping the new part of your brain learns what to do (I’m sure I described that badly but that’s why I’m an economist and not a doctor). More on the operation here: https://www.dysphonia.org/surgery.php

I haven’t done the operation because the Botox seems to be working (after some trial and error), the operation isn’t always successful and there are always risks with surgery. Maybe I’ll do it someday . . .

When I first developed the condition in 2010, I thought it was weird to be losing my voice after spending so much time working to develop it. But there are several famous people, including Robert F. Kennedy Jr., who have this condition, live with it, and also speak quite a bit. So it hasn’t stopped me from giving speeches around the country and it’s given me a chance to let people know about this — and it makes you choose your words more carefully (why waste the voice?).

What it does mean, however, is that my voice, even when clear does not project well — basically, I couldn’t yell if there was an emergency (which surprised me the first time I realized that) so you might want to have other friends around for dangerous situations.

As a result, I always ask for a microphone, even in situations where the room may be small (unless it’s a very small gathering) and it’s important that this is in place. It’s also important not to schedule me for talk after talk (folks like to have you chatting the whole time) but to build in rest periods.

Also, sometimes when I’m on a prep call for a speech, I can tell the folks on the other side can be thinking: “Gee, he sounds pretty flat. Hope he gets animated when he arrives.” Not to worry — as noted, phone conversations are harder and I figure why use the good voice for the prep when I can save it for the event.

Hope this all helps folks understand my speaking constraints. And let’s work together to get out a message of inclusion and justice: my voice that may not be as strong as it used to be in tone but, I hope, it is even clearer and stronger about why making change and achieving equity is imperative for the country’s future.

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Video examples of me speaking:

While some might folks have a “bad hair” day, I can have a particularly “bad voice” day— as was the case in this video:

Manuel Pastor on "Race and the Economy" - https://www.youtube.com/watch?v=oNQbc7KwY6U

Of course, I also (and generally) have “good voice” days. And with the aid of a microphone-- be it a podium, lavalier, headset, or handheld mic-- we get even better results as you can hear in the videos below:

Liberty Hill 2012 Changemaker Award - https://www.youtube.com/watch?v=s7n3uCHlSEM

2014 State of the Valley, Manuel Pastor Keynote - https://www.youtube.com/watch?v=M83TZSiQt-Q