

Spasmodic Dysphonia: Much More Than A Voice in A Movie

Actress Lupita Nyong'o recently shared that the sound of the voice of Red, her evil doppelgänger character in the new Jordan Peele movie, *Us*, was inspired by the voice of Robert Kennedy, Jr.* Mr. Kennedy suffers from spasmodic dysphonia, a neurological disorder that affects the voice. The most evil part of this voice condition is the life-changing impact it can have on those coping with it daily. It can rob a person's ability to speak and communicate clearly.

Normally, when a person speaks, the vocal cords vibrate in a synchronous manner. When a person has spasmodic dysphonia, the vocal cords will go into a spasm resulting in a very strained, broken, or whisper voice. The brain is sending the wrong signal and voice is impacted depending on whether the muscles in the larynx adduct (move together) or abduct (pull apart).

One of the toughest parts of having a disability is that people make assumptions based on the way you walk, talk or act, sometimes with little understanding of what is causing it. While this portrayal may raise much-needed awareness about spasmodic dysphonia, it is important to understand that a voice disorder can significantly affect an individual's social life, emotional well-being, and career. In a recent survey of people with spasmodic dysphonia, one participant shared, "Your voice is you. Your intelligence, emotions, abilities all come through in your voice... without it you become invisible."

We understand that hearing the unique sound caused by symptoms of spasmodic dysphonia was the spark of inspiration for the voice of this character. What is difficult for us, and for the thousands of people living with spasmodic dysphonia, is this association to their voice with what might be considered haunting, wilted or a result of emotional trauma especially since spasmodic dysphonia is a neurological disorder. We applaud the work of Ms. Nyong'o and this opportunity to educate about this rare voice condition, but for the Spasmodic Dysphonia community, this disorder does not end when the movie is over.

Spasmodic Dysphonia Quick Facts

Cause: Exact cause is unknown but based on current research, it is a neurological focal form of dystonia

Multiple Forms of Spasmodic Dysphonia: Adductor, Abductor, Mixed
Other voice conditions including vocal tremor and muscle tension dysphonia may be present

Common Treatments: Voice Therapy, Botulinum Toxin Injections, Surgical Interventions

Prevalence: Estimated 1 person per 100,000 in the United States, but SD is often misdiagnosed or undiagnosed so prevalence may be higher

Age of Onset: Typically 40-to-60 years-old but can occur even younger and often more common in women

About the National Spasmodic Dysphonia Association

The National Spasmodic Dysphonia Association is a non-profit organization dedicated to improving the lives of people affected by spasmodic dysphonia and related voice conditions through research, education, awareness, and support.

Contact Information

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*Reference to Spasmodic Dysphonia and Robert Kennedy, Jr. <https://www.nytimes.com/2019/03/20/arts/lupita-nyong'o-us.html>