

YOU ARE THE EXPERT:

What do you wish others would understand about living with spasmodic dysphonia

The National Spasmodic Dysphonia Association asked people with spasmodic dysphonia to share their thoughts on what they wish people would understand about what it is like living with spasmodic dysphonia. Not all may apply in your case but some of the advice may resonate with you. We thank all those who participated and hope this is helpful!

Personal/Regarding the sound of your voice

- I am not sick. I am not anxious. My spasmodic vocal sounds are not contagious. Please do not be afraid to treat me as a normal person.
- Me not talking doesn't mean I'm not interested. It probably means I'm tired from trying to talk. Talking takes a lot of energy. I hate when people say "It's ok. Don't talk." I have things to say too.
- That I hate the way my voice sounds. Kids stare at you like you are a freak so it is just easier to not talk. I guess you can see that I am very self-conscious.
- I took speech for granted until one day no sound emerged out of my mouth when I opened it to speak. The onset of SD was a shock beyond imagining. Not being diagnosed for years caused terrible consequences.

Tips for the outside world

- I appreciate when you treat me just as you would anybody. Lastly, be patient. I may speak slowly but I need to say what's on my mind just like anyone else.
- It makes me sad and frustrated when I have something to say and I just can't seem to break into the conversation. It is tiring. Sometimes it feels like too much work. When I'm with my family, I will sometimes raise my hand and wait to be called on. Funny and frustrating at the same time.
- I wish people would understand how difficult, frustrating and exhausting it is communicating with a voice that cuts in and out. Please don't dismiss our thoughts and ideas just because we can take longer when we struggle to express them.
- It is really frustrating being asked "What is wrong with your voice?" over, and over, and over again, by the same people who have known you for years.
- When I do talk, I wish someone would just listen and not criticize what I sound like.
- I wish people would understand that I'm not disabled physically or mentally - I just can't speak well. I've had people at work get angry at me because they couldn't understand what I was saying.
- I love how when my Botox works, like right now, that I almost forget how bad things can be when it doesn't work or when I need more!
- I've had solicitors call and ask what is wrong with me - am I laughing or crying? Don't question people about how they look or sound until you've walked in their shoes. No one would intentionally try and sound like that!

- People assume you're "slow" or anti-social. It's been hard for me to reconnect just from past ostracization. Nervousness makes talking harder, and then add in embarrassment when people ignore your input.
- The toughest part is that people think I am anti-social because of my inability to join in on a conversation. By the time I try to get the words out, the next person is already speaking. So my views mostly get left untold, unless it's a one-on-one conversation. I try my best though.
- I wish people wouldn't yell for me and expect me to answer them from the other room. I won't answer them back!
- Solitude is sometimes easier than the constant struggle to communicate.
- Companies and employers should read and learn about SD so they can better understand us and support those that continue working against the circumstances.
- I would appreciate it if people did not interrupt me.
- Living with SD isn't easy or cheap.
- I'm tired of being told to speak up, as my voice has always been soft.
- I want people to know that I'm not afraid of SD.
- It's hard to order at a drive thru.
- SD is isolating without a diagnosis. I have had it for 20 years and still feel isolated.
- I use sign language to communicate with my family and kids when in public. It's just easier when my voice is not there.

To those uncertain about it

- You can't catch it. And there is no pain.
- I hate when people say I sound terrible and that they hope I feel better soon and when I explain it's a neurological condition, they look like they want to back away from me.

The positive side

- I try to see the humor in every bad situation. It helps get through it. I got to where I couldn't pronounce my "P's" and my name is Pam. So it comes out as "Bam." Well, I work in Property Management and I deal with a lot of people from the Middle East who are coming to our country for the first time. So the majority of my residents think my name is Bam and that's how they address me. It's really funny if you think about it. The Botox injections every three months have been a miracle solution for me, though, and as long as I can keep them up my voice is great!
- SD is worse in our minds than in the minds of others. Don't blow it out of proportion. Also, it's just a part of you and not who you are. Concentrate on the positive and move forward.
- Even though this SD condition doesn't hurt, isn't fatal and isn't contagious, it is extremely exasperating and can almost push one into a state of frustrated hysteria! However, when one gets past this stage and realizes how others (without this condition) are trying their best to decipher what's being said and care what's being said, it can warm one's heart, because acceptance and support are vital in the life of those with SD.
- It's comforting to know we have each other. Helps to not feel so alone and frustrated.
- I have yet to meet face-to-face and converse with another person who has it. Without the NSDA, I am sure I would have no forum. I am thankful for its companionship and advocacy.