

YOU ARE THE EXPERT:

Spasmodic Dysphonia and Social Situations

The National Spasmodic Dysphonia Association asked people with spasmodic dysphonia to share their advice about how to manage social situations such as parties and family gatherings. Here are some suggestions that were collected. We share this as information only and not as an endorsement of the individual suggestions. We thank all those who participated and hope this is helpful!

Practical Tips

- Place an ear plug in one of your ears. It helps you dial down your volume (It affects how you hear yourself. Easier on the vocal folds so you do not strain so much)
- Raise your hand to let others know that you want to contribute or if you are not done talking.
- Decide if the situation is worth investing the effort to contribute.
- Use breathing techniques to start words.
- Give yourself permission to say “no” to going to events that you don’t really want to attend.
- If possible, avoid noisy environments but if you are in a noisy room and struggling to project your voice, look for an opportunity to move your conversation to somewhere quieter - perhaps an adjoining room, or lobby or hallway.
- Pretty much my standard way of introducing myself within a group: "Hi, my name is ____ and I have a voice disorder." Works for me, but I continue to be a great listener and not a big talker.

Rest & Hydrate

- Water. Lots of water.
- Get plenty of rest and use relaxation techniques.
- Deep breathing and more deep breathing.
- I find that a teaspoon of olive oil every morning soothes my throat.

Listening/Speaking

- Try not to speak over everyone. If they can't hear you, ask them to move closer.
- I find that when I listen better, my responses are better, and my voice has more strength.
- Remember that listening can be fun too. If I don't set high expectations for talking a lot, I can still be part of the fun without the personal disappointment.
- Talk softer and ask people to come close when speaking with them. Do not strain to talk louder.
- Speaking on the out breath with only 3 words at a time, and preparing 3-word social responses beforehand, has helped me cope better with parties. I attempt to redirect the conversation in this way with short questions + positive statements, such as "You look well/How's things?/love the music/food is good/let's sit down/are you dancing?" pausing to breathe in-between. I try to avoid questions that require long answers with 'long story really'/'tell you later'/'won't bore you/and your work?'/ 'that's interesting/oh really/you think so/sure me too/'need a drink?/get you anything?/etc.

- If someone asks about my voice, I say “I have damage to my vocal cords. I’m fine and healthy, but it’s a long story.” It works!
- Speak slowly so that others can understand.
- Try not to speak over too much noise. Only speak face to face.
- Most people are delighted to talk about themselves, so I try to get everyone I run into to do that. I’ve always been more of a listener so it hasn’t been that much of a change. It also tends to lead to a reputation as a good listener and keeper of secrets, so you become sought after as a confidante.
- Find a quiet place and be a good listener, which people will appreciate.
- Take a phone app to type in what you want to say.
- Enjoy those you are with and who love you.
- At social gatherings, scope out those you would like to converse with and try to talk one-on-one.

Fun Tips

- My voice is always at its best in the morning so I try to constantly chat throughout the day. It is at its worst when I’ve been silent (I live on my own) for a few hours and then try to speak.
- A happy mood helps.
- A smile goes a long way!
- Don’t strain to speak, just speak softly and enjoy yourself!
- Go! Have a blast!
- Be assertive in a light-hearted manner – smile.
- Have a sense of humor and talk one-on-one to a person at party.
- Escape to a good book when necessary.
- Don’t waste “verbal calories” (effort) on small talk.
- Humming helps.
- I stay away from caffeine and/or sodas.
- I drink wine as it’s the only thing that helps my voice (besides Botox®).
- Some people are okay with alcohol, but it usually makes me lose my voice, as do cold drinks. I try to stick to drinks that are at room temperature.
- Sing everything you want to say using carols.
- Some people have hearing problems, especially over age 65, so in a noisy situation, I find talking into their ear helps.
- Doesn’t always work, but fun to rehearse before going out because it boosts my confidence.
- Have to admit that I’ve been known to lie and say "it’s my phone" and act as though I am checking it just to give my voice a break or avoid a question.
- Taking a friend who can speak for me when I’m not understood is great.
- Always smiling first before speaking reassures people I’m OK, which is necessary as voice can make me sound very upset as if I’m about to cry.

Motivational Tips

- Don't hide behind your voice. Be social and enjoy the time together
- Try not to be hurt if friends, relatives, and family members do not understand. Sometimes, it can be hard for them to relate to your voice and they might want your old self to come back. Eventually, your friends and your family will accept you as you are now, but sometimes, feelings of anger and fear might get the best of us. When you are comfortable, explain SD to others. You might be surprised to find out how well they accept what you have once they understand it better.
- At a recent party, I listened a lot, moved around to different groups of people and was pleasantly surprised by how many people I was able to 'speak' with in that they read my lips because the rooms were very noisy and I can't speak. It would be so much more enjoyable to be able to speak but I'm slowly getting to the place that if some people don't want to take the time to 'converse' with me then it is their loss too ... not just mine.
- An important reminder from a different perspective on someone whose family member is affected by SD: "I'd say his willingness to talk about SD and answer questions was very helpful to my understanding of what it was and how it affected him. It went a long way to ease my concerns that he was in pain or overly straining his voice when he spoke."
- And remember your voice is just a part of you and you are so much more, so just enjoy the parties. Smile, laugh, use gestures and have a good time. You probably care more about the sound of your voice than others do. Don't worry and enjoy.

The National Spasmodic Dysphonia Association strives to make the lives of people living with spasmodic dysphonia better through research, education, awareness and support.

For more information about the organization, log on to www.dysphonia.org.
