

Staying Connected through Communication Laryngeal Dystonia (Spasmodic Dysphonia) and Communication

Staying connected requires working together. Let others know what you need.

Communicating with others when you have voice changes:

1. Give yourself some grace.

You are doing the best you can for what your body will allow you to do right now.

2. Explain what you know about your voice.

Many people are not familiar with voice challenges and what makes communication difficult. Let your family and friends know that you may have difficulty with your voice. Try this sentence: "I have difficulty with _____. It helps me when you _____ when we talk."

3. Having a conversation may be easier earlier in the day.

Your voice may get tired over the course of the day. If you are tired or having more difficulty than usual, let the other person know. Schedule a time to talk later. Plan to have important conversations or appointments at a time when your voice is most rested.

4. Communicate in a quieter environment; have face-to-face conversations.

Turn off the TV, radios, or other noise distractions. Try to have conversations in quiet places where you can be face to face. Avoid having conversations with someone who is in a different room or far away from you.

5. Connect with people with similar experiences.

As much as your family and friends care about you, they may not fully understand what you are experiencing. Connect with professionals who have expertise in the area or other people with similar experiences. Here are some examples:

- a. **Ask your doctor to refer you to a speech-language pathologist.** While speech therapy does not cure laryngeal dystonia, speech-language pathologists often work with people with voice changes to help them manage their day to day activities and to communicate with other people.
- b. **Connect with groups in-person.** Look for voice groups that may be meeting near you for support and camaraderie. Your doctor or other healthcare provider may know of some groups.
- c. **Connect with online groups, such as dysphonia.org.** Online groups allow you to connect with people with similar experiences but do not live near you. Consider groups backed by a reputable organization, or with strong moderators who keep content safe.

6. Sometimes staying connected does not require conversation.

Invite loved ones to do something that you enjoy together that does not depend on a lot of speaking such as watching a TV show or movie together, or going on a scenic walk that you find enjoyable and relaxing.

7. Your voice does not define you.

Having changes to your voice is undoubtedly very challenging. Remember that you are more than your voice. Advocate for your needs, express your concerns, and ask for accommodations when necessary. You have the right to be heard and understood no matter how you communicate.



Communicating with a family member or friend with voice changes:

1. Give yourself some grace.

Sometimes finding the right thing to say is difficult. While you want to be present for your loved one, this impacts you too, and it is ok to acknowledge that.

2. Be patient and give them time to speak.

The pace of conversation may be different from before since speaking could take longer or require more breaks for your loved one. It is helpful to intentionally set time aside for important conversations. Be patient and give them time to communicate their thoughts.

3. Listen actively.

Listen attentively to what they are saying, even if their speech is difficult to understand. Show them that you are interested in what they have to say. Pay attention to other ways that they are telling you their story, such as facial expressions or gestures. Focus on their ideas and thoughts rather than their speech.

4. Avoid interrupting or intervening.

Interrupting their speaking can be frustrating and can make communication more difficult. Allow them to finish speaking before responding. Trying to help by finishing their sentences can be frustrating and can lead to miscommunication.

5. Be supportive and understanding.

Your loved one may feel self-conscious, embarrassed, or frustrated about their speech. Remind them that they are more than their speech. Ask them what might help to make your conversations more successful.

6. Ask them how you can support their communication.

Ask your loved one what might help to make your conversations more successful. What works for one person might be different than what might work for another person. Be willing to explore new ways for communicating.

7. Communicate in a quieter environment.

Turn off the TV, radio, or other noisy distractions. Have conversations in quiet places, preferably face-to-face.

8. Voice with laryngeal dystonia can fluctuate.

Your loved one's voice will be harder to hear in noisy situations, when they have done a lot of talking, or have otherwise had to strain their voice. The effectiveness of their treatment regimen may change from week to week. Just because they could talk easily and clearly at one time does not mean they may do so hours or days later.

9. Sometimes staying connected does not require conversation.

People with voice challenges may notice their voice tiring out quicker than before. If speaking becomes frustrating, suggest activities that do not involve a lot of conversation such as watching a show together or going on a walk together that your loved one finds enjoyable and relaxing.

RESOURCES:

- Dysphonia International <https://dysphonia.org/>



<https://sites.uw.edu/speaclab>