Support Group Meeting Topics Workbook for Spasmodic Dysphonia

Produced by the National Spasmodic Dysphonia Association
Introduction

This “Support Group Meeting Topics Workbook” is a project of the NSDA Support Group Leader Committee. Its members are: Mary Bifaro, Carol Doles, and Concetta Griffin. Additional assistance for this project was provided by Kimberly Kuman, Charlie Reavis, Mel Dubovick, and David Barton.

The pages of this workbook are intended to be used as “lesson plans” by both our new and experienced leaders. We have found that they can be especially helpful for meetings where there are no speakers planned. In addition, an evaluation form has been provided at the end. This form can be distributed to members at the end of each presentation.

We have compiled various meeting topics with goals and background information as well as instructions for implementation which should help to produce stimulating discussions. We are interested in hearing from leaders with other topics that they would like to see developed. Use this workbook as another resource in your leader’s toolbox.

Let us continue to learn from one another!
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Support Group Meeting Topic #1

Discussion Questions for Support Group Meetings

Meeting Goal
Participants will discuss (1) the impact that spasmodic dysphonia (SD) has had on their lives - both positive and negative; (2) how they cope with SD; (3) who and what have been helpful in their SD journey; (4) what they have learned about themselves because of having SD.

Instructions to Meeting Facilitator
Read the introduction information to the group. Have the hand-out available for meeting participants so they can write down their answers. Ask for a volunteer note-taker so a summary can be compiled at the end. Alternatively, read a question and then open it up to discussion.

Introduction
Living with spasmodic dysphonia can affect many aspects of our life. Through the discussion of these questions, we will look at different ways, both positive and negative, that SD has impacted our lives

1. What have you learned about yourself since being diagnosed with SD?
2. Do you usually tell people about your SD? In what context?
3. Does having SD limit your communication? In person? By phone? If so, how do you deal with it?
4. What are three pieces of advice you would give to those new to SD?
5. Fill in the blank: “Living with spasmodic dysphonia is like............”
6. Have you ever used journaling to get out frustration and feelings associated with SD? Does it help?
7. Have you read any of the books about SD? If so, what was your impression? Did they help?
8. Is there any occupation where SD would be a benefit or wouldn't matter very much?
9. Do you think any famous and notable people in history had disabilities, SD or otherwise? Did their conditions hold them back?
10. What is one positive thing about having SD?
11. What have you learned from having a disability like SD?
12. What bothers you most about having SD?

13. Has having SD changed your personality? If so, in what way?

14. Who in your life has been the most supportive of your struggle with SD? How have they helped you?

15. What was the most difficult part of dealing with SD before you were diagnosed?

16. Voice is important for communication, social interaction, career, and personal identity. For which of these four categories do you think voice is most critical? Why?

17. Have you ever found your SD useful as an excuse (or have you ever used it to your advantage)? Explain.

18. What have you learned about yourself since being diagnosed with SD?

19. How do you define “complete acceptance” of SD? What makes someone “well-adjusted” to life with SD?

20. Who is (insert your name here)? List some of your qualities, characteristics, interests, passions. List some things that give your life joy and meaning.
Support Group Meeting Topic #2

Suggested Discussion Topics for the Book: “Easier Done than Said: Living with a Broken Voice”

Goal: Meeting participants will have a better understanding of the information covered in this easy-to-read book. Meeting participants will describe how they cope with SD and what changes they have made in their lives because of SD. Participants will walk away with an action plan on how they can continue to improve their own coping capabilities or ability to live a positive life with SD.

Introduction and background statement: To be read by meeting facilitator:
This book is designed to address the challenges associated with SD. It was written by people who suffer from SD and professionals who work with SD patients. It is a compilation of shared experiences from within the SD community.

Instructions:
Option 1: Have the handout available for meeting participants so they can write down their answers and take notes during the discussion. Divide the list of 10 questions among the meeting participants. Explain that each participant will have five minutes to respond to the topic they have been assigned. Ask for a volunteer note-taker to help compile a summary. Have some copies of the book available so that it can be consulted if necessary during the discussion.

Option 2: Break the group into pairs and assign (or having each pair pick) one of the topics. Each pair will discuss the question for a set time. Then bring the group back together and debrief each pair’s discussion.

Ice-Breaker Exercise: Have the moderator led a contest/game to identify the components of the larynx and their specific functions in voice production. (Chapter 1).

Suggested Discussion Topics

1. The book states that voice is important for communication, social interaction, career, and personal identity. For which of these four categories do you think voice is most critical? Why? (Chapter 2)

2. What was the most difficult part of dealing with SD before you were diagnosed? (Chapter 3)

3. The book postulates that one cannot advocate on behalf of others until one has achieved a measure of acceptance about SD. However, some people feel that advocating helps them accept SD. In your opinion, does advocacy lead to acceptance or is acceptance a prerequisite for advocating? (Chapter 3)
Support Group Meeting Topic #2: Discussion Topics for “Easier Done than Said”

4. One of the differentiators of the Six Stages of Acceptance model is that people do not progress in a linear fashion towards acceptance, as they do in the traditional five step approach. What is the highest level you have attained on the model? What techniques do you use to help you return to a higher level when you feel yourself slipping to a lower level? (Chapter 3)

5. How do you define “complete acceptance” of SD? What makes someone “well-adjusted” to life with SD? (Chapter 3, 4)

6. How do you know if your treatment has been “successful”? What does “success” look like? (Chapter 4)

7. What positive things have you gained by having SD? (Chapter 4)

8. How has SD affected your work life? Have you avoided certain types of work within your chosen profession because of your SD? Have you developed new work-related interests or talents as a consequence of having SD? (Chapter 5) [Suggest adding a follow-up question like “how have you adjusted your work responsibilities to accommodate your SD?”]

9. Conduct an informal support group poll to see how your support group’s responses compare to the overall survey results. (Appendix)

For questions 3 and 9, be sure to position the questions so that the participants walk away with a positive feeling of self-help or ideas for how to move forward. Otherwise, it could be very easy to slip into a very negative/depressing discussion about how everything has gone wrong. While it’s important to give people in support groups a chance to vent such frustration, the support group should also try to help them find their way to the end of the tunnel by focusing on moving forward. Finding the positives or ways forward is always the harder part and the benefit of a group.
Support Group Meeting Topic #3

*Adjusting to Spasmodic Dysphonia:*
*A PowerPoint Presentation*

**Meeting Goal**

Participants will learn how to change, adjust and adapt to our SD disability and why it is necessary to transform and renew our lives through a positive creative approach.

**Instructions to Meeting Facilitator**

*The support group must have the proper equipment to show the presentation. It requires the following:*

- The PowerPoint file (can be obtained from the NSDA) loaded onto your computer; normally this is a laptop for ease of transport.
- A projector that accepts a PC as the input device. These projectors are commonly installed in meeting rooms, usually on the ceiling. However, there are small portable projectors of this type that can be carried with you and are set up on a table.
- Make sure that the projector's AV cord has a connector that fits your laptop.
- A remote control for the projector. Most projectors come with one and it is easier to use the remote than to use the buttons on the projector to make selections.
- A screen or lightly colored wall.

**Setting up the Projector and PC**

Setting up a laptop and a projector can be a little tricky. If you are bringing your own portable projector, then you will probably know which settings to use. If the projector is unknown to you (installed in a meeting room), then ask anyone familiar with it to help you, or be prepared to experiment - before the presentation!

**Giving the Presentation**

Lead the group through the following steps:

1. *Read the introduction statement:* SD is a very difficult disorder to come to terms with. In our journey to accept our condition and experience movement in our lives we need support, education and assistance. One of the tools to help us achieve this is through such visual aids as the PowerPoint presentation, ‘Adjusting to Spasmodic Dysphonia' by Tom Hoffmann, PhD. This presentation can help stimulate group learning and discussion to accomplish our goal. Tom worked on this presentation with his colleague, George Bair, ED. He first presented it in the NSDA Leadership Training Session at the Denver Regional symposium in May 2010. Tom has spasmodic dysphonia and is the Chair of the Applied Psychology Program at Hodges University in Florida.
2. Each individual member will take turns reading the text on each slide as it is presented so that everyone has an opportunity to participate.

3. Halfway through the presentation, you can pause for a quick summary. There's an appropriate point when the three stages of the grief process are explained. The presentation can be paused at this point to ask, "What stage do you think you are in and why?" The three stages are: pre-acceptance, acceptance and renewal. We will come back to this at the end of the presentation for discussion. So far we have learned the functional communication effects of SD and its impact on our personal, physical and social lives. An emotional adjustment is necessary through a grieving process when we suffer an emotional loss. We must learn to adapt and then transform ourselves. This is the ‘psychological cascade’ model that goes through the stages of coping with our voice disorder.

4. After the presentation, get a general consensus of the presentation, e.g. helpful, not helpful, positive, etc., and the reactions about how the slides speak to each of us differently.

5. Break up into three smaller groups to discuss each stage of the grief model in emotionally coping with SD. For each stage the group is to discuss: if they are at that stage, why, the challenges and chronic themes of that stage and how to move on in a creative and positive manner. A spokesperson and recorder should be chosen in each group. Set a time frame for the small group discussions.

   **Group 1** The first stage is viewing our voice disorder as a threat or the pre-acceptance stage.

   **Group 2** The second stage is falling into the pit where we learn acceptance. This is giving in **without** giving up.

   **Group 3** The third stage is renewal or transformation in the functional/social/psychological domains.

6. Join back together in the large group to report on each stage and then open it up to general discussion. Some may feel that there is not a linear progression in the stages but rather a moving back and forth between stages. Some may not identify with the stages in the same way as others.

**Summary**

*Read the summary statement:* For each of us the death of our old voice bothers us, but we have to move on and accept what is. SD is not what we wanted or wished for as it changes our lives dramatically, but we learn that change happens and that it's part of the human condition. SD people are unique and have a wonderful stubborness. There are examples amongst us of moving on to more appropriate and better careers as we adapt to SD. One's reaction to SD is dependent on each person's approach to life in general. To gain acceptance and a positive approach to our SD we must change what we can and accept what we cannot change in order to move forward.
Support Group Meeting Topic #4

How Spasmodic Dysphonia Affects Our Family and Us

Meeting Goal
Participants will examine: (1) the emotional impact of having SD; (2) how friends, family, co-workers and strangers respond to our SD diagnosis affects us; (3) how support groups can help us and our friends and family

Instructions to Meeting Facilitator
Hand a copy of this sheet to each meeting participant. Explain to them that the sheet will be read aloud. Instruct them to circle the parts that they would like to comment on. Use this as a discussion starter. Write a summary of the discussion to be used as a handout for the next meeting and to be shared with the entire SD community.

- SD is a unique and individual disorder.
- SD affects us both physically and emotionally.
- Support Groups give help and support.
- Support is a critical piece to understanding and dealing with SD.

How our families, work colleagues, friends, and strangers deal with our “elephant in the room” is very important. How they deal with it affects them, and how they react affects us.

- Husband or wife
- Children
- Boss
- Friends
- Extended families
- Strangers

Support Groups help in giving information and understanding to our loved ones. Members and attendees can hear other SD voices. They can listen to our unique problems re: how to cope with the everyday challenges of living with SD.

- Looking for a job
- Losing a job
- Explaining why we sound different to a child

Since there is no cure for SD, the reaction by others to our SD problem is very important. We have to accept ourselves as we are and our loved ones do too. Sometimes the loss of our voice can be so overwhelming that we have to remember that we have SD but it does not have us. SD is a part of who we are, but it is not our whole being.
Support Group Meeting Topic #4: How Spasmodic Dysphonia Affects Our Family and Us

Things to Remember:

- Try not to be hurt if friends, relatives, and family members do not understand. Sometimes, it can be hard for them to understand and they might want your old self to come back.
- Eventually, your friends and your family will accept you as you are now.
- 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.
- Listen to the explanations that family members and close friends give re: SD and how you cope with it.

*Special thanks to the Altoona, PA Spasmodic Dysphonia Support Group for sharing this discussion topic.*
Support Group Meeting Topic #5

*Top Ten Things We Hate about Spasmodic Dysphonia*

**Meeting Goal**
Participants will list obstacles presented by the SD voice that bother them. Participants will discuss obstacles and will determine possible solutions for lessening the frustration with those obstacles.

**Instructions to Meeting Facilitator**
*Read the introduction information to the group. As a large group, brainstorm obstacles/frustrations presented by having SD. Examples are provided to help lead that portion of the discussion.*

*Then divide the large group into small groups. Each small group should choose some items from the list that are particularly frustrating to those in the small group, prioritize their list, and begin discussing ways that they cope successfully with the items.*

*After, join back together for a time of sharing. Each small group should share an obstacle and the possible solutions. Then, other groups should be given a chance to comment and give additional ideas for dealing with that obstacle. Then, the next group will tell about a different obstacle, etc.*

**Introduction Information**
Spasmodic dysphonia is here to stay. Sometimes it really stinks. There are hard things that SD patients deal with in regard to their families, work, insurance, emotions, isolation, etc.

One positive note is that we all understand. We all deal with many of the same issues. We can discuss things together and share our successes with one another.

Today, we will list the top ten things that we really don’t like about SD. Then we will brainstorm some ways to address, work through, overcome, and deal with these problems.

**Examples for Large Group Discussion**
*These examples from Columbus area SD support group may be used to “jump start” the discussion: meeting strangers, rejection/dismissal, being misunderstood, being asked frequently and over and over to repeat ourselves, the effort it takes to express an idea, being cut off by impatient people, disqualification from some jobs and areas of society, side effects from treatments, fear of public speaking, loss of the ability to be spontaneous in speech - make jokes - join in on conversations, the reaction of fear that we have something contagious (cold, flu), having to explain our voice problem, using the phone, the inability to have long chats on the phone, trying to judge how much to share about our SD and to guess how much this person really wants to hear, frustration at the inability to perform, fear that we will not be able to be understood in an emergency situation, trying to order at drive-throughs, noisy situations...*
Examples for Large Group Discussion (continued)
voice-only activation systems, restaurants, physical exhaustion from a day of speaking, the
discomfort in talking, sounding like we are upset and about to cry, lack of awareness about SD,
the look and sound of pity given to us by others, feeling the need to lie to cover up our SD, not
wanting to explain our condition, loss of a singing voice, feeling that our opinions are dismissed
and not respected, people finishing our comments, social gatherings, not being able to read
stories out loud, loss of ability to connect with others through speech.

Example of Small Group Presentation
Obstacle: Talking clearly in front of groups/situations that are stressful.

Possible Solutions:
- Get plenty of rest.
- Practice so that the material is recited from memory.
- Practice relaxation techniques.

Additional solutions from Columbus area SD support group:
- Raise your hand to let others know that you want to contribute and are not finished
giving your thoughts.
- Be assertive in a light-hearted manner – smile.
- Speak slowly so that others can understand.
- Prepare short explanations in advance.
- Decide if the situation is worth investing the effort to contribute.
- Use a voice amplifier/microphone as a visible sign to others
- Be aware that certain situations are inevitable. Accept and anticipate the problem and
determine to change your attitude.
- Use breathing techniques to start words.
- Get plenty of rest and use relaxation techniques.
- Have a small card ready to distribute to share information about your SD.
- At social gatherings, scope out those you would like to converse with and try to talk
one-on-one.
- Don’t waste “verbal calories” (effort) on small talk.
- Weed out the people that will not offer understanding and will not listen to you.
- Avoid noisy gatherings that you don’t want to attend.
- Use a speaker phone.
- Dismiss difficult strangers remembering that you will not have to talk with that
person again.
Support Group Meeting Topic #6

New Year’s Resolutions for the Faint of Voice: Living with Spasmodic Dysphonia Ain’t for Sissies

Meeting Goal
Participants will (1) think of resolutions relating to communication, career, social interaction and personal identity that can help them cope with SD; (2) realize that living with SD takes courage and determination.

Instructions for Meeting Facilitator
Read the introduction information to the group. Have the hand-out available for meeting participants so they can write down their answers. Ask for a volunteer note-taker so a summary can be compiled at the end. The examples below are an assist to facilitate the discussion.

Introduction
As we move closer to the end of the year, we often start making resolutions to help improve our lives. List some New Year’s resolutions you have made in the past (examples: lose weight, quit smoking, get a new job, become more spiritual, etc.) Let’s now consider the four areas which are affected by voice: Communication, Social Interaction, Career, and Personal Identity. Think of some New Year’s resolutions that might help you cope with your SD or focus more on yourself instead of on your SD. Try to fit them into the various categories.

Communication
- Join Toastmasters
- Take a Dale Carnegie class
- Try voice exercises
- Read a book about SD
- Become part of a study at NIH
- Send more cards and letters
- Email an old friend

Others:

Social Interaction
- Volunteer
- Join a group – flower club, fire company
- Connect with old friends
- Start a dinner club

Others:

Career
- Take a course
- Go to a website and do a career matching quiz
- Have a professional help you with your resume
- Visit the Office of Vocational Rehabilitation

Others:

Personal Identity
- Take a non-credit course
- Write a book
- Read more books
- Find a cause – volunteer
- Find a new hobby – painting, crafts
- Learn a musical instrument

Others:

Special thanks to the Lehigh Valley Spasmodic Dysphonia Association for sharing this topic discussion.
Support Group Meeting Topic #6: New Year’s Resolution for the Faint of Voice

List some New Year’s Resolutions you have made in the past.

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Now think of some New Year’s resolutions that might help you cope with your SD or focus more on yourself instead of on your SD. Try to fit them into the various categories.

Communication:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Social Interaction:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Career:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Personal Identity:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
Support Group Meeting Topic #7  
*Dealing with Stress and Spasmodic Dysphonia*

**Meeting Goal**
Participants will acknowledge the negative effect stress can have on the SD voice and will determine ways to reduce stress overall and as it directly relates to SD.

**Instructions to Meeting Facilitator**
*Read the introduction information to the group. Follow the directions for the large and small group activities as outlined.*

**Introduction**
Stress can have many negative side effects. For the SD patient, stress can adversely affect the sound of the voice. Since the SD patient may perceive this as a negative event, the sound of their own voice can also be a source of stress for the SD patient.

Managing stress is all about taking charge: taking charge of your thoughts, your emotions, your schedule, your environment, and the way you deal with problems. Stress management starts with identifying the sources of stress in your life. This isn’t as easy as it sounds. Your true sources of stress aren’t always obvious, and it’s all too easy to overlook your own stress-inducing thoughts, feelings, and behaviors.

*Facilitator may insert a personal example or read example provided. Example: I find that speaking in front of large groups is stressful. In reality, I enjoy speaking in front of groups when my voice is working. It isn’t the large group or the speaking that is the source of stress; it is the sound of my voice.*

To begin the process of learning to identify the true sources and to manage stress, start with a stress journal. A stress journal can help you identify the regular stressors in your life and the way you deal with them. Each time you feel stressed, keep track of it in your journal. As you keep a daily log, you will begin to see patterns and common themes.

Write down:
- What caused your stress (make a guess if you’re unsure).
- How you felt, both physically and emotionally.
- How you acted in response.
- What you did to make yourself feel better.

**Large Group Activity:** *As a group, list stressful situations. Examples: phone, drive-throughs, meeting new people.*
Additional Background Information: After a time of brainstorming and recording ideas, the meeting facilitator should read additional background information.

If your methods of coping with stress aren’t improving to your greater emotional and physical health, it’s time to find healthier ones. There are many healthy ways to manage and cope with stress, but they all require change. You can either change the situation or change your reaction. When deciding which option to choose, it’s helpful to think of the Four As: Avoid, Alter, Adapt, or Accept. The first two deal with changing the situation. The last two deal with changing your reaction. Since everyone has a unique response to stress, there is no “one size fits all” solution to managing it. No single method works for everyone or in every situation, so it may be helpful to experiment with different techniques and strategies, and focus on the ones that help you to feel calm and in control.

The four techniques can be explained this way:
1. Avoid unnecessary stress. Not all stress can be avoided, and it’s not healthy to avoid a situation that needs to be addressed. You may be surprised, however, by the number of stressors in your life that you can eliminate.
2. Alter the situation. If you can’t avoid a stressful situation, try to alter it. Figure out what you can do to change things so the problem doesn’t present itself in the future. Often, this involves changing the way you communicate and operate in your daily life.
3. Adapt to the stressor. If you can’t change the stressor, change yourself. You can adapt to stressful situations and regain your sense of control by changing your expectations and attitude.
4. Accept the things that you can’t change. Some sources of stress are unavoidable. In such cases, the best way to cope with stress is to accept things as they are. Acceptance may be difficult, but in the long run, it’s easier than railing against a situation you can’t change. Yes, life can be unfair, but you are only on this planet once.

Small Group Activity: Meeting facilitator should divide the group into smaller groups of 4-6 persons. Support groups may opt to stay as one group and do the activity together. Explain that groups should look at the list of stressful situations and should apply the Four As to determine ways to reduce the stress in the situations. After a time of discussion, the groups should meet back together to share findings.

Large Group Activity: Share findings.
Support Group Meeting Topic #7: Stress and Spasmodic Dysphonia

Small Group Leader Instructions: Examine each of the four ways of dealing with stress. Apply the techniques to the items listed in the large group activity. Example: How can we use avoidance to reduce the stress created by one of the situations listed? Read examples below if needed to get the discussion started. You will be asked to share your ideas with the other groups.

AVOID unnecessary stress. Eliminate stressors when possible.

- **Learn how to say “no”** – If agreeing to a request will create stress and you cannot alter the situation, feel free to reply, “No”. Example: if asked to make phone calls for a non-profit organization during a “bad voice” time, suggest that you could help in another way by recording results, assembling a direct mailing, etc.

ALTER the situation. Change things so the problem doesn’t present itself in the future. Often, this involves changing the way you communicate and operate in your daily life.

- **Be more assertive.** If you will be dining out with others, share your needs with the group and suggest a quiet environment. Ask the waiter to seat you away from noise if possible. Let others know your needs and how they can help make a situation less stressful.
- **Take control of your environment** – If you will be speaking in front of a large group, arrange a good microphone system. Memorize your speech so that you are not trying to think about what you are going to say. Get plenty of rest the night before.
Support Group Meeting Topic #7: Stress and Spasmodic Dysphonia

ADAPT to the stressor. If you can’t change the stressor, change yourself. You can adapt to stressful situations and regain your sense of control by changing your expectations and attitude.

- **Reframe problems.** Try to view stressful situations from a more positive perspective. Example: Rather than fuming about not being able to converse freely at a social gathering, look at it as an opportunity to listen and allow others the valuable opportunity of having someone really listen.

- **Look at the big picture.** Assess the stressful situation. Ask yourself how important it will be in the long run. Will it matter in a month? A year? Is it really worth getting upset over? If the answer is no, focus your time and energy elsewhere. Example: If you cannot order through the drive-thru window, could you go inside instead to speak face-to-face to the cashier?

- **Adjust your standards.** Perfectionism is a major source of avoidable stress. Stop setting yourself up for failure by demanding perfection. Set reasonable standards for yourself and others, and learn to be okay with “good enough.” Example: your voice may not sound “normal”, but you have valuable insight and thoughts to share. Be willing to allow others to hear the content of your ideas and see past the sound of your voice.

ACCEPT the things that you can’t change. Some sources of stress are unavoidable. In such cases, the best way to cope with stress is to accept things as they are.

- **Don’t try to control the uncontrollable.** Example: You may not be able to control the results of every botulinum toxin injection, but you can enjoy the good injections and accept the not-so-good ones. Your voice may not work well enough for you to continue in your current career, but there may be other ways to work in that area. Example: You may not be able to teach in a classroom, but you could teach an on-line course.

- **Focus on the positive.** When facing major challenges, try to look at them as opportunities for personal growth. Take a moment to reflect on all the things you appreciate in your life, including your own positive qualities and gifts.

**Resources**

Support Group Meeting Topic #8

Being Assertive with Spasmodic Dysphonia

Meeting Goal
Participants will distinguish between positive and negative behaviors associated with assertiveness. Participants will identify situations in which personal assertiveness would be beneficial and will list behaviors that they will employ to bring about a better outcome in those situations.

Please note that there is no shortage of self-help material available to teach a person to be assertive. This meeting topic cannot begin to adequately cover the philosophy or specific techniques taught. The goal of this topic is to recognize that there are situations in which they could be more assertive and to discuss some possible ways to address those situations.

Instructions to Meeting Facilitator
Read the introduction information to the group and lead discussions for each section. Ask someone to record answers on white board or large paper.

Introduction
Many SD patients find that the inability to converse freely has affected their ability to be assertive. They find themselves in situations where they are not comfortable sharing their thoughts and needs. We first need to determine what assertiveness is and what it is not.

1. Defining Assertiveness
About.com defines it as, “Assertiveness is a form of communication in which needs or wishes are stated clearly with respect for oneself and the other person in the interaction. Assertive communication should be distinguished from passive communication (in which needs or wishes go unstated) and aggressive communication (in which needs or wishes are stated in a hostile or demanding manner).”

Being assertive does not mean that you get your way in every situation. There are times when we should not be assertive. We will look at situations in which assertiveness would be beneficial and some techniques for implementation.

How do you define assertiveness?

Discuss and record answers.
2. Verbal Characteristics and Body Language

Assertiveness training involves both verbal characteristics and body language. Verbal characteristics cover the way our voices sound and our choice of words. In addition to verbal messages, our body language also conveys a message. What are some behaviors that would convey confidence and a positive message to our listeners?

Brainstorm situation and record answers. Examples may be used as needed to “jump start” brainstorming process.

Examples (verbal):
- Voice: firm, relaxed, appropriate volume, “I” statements
- Tone: even, sincere, clear
- Phrases: avoid “should” and “ought”, make statements of facts, avoid placing blame, make requests for opinions/ideas

Examples (non-verbal):
- Attentive listening
- Direct eye contact
- Level head
- Open body stance
- Appropriate facial expressions

3. Improving Assertiveness

Assertiveness training literature states that being assertive will help you improve/strengthen personal and professional relationships. When two workers have similar experience and expertise, but one is assertive while the other is not, the assertive worker will have an advantage. Some other benefits of assertiveness are a reduction in stress, fewer conflicts, and healthier interactions with others.

There are many reasons why we are not assertive when we should be. There are some very real obstacles for anyone who has SD such as the ability to speak clearly, to achieve an even tone with some level of volume, and to respond quickly in a group where many are sharing thoughts in rapid succession. Instead of participating in a conversation, it is tempting to fall into a negative thought pattern. In some situations it is best not to be assertive (e.g. road rage, dealing with an unreasonable person). Let’s think of some situations where your SD has hindered communication and resulted in a lack of assertiveness.

Brainstorm situation and record answers.

Examples:
- a. Family
- b. Work
- c. Social gatherings
- d. Places of business (grocery, bank, school)
Consider the list of situations just completed. List possible reasons for not being assertive.

Examples:
Work - inability to speak loud enough to be heard, sound like I am upset or emotional

Brainstorm suggestions about how to be assertive in these situations. It is not necessary to record responses on a large board.

Examples:
Work: inability to speak loud enough to be heard
Communicate with the leader of the meeting about your needs, determine a signal or way for you to communicate that you have something to add (raise your hand), use a voice amplifier, ask for a change to a quieter location

Work: sound like I am upset or emotional
Explain to co-workers that you have a voice disorder and one characteristic of that is you can sound upset or emotional. Let them know that you are neither. Use body language to confirm that you are not upset. Determine to focus on the content of your message and not worry about the sound of your voice.

Other tips/suggestions:
• Write it down. Be specific. Be brief.
• Expect others to listen to you.
• Practice in front of a mirror.

Resources

How to be Assertive by Speaking Fluent Body Language by Michael Lee:

Being Assertive by Gina Gardiner: http://www.earthlingcommunication.com/a/assertive-skills/assertive-tips-techniques-communication.php

Reduce Stress with Increased Assertiveness by Elizabeth Scott, M.S. www.about.com
Support Group Meeting Topic #9

Psychological Aspects of Spasmodic Dysphonia

Meeting Goal
Participants will explore the psychological aspects of SD by considering their restrictions in occupational and social domains; rating their particular voice quality; and deciding what their self-view is as a consequence of having SD.

Instructions to Meeting Facilitator
Hand out a copy of the worksheet (second page) and a pen to every meeting participant. Read the introduction information to the group leading up to Parts One, Two and Three. Inform meeting participants that friends/spouses of SD persons can answer/discuss based on their interpretation of how their SD friend/spouse is coping with SD.

Explain that there are three parts and each part has three options. Ask them to circle the option which is most relevant to their SD experience. They will then be asked to explain why. Ask for a volunteer note-taker so that a summary can be compiled after the meeting.

Introduction
Having a voice disorder, such as SD, interacts with many personal and environmental variables that shape each person’s experience. Each SD person is the expert on how they interpret the day to day experience of having SD. An SD person has lost full control over their voice.

Spasmodic Dysphonia was once thought to have a psychogenic cause and patients were often misdiagnosed or undiagnosed. Some SD people feel they have a social stigma due to communication difficulties.

There is no cure for SD. Treatments often have to be repeated since the beneficial results can be temporary. There are many misconceptions due to lack of understanding of this neurological voice disorder. The condition is rare, but it is not life-threatening and it remains a medical mystery.

Proper diagnosis and successful treatment are most helpful. So is social support which can help reduce depression and anxiety – both fairly common among SD patients.

Resources
Ideas for this meeting topic were found in the article, “The consequences of spasmodic dysphonia on communication-related quality of life”, Baylor, Yorkston, Eadie, 2005.
Part One
What restrictions are you having at work and relating to others because of SD?

1. Are you having problems securing or retaining employment?

2. Does a prospective employer view your abnormal voice as being potentially offensive to their customers?

3. Are you holding back from full engagement in social roles because of SD?

Part Two
What is the self-rated voice quality of the SD patient? How do you rate your voice handicap? What is your voice-related quality of life?

1. My voice does not work, and it sounds different.

2. Talking requires great physical effort.

3. My voice is undependable.

Part Three
What is your self-view as a consequence of having SD?

1. SD has changed how I feel about myself. I feel embarrassed by my voice. I can be reclusive and depressed at times. My confidence and self-esteem have plummeted because of my having SD.

2. My voice does not represent me. I am unable to control it. I avoid noisy settings and telephone usage. I am quieter in social situations.

3. I just deal with SD and live my life while not letting SD define who I am.
Support Group Meeting Topic #10

*Relationships: How they are affected by SD*

**Meeting Goal**
Meeting participants will decide: (1) where they are in the grief stages of SD; (2) what steps they have taken in learning to live with SD; (3) what assistance they have been offered by family and friends; (4) which characteristics of the typical SD patient describe themselves; (5) what the overall life impact of SD has been for them.

**Instructions to Meeting Facilitator**
*Hand out a copy of the worksheet (second page) to every meeting participant. Either read the introduction information to the group or ask others to each read one paragraph. On the worksheet, there are five blocks of related issues. Ask each person to identify which block best describes where they are in their SD journey and then to explain their thoughts. Ask for a volunteer note-taker so that a summary can be compiled after the meeting.*

**Introduction**
Webster defines relationships as “the connections between and among persons.” The voice is the main instrument of communication and a tool of self-representation. It is crucial in social relationships and work-related interactions. Obviously personal relationships are affected by spasmodic dysphonia.

Spasmodic dysphonia is a life-challenging neurological disorder that can be both stressful and embarrassing. You have to learn to live with SD while coping with its daily frustrations. Relationships change when you can no longer be yourself. Family life can suffer as the result of the emotional upset of the SD person.

SD is chronic and non-fatal. We have to accept the ups and downs of SD – it is unpredictable. Even when an SD patient receives successful botulinum toxin injections, the broken voice eventually returns and the voice is no longer as serviceable. In public where the voice has to be projected, and on the phone where there is no way to communicate other than by using one’s voice, the SD voice can be at its worst. Stress and fatigue tend to exacerbate SD symptoms.

Reacting to SD depends on when you first experienced its mysterious symptoms. If it came early in life, it can force you to rethink life’s prospects. If it hits you in middle age, SD may transform the way you are perceived by others. Older persons may tend to take a more philosophical approach to SD. No matter your age, one challenge that remains for the SD person is not being able to express yourself as you wish.

Having SD is often a humbling experience. Some SD patients report that they have greater sensitivity and empathy for the struggles of others because of what they are going through with SD. Bear in mind that SD shows itself differently in each person, and people react differently to challenges.
Support Group Meeting Topic #4: Relationships: How they are affected by Spasmodic Dysphonia

I. Five stages of grief related to having SD.
   1. Denial. I can’t believe that I have this diagnosis.
   2. Anger. I am angry over the loss of my voice.
   3. Bargaining. I ask God to make SD go away in exchange for something that I will do.
   4. Depression. I have no energy, and I do not want to socialize.
   5. Acceptance. SD “is what it is”. I am OK even with SD.

II. Learning to live with an SD voice
   o Joining an SD support group
   o Keeping SD in its proper perspective
   o Becoming more self-tolerant
   o Turning to your faith
   o Counting your blessings

III. Family and Friends
   o Exercising patience with those who have SD
   o Not minimizing the frustrations of living with SD
   o Understanding that communication is often difficult
   o Being supportive
   o Helping the SD person to realize that SD doesn’t define who they are
   o Continuing to communicate with the SD person and keep them involved

IV. SD Patient Characteristics
   o Loss of self-confidence
   o Can’t enter into group discussion readily
   o Silent when you used to be vocal
   o Tentative, not confident, in social situations: fear and shame
   o Phone avoidance
   o Severity of SD
   o Successful treatments for SD – or not

V. Overall Life Impact of SD
   o Personality change
   o Loss of communication
   o Depression
   o Ruined/impacted career
   o Impacted family/social life
   o Learned to live with it

Resources
Ideas for this meeting topic were found in Chapter Three of the book, “Easier Done than Said: Living with a Broken Voice” by Karen Feeley, pages 49 – 77. Other ideas were found in a study by Don Edgar entitled, “Spasmodic Dysphonia: What’s wrong with your voice?”
Support Group Meeting Topic #11

Breaking the Preoccupation with our Voice Problem: Real and Imagined Limitations

Meeting Goal
Meeting participants will discuss (1) real and imagined limitations of SD; (2) how to overcome real SD limitations; (3) how to minimize imagined limitations.

Instructions to Meeting Facilitator
Read the introduction information to the entire group. Break participants into two groups and give a set amount time for discussion. Each small group should identify a leader and a note-taker. The italic examples are an assist to the leader to facilitate the discussion. The two groups will report their findings. Then they will break off again into their groups to discuss the second topic. Again, allocate a set amount of time, and then reconvene the two groups and summarize their findings.

Introduction
When we develop a disability there are very real limitations, but often we are hard on ourselves and throw up imaginary roadblocks. We then become so preoccupied that spasmodic dysphonia (SD) takes all our attention and energies. It lowers our self esteem and capabilities, arrests our potential for growth and leads to depression and unhappiness.

Topic A: Identifying the Limitations of SD

Group 1 will discuss amongst themselves the true or real limitations of SD.
Items such as impacts on social and employment functioning when expressing oneself verbally, problems with noisy environments and using the phone.

Group 2 will discuss some of the imagined limitations with SD.
Items such as not being able to socialize because you feel you are an embarrassment and no one will want to be with you, or your voice can never be understood by anyone.

Topic B: Minimizing the Limitations of SD

Group 1 will discuss how to tackle effectively your real SD limitations.
Items such as using other communication modes such as e-mail, being upfront with friends and co-workers about your condition and asking for their patience, finding quieter environments to socialize, pacing yourself to what your voice will allow, developing a sense of humor and not sweating the small stuff.

Group 2 will discuss how to minimize imagined limitations.
Items such as seeking out support groups and learning from others, counseling to build confidence, focusing on what you can still do and enhancing those skills, training yourself not to worry about what others are thinking about you, putting things in perspective.
Support Group Meeting Topic #12

Meeting the Challenge of Change in your Life Goals after the onset of SD and then Rebuilding your Life

Meeting Goal
Participants will examine (1) the change that SD brings to our life; (2) how we respond to change; (3) how to reassess your life goals after you receive an SD diagnosis.

Instructions to Meeting Facilitator
Read the introduction information to the entire group. Have each participant read a question and then open it up to discussion. The italic examples are an assist for the leader to help start discussion. Ask for a volunteer note-taker so a summary can be compiled after the meeting.

Introduction
Life is in a constant state of change. We need to flow with the change or we will be left behind and immobilized. Developing a disability, like spasmodic dysphonia, is life-altering, but we need to move past it, examine what is really important to us and prioritize our goals. The definition of change is to make or become different by substituting or taking the place of.

A. Once we develop SD, what changes does it bring to the table?  
   Such as difficulty finding and maintaining employment, difficulty relating to current friends and making new ones, adding stress to a marriage or family, problems with depression and anxiety, problems dealing with strangers e.g. store clerks, etc.

B. What are some life goals we all have in common?  
   Such as feeling happy, loved and valued, feeling competent, feeling part of society, having friends, being able to financially support ourselves and our family

C. What are some different ways how we handle change?  
   Such as resisting change due to fear of the unknown, being realistic and accepting the change, running away or avoid dealing with the change, getting support from others to help with the change

D. What are different ways how we handle challenges?  
   Such as head on, getting more information about it, developing a plan, talking to others, finding a coach or mentor who faced the same situation

E. How do you form a sound base so you can start rebuilding your life goals?  
   Such as accepting your disability and limitations, finding strengths and developing other skill sets, practicing patience and persistence, pacing yourself by controlling your environment when you can, seeking support from others
Support Group Meeting Topic #13

**Taking Charge of Your Health**

**Meeting Goal**
Participants will learn about taking charge of their healthcare. They will develop tools for asking questions and receiving answers.

**Instructions to Meeting Facilitator**
Read the introduction to the entire group. Divide people into small groups of approximately six to eight people. Read the directions for the activity (listed below prior to the questions). Explain that groups should feel free to move quickly over the sections where they believe they are well-informed, and spend more time on the sections where members have questions. Each small group will need a copy of Understanding SD, the NSDA's Botulinum Toxin Tracking Chart, the brochures on botulinum toxin treatments and surgeries, and blank sheets of paper for participants to make their own lists (another option would be to copy the list of questions for each participant).

Once time is up, bring the small groups back together and have each group share some of the questions that were posed during the discussion and any additional questions. Ask for a volunteer to compile all of the questions into one list. This could be distributed electronically and saved so that it can be offered to group members in the future.

**Introduction**
Before making any major decision, it is common to research the options and ask questions. Even when purchasing a cell phone or when ordering dinner at a restaurant, it is not uncommon to ask several questions before making a final decision. When we go to our doctors, we should prepare beforehand, and while in the office ask any questions needed for full understanding.

Proper treatment for any condition is dependent upon an accurate diagnosis. This requires a team effort. The patient is the most important person in this process. The patient’s ability to accurately convey information about their symptoms, duration, onset, etc. will affect the clinician’s ability to make the diagnosis. Once a diagnosis is made, the patient should continue to take an active role in his or her health care. Patients should ask questions, record the answers, get second opinions when necessary, and become fully educated about the condition and the treatment options. Treatments for SD are an inexact science. What works for one patient or at one point may not work for another. It is important for an SD patient to record the results of treatments and convey the results and any desired changes to their doctor.

Go to your doctor prepared to communicate effectively. This applies to dealing with the initial diagnosis, and the frustrations of treating your SD and coping well.
Do your research. The NSDA offers brochures on SD and treatment options.

Take a list of questions to your doctor. When you are dealing with a new diagnosis of the magnitude of SD, it is easy to become overwhelmed and forget what you wanted to ask. Writing out your list can help. Prioritize your questions. Ask the questions that are most important to you first. As you ask questions and think of additional questions, jot down the new ones at the bottom of your list.

Take a companion with you to take notes. This will allow you to focus on asking the questions and understanding the answers without the pressure of having to remember every detail. Afterwards you can review the information to make sure your understanding matches that of your companion. You can also ask your doctor to send you a copy of your evaluation results and the recommended treatment options for you to review.

Directions for Small Groups
Read the list of categories to consider. Look at the list of sample questions provided. Discuss which questions group members would like to ask their doctors. Ask members to add other questions they have about SD or treatment. Feel free to move quickly over areas where your group members do not have questions, and spend more time on areas of concern.

Understanding SD: What do you still need to know to fully understand spasmodic dysphonia?

• Types of SD: The type of SD affects your treatment options.
• Causes: Understanding will alleviate unnecessary fears.
• Symptoms: Are my symptoms “normal?” What if I have atypical symptoms? Do I know when a symptom is not SD?
• Long-term outlook: Does SD progress in severity? Will it go into remission? Will treatments affect the progression?

Understanding Treatment Options

• Information to consider before choosing a treatment option
  ○ Health history
  ○ Current medications

• Treatment options
  ○ Do nothing
  ○ Voice therapy
  ○ Botulinum toxin injections
  ○ Surgery
  ○ Alternative therapies
  ○ Combination of treatments
Support Group Meeting Topic #13: Taking Charge of Your Health

Understanding Treatment Options, continued
   • Treatment considerations
     o Potential side effects/risks
     o Potential benefits
     o Feedback about reaction to treatment
     o Follow-up treatments
     o Insurance coverage and costs
   • Medical professionals
     o Family physicians
     o Speech and language pathologists
     o ENT/Otolaryngologists
     o Neurologists
     o Other

Understanding Your Diagnosis
   • What do you think is causing my problem? What is my diagnosis?
   • Is there more than one condition that could be causing or contributing to my problem?
     Do I need to seek input from any other medical professionals for this or other conditions?
   • What test will you do to diagnose the problem? How accurate is the test at diagnosing my problem? Are there other diagnostic tools available that would confirm the diagnosis?
   • What is the likely course of this condition?
   • Will treatment affect the long-term outlook?
   • How will I know when I have reached my plateau and will not get any worse?
   • What changes will I need to make?
   • What organizations/resources are available to help me with making these changes?
   • Where can I find information about clinical trials/research being conducted on SD?
   • Is there a chance that anyone else in my family may get this condition?
   • What tools are available that will help me with the tasks that are difficult for me (voice amplifiers, telephones)?

Understanding Treatment Options
   • What are my treatment options?
   • What is the standard treatment for SD? What do you recommend?
   • How effective is each treatment option?
   • What are the benefits versus risks of each treatment option?
   • What are the chances that this treatment will work?
   • How much does this treatment cost?
   • Does my insurance cover the cost?
   • Who can I talk to about getting treatment if I don't have insurance?
   • Who can I talk to about pharmacy assistance programs if my insurance doesn't cover a particular medication?
Support Group Meeting Topic #13: Taking Charge of Your Health

Understanding Treatment Options, continued

- Is it an acceptable choice to not pursue treatment and live with the symptoms?
- Will voice therapy help? How much will voice therapy alone help my voice?

**Botulinum Toxin Injections**

- How is the botulinum toxin administered?
- What can I expect to occur during an injection (coughing, discomfort)?
- What are my options if I want the injection, but am uncomfortable with the procedure?
- Are there any restrictions for me following an injection?
- Are there side effects? Do you have suggestions for dealing with these?
- How long will the side effects last?
- Are there any health conditions that would prevent me from being a candidate for this option?
- How long will it take for the injection to begin working?
- How long will the benefits last?
- Can I continue to get botulinum toxin injections for my entire life?
- What if the injections do not work? What are the possible reasons?
- Do you re-inject right away if an injection is ineffective?
- How would you like for me to keep track of my side effects and benefits and communicate that with you?
- What is your approach to finding the dosage that works for me?
- Do you ever inject unilaterally, and under what circumstances?
- How many patients have you treated with this treatment? What have been the results? How do your results compare with other institutions?

**Surgery**

- Am I a candidate for this surgery?
- How successful is this surgery?
- What are the benefits of having this surgery?
- What are the risks involved?
- What happens if I don’t like the results? Is the surgery reversible?
- Have you done this surgery before?
- Which hospital is best for this surgery?
- Will I need anesthesia?
- How long will the surgery take?
- What will happen after the surgery?
- How long will it take me to recover?
- What will recovery entail?
- How long will I be in the hospital?
- Will my health insurance cover the surgery?
- Where can I get a second opinion?
Resources

http://www.ahrq.gov/questionsaretheanswer/questionBuilder.aspx;
http://www.ucsfhealth.org/adult/edu/QuestionstoAsk.html

NSDA Handouts and Brochures – available either by download or order from website:
http://www.dysphonia.org/publications/publications.asp
  • Understanding Spasmodic Dysphonia
  • Botulinum Toxin Tracking Chart
  • Treatment Options for SD: Surgical Procedures
  • Treatment Options SD: Botulinum Toxin Injections

NSDA Healthcare Referral List:
  • http://www.dysphonia.org/healthcare/
Evaluation Form

Topic: _________________________________________________________________

Support Group: _________________________________________________________

Date Presented: ______________________

What part of today’s program was most valuable to you?

What would have improved today’s session?

What would you like to see at future Support Group Meetings?

Other comments