

NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

**2009 Leadership Day Notes**

**Unlovable Behaviors in Lovable Support Groups**

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**Unlovable Behaviors**

- Talking off agenda
- Talking about self
- Sharing too much
- Trying to take over group
- Negative behavior
- Argument
- Interruptions
- Focus on religion
- Joking (excessive)
- Side conversation

**What to Do About**

- Address the issue and tell the person
- Egg timer (limit on long people can talk)
- Announce number of minutes allocated for speaking
- “All want to share”
- Leading / Doing

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**“SWOT” Analysis Activity Review**  
Strengths, Weaknesses, Opportunities, Threats

***Strengths***

- Organization
- Technology
- People skills
- Listening
- Public speaking
- Planning
- Motivator
- Problem solver
- Good listener
- Planning and logistics

***Weakness***

- Phone work (follow ups)
- Too direct (sometimes)
- Fundraising
- Dislike of public speaking (for some people)
- Communicating to generate responses
- Unable to gain interest in meetings
- Procrastinating
- Getting up before people to present information
- Difficult to delegate tasks

***Opportunities***

- Analyze reasons for problem
- SD community apathetic
- Why would they want to get together – resigned
- Webinar topics
- Educate people
- Follow through on commitment
- Webcast / Podcast for leaders in 90 / 120 days
- Leverage techniques in more effective support groups
- Generate ideas

***Threats***

- Fear of change
- Technology fear
- Lack of knowledge (leaders)
- Scheduling
- Taking things too personally
- Asking for help
- Impatient

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*Skills Training: Public Speaking*

**Public Speaking Tips**

- Use Prep Time
- Stick to topic
- Timing
- Good imagination
- Good flow
- Suspense
- Humor
- Know the topic
- Personal thoughts
- Have fun
- Concern for audience
- Good opening
- Inflection
- Storytelling
- Breathing
- Keep start easy and light
- Mention SD at beginning
- Focus on message
- Craft, Support
- Pause and think
- Gestures
- Smile
- Be nice
- Speak directly
- Eye contact
- Watch location
- Address everyone
- Don't get off topic

**Relaxation Ideas**

- Alcohol
- Picture audience as naked
- Prepare (Notes, detailed)
- Practice

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*How Do We Maintain and Grow Support Groups?*  
**Topics for Meetings**

- Speech Therapy
- Coping with Stress
- Relaxation Techniques
- Botulinum Toxin Injections:
  - Patient Assistance
- Living with SD:
  - Medical
  - Emotional
  - Financial
  - Advocacy
  - Technology
- Work Related Issues:
  - Workers Comp
  - Insurance
  - Disability
- Vocational Rehab / State Programs
- NSDA (resources)
- Technology
  - Assistance
  - Adaptations
- ADA – American Disabilities Act
- Fund Raising
- Awareness
- Advocacy
- Speakers:
  - Attorney
  - Social Worker
  - Counselor
  - Family Member
  - Speech Pathologist

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**2009 Leadership Day Notes**

*How Do We Maintain and Grow Support Groups?*  
**Increasing Attendance**

- Flyers
  - Speech Language Pathologists
  - Doctors Offices
- Buddy and RSVP
- Door Prizes
- National Website
- Media Publications (use paragraph)
- Prepare and circulate minutes
- Share Tasks
- Hosting

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**2009 Leadership Day Notes**

*How Do We Maintain and Grow Support Groups?*  
**Empowering Members**

- Get people to take heart, and focus on what they are talking about, not how they sound.
- Talk about what you still love about life despite SD.
- Connect with individuals in group with similar struggles: (Job-wise, emotion, family).
- Establish meeting as a safe place to openly express emotions – good or bad (assure confidentiality).
- Discuss coping strategies.
- Highlight role models who persevere despite their symptoms.
- Allow a forum to vent the negative and what sucks about SD. Not everyone is at the same place.

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*How Do We Maintain and Grow Support Groups?*  
**Meeting Planning for the Year**

Top Five Meeting Topics

- *Medical*
  - Speech
- *Emotional*
  - Relaxation
- *Financial*
  - Insurance
  - Medicare
- *Technology*
  - Websites
  - Equipment
  - Assistance
- *Advocacy*
  - Awareness
  - Letter Writing

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**2009 Leadership Day Notes**

*How Do We Maintain and Grow Support Groups?*  
**Member Retention**

- Food
- Personal contact
- Speakers
- Involve maximum number of members
- Meeting frequency based on consensus
- Link to wider NSDA community, not just local personal contacts.
- Phone call from someone (may not be support group leader) to make the invitation.
- The SG is more than just the members / Synergy.
- Minutes / Newsletters
- Flyer
- Advertising meeting
- Health Care Professional to post meeting information.
- Welcome all (follow up with individuals)
- Self investment
- Be present
- Scarce resources
- Offer incentives to attend / join (e.g. desserts, refreshments etc.)
- Plan communication strategies
- Regard the meeting as a social Occasion
- Plan speakers for the year
- Timing the meeting schedule (mix it up)
- Topic requests from members
- Location, location, location
- Convenient time and location. Vary when needed.
- Neutral location
- Acoustics
- Build in levity
- Guidelines for behavior
- Planning responsibilities