



Support Group Leader Volunteer Position Description

Thank you for your interest in becoming a Support Group Leader with Dysphonia International, formerly National Spasmodic Dysphonia Association (NSDA). No one understands what you are going through better than someone who also lives with a voice disorder. Most people say, "I never heard someone who sounded like me until I went to a support group meeting." A support group can provide a lifeline, information on doctors, experiences with treatments, tips to help you thrive and lifelong friendships. By being a Support Group Leader, you have the ability to bring people together in a positive, supportive and nurturing environment while empowering both your members and yourself as a leader. Please read through this position description to better understand the responsibilities, qualifications, and benefits of leading a support group in your community.

About Dysphonia International

Established in 1989, the NSDA, now Dysphonia International, is a 501(c)3 nonprofit dedicated to improving people' with spasmodic dysphonia and related voice conditions through research, education, awareness, and support.

Dysphonia International Support Group Leaders

Dysphonia International Support group leaders are very special individuals who give freely of their time and talents, working on behalf of their community without financial compensation.

Dysphonia International Support Group Leaders work in their local community to:

- Increase awareness about spasmodic dysphonia and related voice conditions within each community
- Increase the number of support groups
- Provide a local contact for educational information
- Develop and increase fundraising potential
- Develop and enhance a relationship between Dysphonia International and the local community

What are the responsibilities of the Support Group Leader?

- Maintaining an active support group with a minimum of two meetings per year (either virtual or in-person)
- Keeping the Dysphonia International staff informed about meeting dates, times, and locations
- Building relationships with local physicians, health care professionals, and government and community representatives in order to increase group membership and recruit guest speakers
- Dispensing Dysphonia International literature to support group members, health care providers, libraries and other businesses and organizations, as needed.

As a volunteer, we know life changes and other commitments may come up. If at any time you feel the need to step down as a Support Group Leader, just inform our staff who work with Support Network Team to transition the group to new leadership. Also, we encourage groups to have co-leaders to share the responsibilities.

How does Dysphonia International support me as a Support Group Leader?

When you become a support group leader with our organization, you are not on your own! We have a robust support network to help you be successful in the role. The staff is here to support you with the administrative side of advertising and to host meetings too.

Leader Development

- You will be introduced to our Support Leadership Team along with the staff
- You will have mentors to help guide you through the process of setting up your first meeting and future meetings
- You will have access to the Leadership Library designed specifically for our Support Network
- You will be invited to join the Leadership Facebook Group so you can connect with other leaders
- You will be invited to participate in the annual Leadership Workshop
- You will be invited to join quarterly calls with other Support Group Leaders
- You will receive and have the opportunity to contribute to the quarterly newsletter of the Support Leadership Network called *Voices of Support*.

Meeting Support

Our Dysphonia International staff is here to help support you. They will:

- Mail out educational materials, literature and awareness materials to you at no charge upon request.
- Provide support materials that outline all the aspects of planning meetings.
- Connect you with local healthcare professionals to be speakers at your meetings.
- Provide the Zoom interface to host the meeting if the meeting is virtual.
- Manage the registration for Zoom and participate in virtual meetings providing technical assistance if needed.
- Send out email announcements about your meetings to people in your community who are part of our database.
- Add your group to our website list, including your name and email.
- List your meeting dates and information on the organization's website meeting page.

What do I need to become a Support Group Leader?

We ask that Support Group Leaders have the following qualifications to be considered for volunteer service:

- Good communication skills, including the ability to listen and empathize and the ability to encourage and moderate active discussions to include all meeting attendees
- A strong desire to help support and educate others about spasmodic dysphonia and related voice conditions
- Willingness to learn more about spasmodic dysphonia and related voice conditions and to share their own experiences
- Access to the internet and an active email account
- Willingness to have your name and email listed on the Support section of the Dysphonia International website
- Being comfortable using Zoom to meet virtually. If Zoom is new to you, we can walk you through the process. The staff will participate in your virtual meeting to provide support.
- Ability to communicate with diverse groups.

Once you become a leader, you will be expected to:

- Review and understand the organization's Vision, Mission, and Core Values
- Follow the Conflict of Interest Policy and Code of Ethics, which reinforces the values and standards of conduct applicable to the staff and all individuals who act on behalf of Dysphonia International.
- Maintain confidentiality about all internal matters of the organization

Reasons to be a Support Group Leader for Dysphonia International

- You are providing a place where people can connect and feel at ease to talk about experiences they've had living with spasmodic dysphonia and related voice conditions, both in-person and online.
- You will gain insight by listening to how other people with vocal conditions feel about themselves, what treatments have been helpful and not helpful for them, and how as a community we can better support them.
- You will feel good about helping your group get together to express how they feel, to enjoy the social contact, and to learn more about their vocal challenges from speakers and from each other. The meetings can be one of the few social contacts some of us have and these meetings can help create a local network.
- Not everyone wants to or is able to attend meetings, so you will feel good that you can offer support to people individually by email, Zoom, phone calls and/or meeting them for coffee, where they can feel they have the privacy to share.
- Especially for those people who are anxious, having been recently diagnosed and/or who are going for their first treatment, it feels good to have a meeting they can attend to help them realize they're not alone and others have walked a similar path.
- In many cases, by serving as a Support Group Leader, you are 'paying forward' the support that you yourself have received from others.
- You will have the satisfaction of leading a group of people who feel they are each being listened to by everyone else in the room. To be really heard is so important and it helps to empower people to advocate for themselves.
- You will feel part of the Dysphonia International community that works as a team to help advance the Mission of our organization, which is "to improve the lives of people affected by spasmodic dysphonia and related voice conditions through research, education, awareness and support."

What steps do I need to take to become a Support Group Leader?

- Review the position description outlined in this document
- Contact Dysphonia International at support-leadership@dysphonia.org to express your interest in becoming a leader.
- Review the materials on our Leadership Library and begin planning your first meeting.

Please Note: If you are not ready to become a Support Group Leader, we encourage you to volunteer as an Area Contact Leader so that we have time to build the local community to ensure the success of the support group.

If you have any questions, please contact us via email at support-leadership@dysphonia.org or phone at 630-250-4504. We look forward to discussing your interest in becoming a volunteer leader for Dysphonia International.