

## SWALLOW SUPPORT GROUP WELCOME PACKAGE

Whether you are new to NFOSD or a long-time supporter, we want you to familiarize yourself with our website, mission statement and resources at [www.nfosd.org](http://www.nfosd.org). The website has been designed for your ease in finding relevant, interesting and educational information about dysphagia that can assist you in forming your support group.

### WHAT ARE THE BENEFITS OF A SUPPORT GROUP?

- Reduces Stigma
- Reduces Isolation
- Builds Trust
- Provides education for patients and caregivers
- Provides a safe, non-judgemental atmosphere to share success and challenges
- Provides opportunities for friendship, camaraderie and laughter

### WHAT IS THE PURPOSE OF A NFOSD SWALLOW SUPPORT GROUP?

To provide the community of patients, caregivers, clinicians and educators with:

#### SUPPORT

- Create a supportive, safe and non-judgmental outlet to discuss the experience(s) of dysphagia.
- Provide an atmosphere of good will that generates a positive impact upon quality of life for patients, caregivers and loved ones.

#### EDUCATION AND RESOURCES

- Provide ongoing education the general public and swallowing disordered population on normal and abnormal processes of swallowing.

- Facilitate discussions regarding current dysphagia research as well as patient-generated topics.
- Create a forum for professionals in the field to share their knowledge.
- Cultivate and strengthen collegial relationships in the dysphagia community by collaborating with speech pathologists, health professionals, students, educators, patients and caregivers.
- Continue to direct participants to the NFOSD website as a valuable resource [www.nfbsd.org](http://www.nfbsd.org)

IT IS IMPORTANT TO NOTE THAT A SUPPORT GROUP IS:

- NOT a therapy session. Although your support group is not a therapy group, it is predictable that when people feel safe and free to talk, share their own experiences and listen to others, emotions and feelings are likely to arise. This is a good thing because quite often participants gain great value from sharing and listening to others; as it eases isolation, builds empathy engenders group support and builds a sense of trust and camaraderie.
- A support group alone is NOT a replacement for treatment or counseling. So if the need arises it is suggested that you have a current list of qualified psychotherapists/mental health clinics in your area that you can (confidentially) refer participants to if they request further support.
- NOT a “12-step” program.
- NOT a replacement for family, friends, or caregivers.
- NOT a replacement for medical care

FAQS

**(Frequently Asked Questions)**

***Q: I want to start a support group. Where and how do I begin?***

When considering starting a support group, consider your current workload and personal, family and/or extracurricular commitments. While you can determine how often the group meets, leading a support group is a regular time commitment. You must also evaluate the support you may need from your facility (or another facility) and SLPs in your community to facilitate and grow a successful group. We are offering **4 EASY STEPS** to implement your own group:

- **REVIEW**
- **CONTACT**

- **COLLABORATE**
- **ADVERTISE**

**REVIEW:** Go to the NFOSD website ([www.nfosd.org](http://www.nfosd.org)) and learn more about the resource materials from the NFOSD website

**CONTACT:** Email JAN PRYOR at [cologirl1@aol.com](mailto:cologirl1@aol.com) to express your interest and identify your geographic area. Set up a phone conference with Jan to discuss goals and realistic expectations.

**COLLABORATE:** with others to gain their support, feedback and patient referrals.

Director of Rehabilitation, Regional Rehabilitation Director

Director of Marketing, Director of Social Services

Director of Nursing, Assistant Director of Nursing

Executive Director

Local clinicians (speech–language pathologists, physical therapists, occupational therapists, respiratory therapists)

Physicians (Gastroenterologists, Otolaryngologists, Pulmonologists)

Local hospitals

Head and neck cancer centers

***Q: How do I build/advertise a participant group?***

- **Just get started!**
- Set meeting date and schedule. Some groups meet quarterly and others meet monthly. Meeting frequency can be decided upon by your group (a good topic for your meeting) and also by your availability.
- Identify a meeting location. Suggested places for meeting include hospitals, rehabilitation centers, nursing homes, adult day care centers, speech/hearing centers, senior citizen centers, churches, community halls, libraries or schools.
- Identify committed participants to who will facilitate regular attendance and attract new participants

- Consider selecting a co-leader to ensure continuity and regularity of meetings and to help with logistics, discussion topics and recruitment
- Submit your support group meeting dates to [info@nfosd.com](mailto:info@nfosd.com) to appear on the event calendar on the website. This will allow your meeting to also appear on the NFOSD Facebook post and Twitter tweets.
- Check with community or public van/bus services for special circumstances for those unable to drive. Don't forget carpooling.
- Don't forget to use social media and the internet to advertise: FACEBOOK, TWITTER, EVITE, FLYERS

***Q: What can I do to ensure a positive experience for participants?***

- Mail flyers/brochures/invitations and social media notifications a minimum of 3 weeks in advance of the first meeting.
- Prior to start of the first meeting have SIGN IN sheet available, make sure each participant signs in and be sure to capture phone numbers and emails to facilitate group communication.
- Provide name tags and have Kleenex available
- Provision of light refreshments/drinks is a topic to be discussed with the group. Groups may vary as to whether or not they want this as a part of their group experience
- Provide a predictable structure (FOR EXAMPLE):

**7:00-7:15** SIGN IN/NAME TAGS

**7:15-7:30/7:45** INTRODUCTIONS

Facilitator opens with welcome and self-introduction and purpose of group. Participants are given the opportunity to introduce themselves and their guest and say a little about themselves

**7:45-8:15/8:30** GUEST SPEAKER OR TOPIC OF INTEREST

***Q: How can I encourage ongoing participation and interest?***

- Keep the topics fresh. The NFOSD website has many available articles posted that make excellent topics for support group discussions.
- The webinars provided by NFOSD can also be used for group discussion.
- Continue to ask participants at the end of the sessions for ideas about future topics. This makes a great “topic” for group discussion!
- If the group becomes large, one option is to split into groups of 3 or 4 after introductions for discussion so everyone has a chance to participate.
- Thank participants for coming and let them know how much you appreciate their support.