

Better Breathers Club Facilitator's Guide



Welcome Better Breathers Club Facilitators!



The American Lung Association is working across the United States for healthy air and healthy lungs, and we are so proud to have you join in that effort. The American Lung Association has a strong history as the first voluntary health agency formed in this country to fight a specific disease. In 1904, our fight was singularly focused on tuberculosis, and today our mission is to save lives by improving lung health and preventing lung disease for all people through

health education, advocacy efforts and advancements in research. The American Lung Association deeply appreciates all of our Better Breather Club Facilitators for your generous time and efforts to make an impact on the lives of individuals living with chronic lung disease and working toward a healthier future.

This Better Breathers Club Facilitator's Guide, along with your Better Breathers Club Facilitator Agreement, provides a reference guide for your service with the American Lung Association. We look forward to moving toward our vision of a world free of lung disease, and we couldn't do it without your support.

Yours in lung health,



Harold Wimmer
President & CEO
American Lung Association



Table of Contents

Welcome Letter	2
Introduction to Better Breathers Club	4
Purpose and Goal of Better Breathers Club	5
A Proud History	6
The Role of the Facilitator.....	6
Getting Your Better Breathers Club Started	8
Meeting Format	9
Promoting Your Club.....	10
Tools and Resources.....	10
Making the Most of Your Club Meetings	11
Planning Meeting Topics.....	11
Running the Club Meeting: Before, During and After	15
Effective Facilitation	17
Meeting Evaluation	23
Recruitment and Retention of Members	24
Member Recruitment.....	24
Member Retention.....	25

Introduction To Better Breathers Club



Thank you for becoming a certified Better Breathers Club Facilitator! The American Lung Association could not fulfill its mission of saving lives by improving lung health and preventing lung disease without volunteers and partners in the community like our Better Breathers Club facilitators—without you. You can be proud that you are joining a national network of some of the most dedicated, compassionate lung health educators and advocates we know. Some of our facilitators have been leading a Better Breathers Club for over 20 years! Whether you end up leading a Club for 3 years or 30, please know you are making an important difference in the health of your members and your community.

How to Use the Guide

This *Better Breathers Club Facilitator's Guide* is your go-to manual for Club reminders and next steps in the planning process. This facilitator guide will review the elements that are necessary to start the Club, which include the logistical set up, planning your meeting, gaining confidence in your facilitation skills and Club promotion and recruitment.

Facilitator Resource Center

The *Facilitator Resource Center* is your source for tools to help Clubs run smoothly and effectively. This resource center is for American Lung Association trained facilitators. You will find links to templates and sample documents such as a meeting calendar, agenda, meeting evaluation form and more. You can download these forms from the online Facilitator Resource Center and print copies as needed.

The *Facilitator Resource Center* is your source for tools to help clubs run smoothly and effectively.



Better Breathers Clubs give members the tools they need to live their healthiest life.

Purpose and Goal of Better Breathers Club

The purpose of the American Lung Association Better Breathers Club is to offer patient-centered and community-based educational opportunities and support to persons with chronic lung disease (like COPD, pulmonary fibrosis/IPF, asthma, lung cancer and other chronic lung diseases) and their families, friends and support persons.

The goal of Club support groups is to improve the quality of life and functional status for members by providing disease self-management education and emotional connection which may prevent exacerbations and reduce the health, economic and social burden of lung disease. Specific objectives of the program include:

1. Provide individuals with lung disease and their caregivers the education and skills needed to achieve the highest level of functioning given the severity of their disease.
2. Teach members and their families the basic concepts and techniques of pulmonary self-care, including coping skills.
3. Introduce new concepts in the care and treatment options for people with chronic lung disease.
4. Provide an opportunity for members to share ideas and solutions to common problems on an ongoing basis.
5. Provide members with an opportunity to share the psychological and social benefits of group interaction and problem solving.

Effective support groups offer members a sense of acceptance and friendship that they may not find elsewhere. Some topics can be difficult or impossible to discuss with family members or close friends; it is easier to discuss some issues with other patients. Clubs provide a welcoming venue for people with chronic lung diseases that can leave them feeling alone and isolated. The Clubs encourage patients with lung disease to get out of the house and become more active. In addition to enhancing members' quality of life through emotional connections, Clubs help reinforce positive disease management strategies. In this way, Clubs can help reduce the health, economic and social burden of lung disease and fulfill the mission of the Lung Association.

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease, through research, education and advocacy.

A Proud History

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease, through research, education and advocacy. Our work is focused on four strategic imperatives: defeat lung cancer, champion clean air for all, improve the quality of life for those with lung disease and their families, and create a tobacco-free future.

Better Breathers Clubs started informally at the grassroots level in the 1970s. Lung Associations around the country felt the need to provide information and support to people with emphysema and chronic bronchitis, now called COPD. Word quickly spread that patients felt the support groups offered them something nothing else did: a sense of belonging and hopefulness in being able to cope with their disease. Soon, this program was replicated in most states.

Over the years, Better Breathers Club has become a nationally recognized, highly valued community-based program that fills an important need for people living with chronic lung disease. There are currently hundreds of Clubs around the country, in nearly every state. And thanks to facilitators like you, and the many sponsoring organizations we work with, the number is growing.



The Role of the Facilitator

The Better Breathers Club Certified Facilitator is a community member or leader, health professional, or health educator who likes working with adults, and has a genuine sense of empathy for people living with chronic lung disease. As a Better Breathers Club facilitator, you are responsible for all aspects of successful implementation of this time-honored and well-respected support program, from scheduling meetings and securing guest speakers to recruiting, maintaining and supporting the Club membership. Great facilitators have kept the Better Breathers Club a positive, educational and supportive experience for participants for over 50 years.

Responsibilities

- Successfully complete online training for facilitators
- Plan and promote a diverse and engaging calendar of meetings that align with Club members needs and interests, including recruitment of guest speakers as needed
- Recruit and retain Club membership through referrals and promotion
- Commit to regular meeting schedule — most Clubs meet monthly — and maintain a roster of attendee names and contact information
- Provide support for group member concerns and referral to resources in the community for extra help as needed
- Complete an annual online facilitator feed-back survey and facilitate the completion of an annual member feed-back survey

Qualifications

- A tobacco-free lifestyle (which precludes the use of any tobacco products, including e-cigarettes)
- Experience leading or facilitating a diverse group of adults in a nonjudgmental, caring manner
- Interest in and commitment to helping adults with lung disease
- Clinical knowledge and experience with chronic lung disease preferred, but not required.

Time Commitment

While individuals who are leading Club support groups are volunteering their time, the success of the Club often depends on the amount of time a facilitator puts into planning.

Basic time expectations related to managing a Club

- Complete online facilitator training: 1 hour
- Host Better Breathers Club meetings: 1 to 2 hours at least 6 times a year; monthly preferred
- Preparation and follow-up for each meeting: average 2-3 hours per meeting
- Commit to facilitating group meetings for 3 years
- Complete the Club Facilitator End of Year Survey: less than 30 minutes
- Participate in ongoing learning and networking opportunities (webinars, newsletters etc): 4 hours

It can be helpful to have a Club Planning Team, comprised of health professionals and/or patients who are committed to the success of the program.

Getting Your Better Breathers Club Started



Once you have signed the Facilitator and Sponsor Agreement and completed the Club Facilitator Training Course, it is time to put plans in place to start your Club. If you are working within a sponsoring hospital or worksite, or are taking the reins of an existing Club, some of the planning and logistics detailed below will have already been decided. If you need assistance with any aspect of getting started, be sure to contact American Lung Association staff for help. They are as committed to your success as you are!

Building Your Club Planning Team

It can be helpful to have a Club Planning Team, comprised of health professionals and/or patients who are committed to the success of the program. This planning team is tasked with developing the meeting format and schedule, discussing opportunities inside and outside the organization for referrals and recruitment as well as assisting with securing speakers for topics.

Some potential members of this team include (but are not limited to) a member of the sponsor organization's marketing/communications department to help with promotions and recruitment, a local physician/internist, a representative from the respiratory department and community health department. Having this additional support can also help reduce stress on the facilitator and can provide a patient-centered approach to the Club support group. As you continue to grow your Club, share your successes and challenges with the planning team as well as others in your department or within your organization. Ask colleagues in your department to help with member recruitment and Club promotion.



Meeting sites must be public venues that are completely smoke and tobacco-free.

Meeting Format

Frequency

Support group meetings need to take place on a consistent basis. The American Lung Association requires Clubs to plan to meet at least six times a year. Having meetings once a month enables members to provide consistent support to one another and fosters the bonding that builds trust within the group. When the meeting cycle is interrupted, it is easy for members to get out of the routine of attending and drop out of the group.

Timing

Most adults with lung disease find it difficult to get moving early in the morning. Meetings should take place in the late morning, afternoon or early evening.

Meetings usually last one-and-a-half hours. This gives adequate time for a presentation by a guest speaker, sharing of information and feelings, and social time around refreshments.

It is important to begin and end meetings on time. If the discussion goes longer than usual, the facilitator may end the group meeting and allow those who wish to remain to continue the discussion.

Location and Set-up

Meeting sites must be public venues that are completely smoke and tobacco-free. Also, because Better Breathers Clubs are designed for a population that includes some who are mobility-impaired, it is important that the meeting facility be easy to find, with easy parking and handicapped access. It can be very difficult for adults with lung disease to walk any distance. It is optimal when members can park near the door to the building and not have far to walk to the meeting room once they are inside the building. If your location offers valet, ask if members can use this service free of charge during Club meetings. If possible, to further assist members who have mobility limitations, offer complimentary wheelchairs at the entrance and have an escort for those members.

The ideal meeting room for a support group meets several requirements:

- The room has a door that can be closed to ensure privacy. Sometimes personal information is shared during a meeting, and privacy allows members to feel comfortable expressing their feelings.
- Once the door is closed to the meeting room, attend to the ventilation and room temperature. Meeting in a stuffy room can be a problem for anyone and especially for someone with lung disease. Room temperatures that are too hot or too cold can be distracting.
- Since much of the meeting requires listening, it's essential that the meeting room be fairly quiet. For example, meeting next to a noisy kitchen or busy gymnasium would not be optimal.
- The size of the meeting space needs to be proportionate to the size of the group. A large group meeting in a cramped room is as uncomfortable as a small group meeting in a large room.
- People with lung disease like to rest on their arms to allow for deeper

breathing. The room ideally should allow for seating around tables shaped in a U. The U-shape also allows everyone to see each other.

- Attend to the needs of members in wheelchairs and those using portable oxygen. Provide enough space in aisles and at the door for a wheelchair to move freely.

Promoting Your Club

Who will come to your Better Breathers Club? Even if you have a “captive audience” through your sponsoring organization, you still need to get the word out about meeting times, speakers, and topics in a way that will generate some excitement about the Club. Some steps to get you started include:

- You can find editable flyers and business card templates in the [Facilitator Resource Center](#) that you can customize with your meeting information and distribute.
- List the meeting on your organization’s web site and events calendar.
- Members can register to attend Better Breathers Clubs on Clubs listed on Lung.org
- Before each meeting, write up a brief news release and send it to local news media with information about the topic and speaker.
See Section: Recruitment and Retention of Members for more information.

Tools and Resources

The Lung Association has a number of resources available to you to get your Club off to a strong start. There are also lots of other educational resources for people with chronic lung disease available for download in the Lung Health and Diseases section of Lung.org. Of course, you should feel free to find or develop other educational materials that meet the needs of your membership.

Better Breathers Club Meeting Modules

The Better Breathers Club Meeting Modules and toolkits are developed programs that come with a facilitator guide, PowerPoint presentation and handouts. Currently three meeting modules are offered:

The Benefits of Supplemental Oxygen, which aims to build awareness and educate Club members about using supplemental oxygen.

Getting the Most Out of Your Inhaled Medication aims to explain the importance of selecting the right medication delivery device.

Climate Change and Lung Health: A Guide to Build Awareness and Education to Protect Lung Health

The programs can be accessed in the Better Breathers Club Resource Center.

Making The Most of Your Club Meetings



Planning Meeting Topics

It will help your Club run more smoothly if you plan a calendar of meeting topics for the year. (See the *Annual Calendar template* in the [Facilitator Resource Center](#).) Consider whether there is a certain time of year that is best to present specific topics. For example, a presentation on the importance of getting immunized against flu and pneumonia would be timelier in October than in March. You might also want to plan around some of the relevant annual observances, like Pulmonary Rehabilitation Week in March, the Lung Association's LUNG FORCE Turquoise Takeover in May, Pulmonary Fibrosis Awareness Month in September, and COPD and Lung Cancer Awareness Months in November.

Some of the best ideas for meeting topics come from group participants. If they request the same topic more than once, consider repeating it. Remember that people don't retain most of the information they hear or read the first time. It may seem that the topics members request are too repetitive, but even if the group hears the same speaker on the same topic every year, they are likely to learn something new each time.

When planning your meeting topics, remember that the goal of the Better Breathers Club is to improve the quality of life and functional status of members. Learning should result in changes in knowledge, attitude, and/or behavior. Think about changes your members can realistically achieve over the year when you are choosing your meeting topics. These desired changes can be stated and evaluated as your Learner Outcomes.

Learner Outcomes help support group facilitators by providing guidance to achieve the end result of the learning opportunity. By setting clear objectives, facilitators

- Help members learn more effectively
- Make it clear what members can hope to gain from participating in a particular session
- Design and plan their meetings more effectively



Mixing up the meeting format, and sprinkling in fun activities or unusual topics throughout the year, can help spark the interest of members and keep them coming back.

- More precisely communicate with their speakers what a particular session is designed to achieve
- Design evaluation questions based on learner outcomes

Mixing up the meeting format, and sprinkling in fun activities or unusual topics throughout the year, can help spark the interest of members and keep them coming back. You might consider art therapy, laughter yoga, or playing the harmonica to help with breathing, for example. Some facilitators or group members organize off-site field trips to local museums or afternoon lunch cruises. Many groups hold their own holiday parties. Not only do members have fun on these trips, some of them also learn that they can become more comfortable getting out and safely managing their lung disease with confidence.

Better Breathers Clubs can also get involved with American Lung Association special events, and advocacy. This can include participation in or volunteering at special events or advocacy days, testifying at state houses, becoming a planning committee member and more. Talk to your American Lung Association staff lead about local opportunities.

Sample Meeting Topics

While a majority of Club members have COPD, it is important to remember that Clubs serve members with pulmonary fibrosis, asthma and other chronic lung conditions and their caregivers. While there are differences in the lung diseases and management techniques, it is also important to remember there are shared issues as well. Providing general meeting topics can be helpful to all members but there also can be an opportunity for disease specific education. As a facilitator, it is important to find a balance between the two, especially if there are members with different lung diseases in your Club.

When considering the meeting topic and speaker, it is also helpful to allow time for question and answers and member sharing. Allowing this open time for free-flowing conversation, helps members who may have different lung diseases gain awareness and understanding from each other in the group. In return, this will build acceptance and trust among the members.

When considering potential topics, the suggestions below may be common themes of individuals with chronic lung diseases such as COPD, pulmonary fibrosis and asthma. While this list is not exhaustive, it can help give a jump-start in planning your calendar for the next year.

About Lung Disease and Lung Health

- General Anatomy of the Lung & What Major Diseases Do
- Disease review/explanation, i.e. “COPD: What is It?” or “Idiopathic Pulmonary Fibrosis (IPF): What is It?”
- Medications (many of these topics could be stand-alone topics for one meeting)
 - Overview of lung medications
 - Antibiotics and how to use them correctly
 - Oral steroids: Indications and side effects

- Medication interactions: Over the counter and prescription
- Oxygen therapy: what is oxygen, what it does for the body, when it is needed
- Stages of chronic lung disease
- Managing lung disease with co-occurring conditions (e.g. CVD, diabetes, arthritis)
- Lung transplantation and other surgical interventions
- Alternative therapies: how to know what is safe and effective
- Recent developments in research
- CT screening for lung cancer
- Clinical Trials: Pros/Cons and How to Navigate
- Air pollution and your health
- “Ask the Doctor” session (or Pharmacist, Respiratory Therapist, etc.)

Navigating the Healthcare System

- Communicating with your physician: what to report, what to ask, and being understood
- Care coordination: building a health care team
- Getting a second opinion
- Know your rights: privacy, portability and access to your health information
- Medical tests and what they determine: Spirometry, chest x-ray, CT scan, etc.
- Working with oxygen suppliers: choosing among options
- Home health care: what services are available and how to access them
- Understanding Medicare
- Resources for financial assistance
- Advance directives for health care
- Hospice care: What it is and when it’s time



Bringing in informative, engaging outside speakers for some or all of your meetings will help keep your Club a vibrant, positive experience for members.

Living Well with Lung Disease

- Adhering to treatment: finding a routine that works for you
- Getting the most from your devices: using and caring for inhalers, nebulizers and more
- Breathing techniques
- Emergencies and exacerbations: What to do, when to call 9-1-1
- Flu season do's and don'ts
- Energy conservation: pacing the activities of daily living
- How to start and maintain an exercise program
- Chair aerobics
- Low impact gardening and other tips for enjoying the outdoors
- The mind-body connection: massage, relaxation and other techniques
- Eating well: the importance of good nutrition for lung health
- Getting a good night's sleep: managing sleep disturbance
- Pulmonary rehabilitation
- Healthy air at home: how to assess and improve your indoor air quality
- Stress reduction and relaxation techniques
- Intimacy, communication, sexuality
- Coping with the emotional toll of lung disease
- Traveling with oxygen
- Disaster preparedness for the patient with lung disease

Social Support and Advocacy

- Sharing the load: making the patient and caregiver partnership work
- Meet the American Lung Association (introduction to the local organization and its programs and services)
- Overview of community services: Local services that can help with every day and special needs such as Meals on Wheels, senior services, transportation, respite care, etc.
- Qualifying for disability benefits
- Worker's compensation
- Estate planning
- Elder law
- Getting involved: state and local lung health policy priorities

Finding Speakers

Bringing in informative, engaging outside speakers for some or all of your meetings will help keep your Club a vibrant, positive experience for members. Every community has a wealth of sources for potential speakers.

Some places to start:

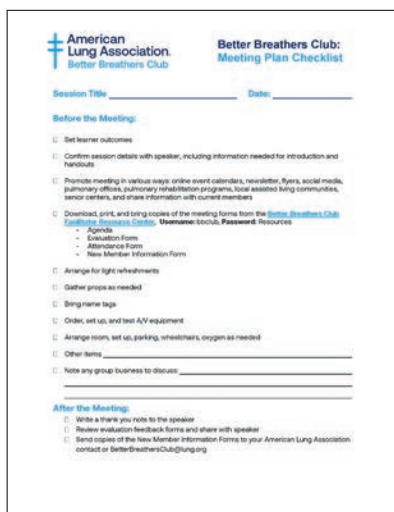
- Tap into your personal and professional network.
- Attend events related to healthcare and wellness to meet new people that may be interested.

- Contact and establish relationships with local hospital clinicians, pulmonary rehab programs, and college programs of nursing and respiratory care. Hospitals often have community outreach coordinators that can help.
- Medical device companies and other service providers are happy to come and demonstrate products and services. You will need to guide these speakers to keep it educational and “brand neutral” – no sales pitches please!
- Local community leaders, educators and business people are good sources for non-clinical topics.
- Ask your members for recommendations and assistance with approaching speakers.

Running the Meeting: Before, During and After

Prior to the Meeting

- Use the *Meeting Plan Checklist* in the *Facilitator Resource Center* to organize the details that can be easy to forget.
- Confirm details with the speaker
 - Get the title of the presentation, as well as the speaker’s full name, credentials and brief bio for introductions
 - Review the meeting objectives together, and make sure the speaker is clear about aligning the presentation to meet the agreed upon objectives. It may help to ask the speaker for two to four important points that he or she will make during the meeting.
 - Make sure the speaker has the exact location of the meeting and directions, if needed.
 - Are there any handouts that need to be copied or is audio-visual equipment or a laptop computer required for the presentation? If a laptop and projector will be used, clarify what format will be used to load the presentation and be sure it is compatible.
 - Ask whether the speaker prefers to take questions at the end of the presentation or will accept questions throughout.



The image shows a checklist titled "Better Breathers Club Meeting Plan Checklist" from the American Lung Association. It includes sections for "Before the Meeting" and "After the Meeting" with various tasks to be completed, such as confirming session details, downloading forms, and writing thank-you notes.





Build time into the agenda for discussion and sharing. This is a time when members can ask questions, share information or express feelings.

- *Publicize* the meeting. For more information see *Marketing and Promotion in Section: Recruitment and Retention of Members*.
- *Arrange* for light refreshments after the meeting to encourage members to get to know one another. Your sponsoring organization may be able to provide something. You can also ask a group member to coordinate refreshments.
- *Gather* props if appropriate. For example, if the meeting topic is about proper use of inhalers, provide display placebo inhalers for members to practice with, or posters that demonstrate the point. Your guest speaker may be able to bring his or her own props.
- *Arrange* for special parking for group members, if possible. Reserving space close to the building entrance for members will encourage their attendance. If cost is an issue, you may be able to arrange for a donation of parking vouchers. Provide wheelchairs at the building entrance, if possible. If it's feasible, offer refills for oxygen.
- *Develop* an agenda and evaluation form, and make copies for all. Having a written agenda is a helpful way to keep members engaged. They can take notes and formulate questions about the topic during the meeting, and feel prepared for the discussion. They can also use the notes as a resource when they get home. (See the *Meeting Agenda* and *Meeting Evaluation templates in the Facilitator Resource Center* for copies.)
- *Bring* name tags so members can get to know each other. Permanent name tags (those that can be inserted into a plastic sleeve) are easy to display prior to meetings. Doing so makes it easy to know who's missing at the meeting. Collect the name tags at the end of the meeting.
- *Bring* an updated copy of the *Meeting Attendance Form* along with some copies of the *New Member Information* form. (See the *Facilitator Resource Center* for copies of both.)
- *Test* any audio-visual equipment that you are providing before the meeting starts. Be ready to assist the speaker with the equipment.

During the Meeting

- Greet attendees individually. Saying hello to everyone helps ease any nervous feelings that some may have about attending a support group meeting. Introduce people to each other, especially those members who walk into the room alone. Thank them for attending. Facilitate conversations among members.
- Begin the meeting on time, even if everyone has not arrived. It sends a message to members that they need to arrive on time and validates the efforts of those who do so.
- Open the meeting by welcoming everyone and having members introduce themselves. Extend a special welcome to newcomers, guests, the guest speaker and any sponsors in attendance. Thank members specifically for any help they have provided.
- Make announcements at this time, such as directing members to the nearest restrooms and refreshments. Request that all cell



The group's success depends on the involvement of its members, good facilitation by a Certified Facilitator, and community awareness of the club.

phones be turned off. Ask participants to sign the attendance form. They only need to enter their contact information the first time they come unless they have changes to report. Briefly review the group touchstones (see page 22). Thank co-sponsors for their donation to the meeting (such as refreshments, handouts or props). Ask the member who has been in touch with missing group members for a status report.

- Introduce the meeting topic and guest speaker if there is one. Use your best facilitation skills to keep the presentation on schedule, and keep members engaged. At the end of the presentation, thank the speaker for his/her time in preparing the presentation and attending the meeting.
- Build time into the agenda for discussion and sharing. This is a time when members can ask questions, share information or express feelings. Guide the discussion to keep on track and to end it on time.
- End the meeting in a formal way. Some groups close with a ritual, such as practicing deep breathing and/or a relaxation exercise. This is the time to announce the date, topic and guest speaker for the next meeting. It is also the time to thank members for attending the meeting and ask them to complete evaluation forms. Be sure to collect the name tags and evaluations.

After the Meeting

- Send thank you notes to the speaker, sponsors and others as appropriate.
- Make a plan to contact missing members. You can ask a group member to assume this role and follow up with anyone who has missed a couple of meetings in a row.
- Review the meeting evaluations, and share as appropriate with the speaker. Use the feedback to make sure that your meetings are meeting the needs of your members and accomplishing the program goals.
- Add any new members to your ongoing Meeting Attendance Form.

Effective Facilitation

Volunteer facilitators, trained and certified by the American Lung Association, lead each Lung Association Better Breathers Club. The group's success depends on the involvement of its members, good facilitation by a Certified Facilitator, and community awareness of the Club.

Part of being an effective facilitator involves understanding how adults learn best

- Members bring valuable life experience that can be beneficial to the trainer and other learners.
- Adults learn by relating new information to past experiences; however, some individuals are resistant to change as they age.
- Adults need to feel that they are in control of their own learning and place value on learning that is important to them.

- Adults want to learn practical, useful, real-world information that they can use immediately and prefer action oriented learning such as hands-on activities.

A good facilitator

- Helps the group function as effectively as possible.
- Helps members feel empowered to be active in the group.
- Is interested in the group members and sensitive to their needs.
- Knows that when members feel safe and open, they will exchange ideas, advice and encouragement.
- Is accepting of others and is non-judgmental.
- Is a good, active listener.
- Pays attention to non-verbal cues of group members.
- Displays an optimistic and hopeful attitude, balanced by realism.
- Deals with conflict in an open, honest fashion and works toward resolution.
- Is able to set boundaries.
- Is willing to learn from the group members.
- Is interested in continually improving the Club.
- Takes responsibility for preparing for meetings and works to offer the best possible meetings to members.
- Is accountable to group members and to the American Lung Association.

Co-facilitation

The responsibilities of running a Better Breathers Club can be shared by co-facilitators. There are several ways this arrangement can work.

The co-facilitators can:

- Be present at all meetings with each one taking responsibility for specific parts of the meeting.
- Choose which meetings they attend (every other one, for example) and be responsible for all parts of the meeting they facilitate.
- Split the responsibilities, with one taking the lead role while the other one takes on more of the behind-the-scenes tasks.

There are a number of benefits of co-facilitation. The two leaders can discuss the group's issues with one another between meetings. In addition, if one facilitator has to miss a meeting, there will always be another trained facilitator available to run the group.

Not a Substitute for Physician's Advice

Better Breathers Clubs are intended to provide health education and social support. While they are designed to be comfortable and personal, as a facilitator you need to take special care not to cross what may seem to be a fine line. You will want to respond to personal questions in a way that does not have you making a diagnosis or offering treatment advice, *even if you are a practicing clinician*. The information and advice published by or made

The Club members should be reminded often to consult their physician in all matters relating to their health, and particularly in respect to any symptoms that may require diagnosis or medical attention.

available through the American Lung Association and its programs are not intended to replace the advice and services of a member's own health care team.

The Club members should be reminded often to consult their physician in all matters relating to their health, and particularly in respect to any symptoms that may require diagnosis or medical attention. The facilitator makes no representations or warranties with respect to any information provided regarding treatment, action or application of medication. This is important because the American Lung Association or sponsoring organizations will not be liable for any direct, indirect, consequential, special, exemplary or other damages that arise.

Should a participant ask a personal diagnosis or treatment question, advise them to consult a healthcare provider. Then try to re-state the question in a more general way. For example:

Q: "Should I be taking (a brand name prescription drug) for my condition?"

A: "I cannot answer that question for you and suggest you talk to your doctor about that particular medication and see if it might be something you should be taking. What I would like to ask the group is how they suggest talking with their healthcare providers about treatments."



Verbal Communication Tips

Whether you're making announcements, introducing the speaker or presenting the educational session for the support group meeting, the way you speak is as important as what you say.

Below are tips to use when speaking to the group:

- *Convey information.* State the essential points, pull together related ideas, summarize and restate often. "What I'm saying is..." "In other words..."
- *Clarify and elaborate.* Define terms and use examples to clear up confusion and reinforce main points.
- *Listen actively.* Respond to participants' comments, reactions and questions in a way that expresses your interest, understanding and

support. Active listening means paying close attention to what the speaker is saying and feeling. State back in your own words your understanding of the sender's message (both words and feelings).

- *Relay.* Pass an idea from one member to another, back to the member or to the group. "Anne, how do you feel about John's statement?" "Jim, what do you think that means for you?" "Cheryl, what has your experience been so far?"
- *Read body language.* Take cues from body language to understand messages from participants. For example, silence may indicate confusion; tapping fingers may indicate boredom or anger.
- *Ask open-ended questions.* Probing questions are the foundation of adult learning. They encourage individuals to think, to go deeper, to evaluate new information or concepts, to clarify issues and to develop solutions to problems. Use them liberally throughout the meetings. "What made you decide to come to the meeting today?" "What experiences have you had with that?"
- *Ask questions to check for understanding.* "Can you give me some examples of how this would apply to you?" "Tell me, in your own words, what you mean by _____." "So, if I understand correctly, what you're saying is..."
- *Reinforce.* Don't forget praise. It's the least expensive, most powerful leadership skill around. People are motivated to keep going when the group's leader or facilitator verbally confirms that they are "right on" or "on the right track."

Finally, remember to project your voice so that everyone can hear you and stand in a place where everyone can see you.

Non-verbal Communication Tips

Facilitators may be so intent on what they are saying that they neglect their non-verbal communication. But your voice, posture and facial expression send important messages to members, and can set the tone of a meeting. Something as simple as smiling and greeting group members with a rousing "Good morning!" tells the group that you are happy to be there.

- *Voice.* Strive for a friendly tone that communicates patience, cooperation, flexibility and a willingness to hear questions and comments. If your tone of voice is impatient or reprimanding, it may spark resistance and resentment from the participants.
- *Facial expression.* People "listen to your face," so smile! If your face shows enthusiasm and openness, your group members will most likely respond with interest and involvement.
- *Acknowledge.* Use non-verbal cues such as a nod of your head, eye contact and attentive facial expressions to let the members know that you have heard them. This encourages them to continue.
- *Eye contact.* Maintain eye contact to connect with your group members. Make sure you are making eye contact with all participants, and not talking to one side of the room or group of people more than the other.
- *Posture.* A relaxed, confident posture sets a positive tone. Passive

posture gives the impression that what you have to say isn't important or credible. Rigid or domineering posture creates tension.

- *Gestures.* Avoid fidgeting and closed gestures, such as a clenched fist, that express nervousness, defensiveness or hostility.

Addressing Challenging Behaviors

Support group meetings usually go quite smoothly, but any group facilitator is likely to encounter some challenging behaviors among members. The difficulties that a person confronts when coping with a chronic illness may affect his or her attitude or behavior. The group needs the facilitator's consistent, positive leadership as an anchor to support and guide the group through difficult situations.



Here are some tips on handling problems that facilitators may encounter with group members:

- Don't allow yourself to be drawn into controversy with any group member. Be aware that a vulnerable person may interpret your words as embarrassing, intimidating or argumentative. Choose your words carefully, particularly in front of the group.
- Ask yourself these questions: How does this person's concern relate to other common concerns? What information can I give that would benefit the individual and the group as a whole?
- Use the group to give different reactions to a specific problem or issue. When individuals realize that they are not alone in confronting a problem, they often feel supported and empowered to take action.
- Use humor to relieve tension, open up communication, and allow group members to connect with you and each other. Keep it positive—avoid any humor that might be interpreted as a “put down.” Avoid telling any joke that may offend someone, even slightly.
- Help problem participants stay involved and feel supported by the group. You may want to give them a special role, such as summarizing for the group during the sessions.

Touchstones, or ground rules, are important for smooth running of any support group. Since people come and go in support groups, it is helpful if everyone knows the expectations for communication.

- If a member is being difficult, try to help identify their underlying problem. It may be different from what the member is saying.
- Walk the room. Standing next to “sidebar” talkers helps quiet them down. Standing near a shy member and quietly asking, “What do you think, Harriet?” may help them participate.

Managing Questions from Group Members

Try to anticipate tough questions that may come up about the meeting topic. Keep your answers brief. Don't spend too much time addressing the concerns of one individual or you will lose the attention of the whole group. If you don't understand the question, ask for clarification or rephrase the question, i.e. “Are you asking ...?” Then ask the person if you have answered the question.

Utilize member input, draw from their expertise to help answer questions within the group. If you don't know an answer to a question, say so. Offer to find the information or ask the whole group if they know the answer. If you try to make up an answer, you risk losing your credibility.

Refer to the Lung HelpLine for answers to questions that you or the group can't answer. Ask the member to report back at the next support group session. This promotes a valuable Lung Association resource and gives responsibility to the member, promoting additional conversation.

Group Touchstones

Touchstones, or ground rules, are important for smooth running of any support group. Since people come and go in support groups, it is helpful if everyone knows the expectations for communication. Having group touchstones is critical because it provides participants with a safe comfort zone, and builds trust among members.

You can create touchstones by starting with a group discussion about the spoken and unspoken rules we have in society. Touchstones create a code of behavior for the group that deals with unspoken rules in particular. Ask the group what guidelines or norms the members think are important for a group to work well together. Write the answers on a chart pad so that everyone can see the list. After all ideas are expressed, ask the group members if there is anything listed that they can't live with or agree to. Then ask if there's anything not mentioned that they can't live *without*. Ask members to agree to the final list.

Keep the group touchstones to a minimum. You might put the final list of touchstones in writing so that they can be posted in the meeting room and briefly mentioned at the beginning of every meeting. Distribute copies to all members. Give new members a copy of the touchstones as they attend their first meeting. It is essential that you, as facilitator, enforce the touchstones. If they are not adequately enforced, then they lose their purpose.

There is no one “right” list of touchstones. Examples of touchstones may include:

- One person talks at a time.
- All personal information shared in meetings is kept confidential.
- Meetings begin and end on time.
- Opinions of members are respected.
- All members agree to participate (even if only actively listening).
- No one person monopolizes the group’s time.
- No offensive language is used.
- Cell phones are turned to silent and are not answered in the meeting room.

Meeting Evaluation

Evaluating your Better Breathers Club meetings is as important as planning for them. Giving members a chance to provide feedback is easy if they are given a brief form to complete at the end of each meeting. Some members may choose not to participate in the evaluation, but those who do can offer valuable insight and suggestions for the future. Members will appreciate being asked for their opinions and ideas, especially if they can see the results. (See *Meeting Evaluation* template in the [Facilitator Resource Center](#).)

The feedback from the evaluation forms will help you determine how well the Learner Outcomes for the meeting were met. You will also get a good idea over time of what types of presentations are most valuable to your members, and what other learning materials and activities are needed to meet the Club program goal of improving quality of life and functional status.

Annual Facilitator Feedback Survey

Once a year, the American Lung Association emails a national feedback survey to all Certified Club Facilitators. This anonymous survey allows facilitators to share your experiences, opinions, and suggestions for improving the nationwide implementation of the Better Breathers Club program. Because this feedback is so critical to the success of this program, participation in this survey is one of the requirements of the Club Facilitator and Sponsor Agreement.

Networking and Learning Opportunities

The American Lung Association offers a variety of networking and learning opportunities for Club facilitators. Several times a year the National Office hosts educational webinars open to facilitators nationwide. These webinars are also recorded and archived for listening at your convenience, and can be accessed through the [Facilitator Resource Center](#). Some state and regional Lung Associations also offer local programs.

The best way to keep up with the latest Better Breathers Club-related information is through the monthly Club Facilitator email newsletter. You should start receiving it soon after completing your certification, but you can always contact the American Lung Association staff program lead if it is not getting to you. Through the virtual Facilitator Meetups hosted by the American Lung Association and led by Lung Association staff, facilitators will learn about new resources available to them and also have the opportunity to network with facilitators across the country.

Think about recruitment as an ongoing process, since even the most successful Club experiences attrition over time.

Recruitment and Retention of Members



Member Recruitment

Experience has shown that adult support groups work best when they are at a size that is neither too small nor too large and encourages interaction with one another. In order for facilitators to give sufficient attention to each participant, a good size group to shoot for is about 20 members. Think about recruitment as an ongoing process, since even the most successful Club experiences attrition over time. If the group gets too big, however, you may want to talk to your sponsoring organization and/or Lung Association staff about splitting the group into two BBCs that have room to grow.

You can recruit members in many ways. Members can pass the word to others they know from their doctors' offices or pulmonary rehabilitation programs. They can help distribute flyers to senior centers, libraries or other public places. If they belong to a listserv for area residents with lung disease, they can send an e-mail message about the group. Hospitals often have an internal educational channel where you can post support group information and some hospitals/ local health plans send quarterly free newspapers which include listings or support groups. Your guest speakers may also be able to help.

Referrals

Ongoing referrals and recruitment for new members will be important for the continuation of the Club.

Below are some potential ways of setting up a member referral system:

- Enlist the support of a "Club Champion" at your organization, this could be a local physician or practitioner who is willing to help promote and build awareness about the Club
- During patient education, the health navigators can promote the local Club
- Rack card and/or flyer can be placed at patient check out, bulletin board, or in waiting rooms at local physician offices, hospitals and community clinics



The best way to retain your Club membership is to make participating in the Club a rewarding experience for as wide a range of patients and caregivers with lung disease as possible.

- Collaborate with local American Lung Association staff on additional ideas

Think about all the people and organizations that work with patients with lung disease in your community. They are all potential sources of referrals to your Club, if they know about it! Look at the [Facilitator Resource Center](#) for available promotional materials such as business cards, flyers and rack cards. These items can be customized with your Clubs information. Possible sources of referrals include:

- Pulmonary rehab programs
- Pulmonary and family practice physicians and internists
- Medical social workers
- Hospital discharge planners/ respiratory educators
- Home health care agencies
- Durable medical equipment companies
- Pharmaceutical representatives
- Health department staff
- Senior centers staff
- Area Agency on Aging
- Chronic disease self-management programs

Marketing and promotion

The American Lung Association has customizable marketing materials available to promote Better Breathers Clubs through a variety of channels. These include print ads, press releases, and social media posts. The [Facilitator Resource Center](#) includes some downloadable promotional materials. You can also check in with your Lung Association staff contact about ways to promote your Club and publicize upcoming meeting topics.

Working with the sponsor organization's marketing department can help advertise and promote your program. Highlighting on social media a guest speaker or topic can reach a larger audience of potential members and caregivers. During observance months, such as COPD Awareness Month or Pulmonary Fibrosis Month, highlight a member's story from your club. Having these observance months recognized throughout the year can help build awareness about your Club and help with engaging your current members.

Member Retention

The best way to retain your Club membership is to make participating in the Club a rewarding experience for as wide a range of patients and caregivers with lung disease as possible. There is no one typical Better Breathers Club member. The people who come to Club meetings are diverse and changing. Be sensitive to issues of cultural and geographic diversity when choosing materials and topics. In addition, consider that more people than ever, at all ages, are active users of e-mail and the internet.



When members become directly involved in running their Club, they are more likely to stay active and committed.

Communication with members

One way to boost member retention is to communicate with Club members before and after meetings. You should be able to put together contact lists from the information collected on the Member Information Forms. A couple of specific suggestions:

- Send reminder postcards or emails about upcoming meetings.
- Make a note of which regular members were not present at a meeting and reach out to let them know that they were missed.
- During meetings, have Club members sign a get-well card for someone you know is not well enough to attend.
- Send out holiday and/or birthday cards.
- Consider getting a Club member volunteer to take on some or all of these duties. It can mean a lot to a member to know that others are thinking of them and care about how they're doing.

Check the [Facilitator Resource Center](#) for customizable print-ready meeting reminders, get well cards and other resources for your use.

Member engagement

When Club members become directly involved in running their Club, they are more likely to stay active and committed. Members can take on roles that help them feel included, give them responsibility for a specific task and help relieve the facilitator of all the tasks.

Suggestions to increase member engagement:

- Establish a member mentoring system, where longtime members can serve as the welcoming committee to new members. New members feel less overwhelmed about trying something new if there is someone there to offer their support right away. This may be especially important for individuals with rarer lung diseases such as pulmonary fibrosis or pulmonary hypertension.
- Briefly review the touchstones, or ground rules, of the meeting, at the beginning of every meeting.
- Serve as a greeter as members enter the meeting room, taking attendance, giving out name tags and handouts.
- Distribute promotional flyers to pre-determined places
- Arrange for refreshments
- Close each meeting by reviewing the techniques for deep breathing
- Set up a communication tree for meeting reminders or last-minute changes, such as when a meeting is cancelled due to inclement weather.
- Call, send greeting cards or e-mails to members who were not at the meeting due to illness, hospitalization, recent transplant, or to the next of kin of a member that recently passed.

Many Club members also welcome the opportunity to get involved with education and advocacy, especially if they see it as giving back to their community, or preventing others from suffering from lung disease as they have. The American Lung Association has a wide range of program

and advocacy initiatives that can provide a meaningful experience for your members, from joining the [Lung Action Network](#), to becoming a media spokesperson, to helping others quit smoking with [Freedom From Smoking](#)[®]. There might be some opportunities that the whole group decides to take on together, such as a lobbying visit in support of issues like healthy air or access to healthcare. Your Lung Association staff contact would be happy to talk to you about local options, and may be able to present them at an upcoming meeting.

Patient & Caregiver Network

Patient & Caregiver Network The American Lung Association [Patient & Caregiver Network](#) provides direct access to education, support and a sense of connection for adults living with chronic lung disease, their caregivers and families. The [Patient & Caregiver Network](#) does not replace the benefits experienced from attending an in-person or virtual, Better Breathers Club but rather this program provides an additional layer of support for Club members.

You can encourage your Club members to register online or assist them with registering during a Club meeting..

Patient & Caregiver Network Highlights:

- Membership is free and available nationwide
- Sign up for easy access to webinars, videos, support groups and more learning opportunities.
- Learn more and join at Lung.org/PCN

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