



# How to Start a Lung Health Support Group

An information booklet to help Team Leaders, Lung Health Ambassadors or anyone who would like to develop a lung health support group in their community.



# Have you or someone you know been diagnosed with a lung disease?

Perhaps chronic obstructive pulmonary disease (COPD), which includes chronic bronchitis and emphysema, or another lung disease like pulmonary fibrosis, pulmonary hypertension, lung cancer, or asthma?

Have you ever wanted to share your own experiences, accomplishments and frustrations in dealing with this disease?

Did you discover that there are no lung health support groups in your community and want to take the initiative to start your own?

At The Lung Association we understand lung disease. We know that it is a disease of loss that can affect every part of your life and that many people cannot relate to it. We also know that with the help and support of a group of people like you, that you can meet the emotional and physical challenges of daily living with lung disease. A support group can offer you a place to share your thoughts with others. It can offer support and empathy only people affected by lung disease can understand. This camaraderie helps you realize that you are not alone in this journey.

The Lung Association of **Nova Scotia** has created this booklet to help guide you in organizing a support group for people with lung disease and their family and friends. Our current team of Lung Health Ambassadors has played a major role in creating this booklet. The purpose of it is to help bring support to those who live with lung-related diseases.



How Do You Start a  
LUNG HEALTH SUPPORT GROUP  
in Your Community?

You'll need a plan that will help establish:

**LOCATION**

of the meeting  
(where would it take place)

**LOGISTICS**

of running a support group (food,  
budget, insurance, and other items)

**STRUCTURE**

of the meeting (when and how  
often it should be held)

**PROMOTION**

(what are the best ways to reach  
those who would be interested in  
your support group)

**TOPICS OF INTEREST**

(how to capture people's interest -  
speakers, topics, events)

Now, let's take a look at all these steps one by one.

# 1. LOCATION

Ideally, the location should:

- Be centrally located - on a bus route and easy to find by car
- Have free, accessible parking available close to the entrance
- Be easily accessible - no stairs, or if there are stairs ensure there is an accessible elevator close by
- Have necessary amenities such as: accessible washrooms, chairs and tables, kitchen facilities
- Offer a meeting room free of charge or at a nominal cost





When searching for an ideal location, it is always best to research and consider a few options so you can compare the pros and cons of each one. If needed, you would have a “back up” location on file should your first choice not work out for one reason or another.

## Possible locations include:

- Grocery stores
- Medical centres
- Schools
- Community centres
- Place of worship (e.g., church)
- Senior centres
- Retirement homes
- Nursing homes
- Private home
- Apartment/condo meeting/party rooms
- Car dealerships
- Library conference room
- Service Clubs (Legions, Rotary Clubs, United Way)
- YMCA
- Hotels
- Hospitals
- Restaurants
- Union Halls



# 2. LOGISTICS

## Food

Groups often choose to have tea/coffee fund to cover refreshment costs. Some groups rotate bringing snacks for social time. Please remember that some members may be allergic to nuts or have other food allergies/triggers. Once the group is established, you may want to organize a potluck lunch or even a dinner party.

## Budget

Some groups charge a nominal yearly membership fee for various purposes, such as: location fee (if needed), tea and coffee, cards, and thank you gifts.

Other groups simply pass around a donation container at each meeting to collect a small donation. (This can be as low as one dollar at each meeting.) Please keep in mind that if you are just starting a group and your membership is quite low, the Lung Association is able to help you with the cost of tea, coffee or other refreshments for meetings, providing you have receipts.

*“Keep it fun! That keeps people wanting to come back.”*

-Doug C.



## Insurance

It is important to verify if you require additional insurance for the location you have selected for your group meeting. Most of the time you will be covered by the location, but it's best to double check!

**Note:** A lung health support group meeting cannot include exercise for a variety of reasons, including insurance. No exercise!

## Contact List

Create and maintain a member list with addresses, telephone numbers, emails and other important personal information such as: birthdays and emergency contact information.



## Events

Here are some examples of events support groups have done in the past:

- Potluck lunch or dinner
- Day outings and bus trips
- Christmas party for participants and family members (you can invite guests like Santa and/or the location staff)
- Summer barbeque (it is possible to do it in a park, but you might need a permit)
- A friendly game of bingo or game of cards
- Garage sale



*“Say what you think, just say it nice.”*

-Dianne L.



## Important Points to Remember

- At each meeting, consider setting up a table with health information on lung diseases, cancer, heart & stroke, diabetes, arthritis, etc. Many non-profit health care organizations will send you material free of charge. Please call The Lung Association for a variety of resources on lung disease, quitting smoking and air quality.
- Some groups have a mission or goal statement (optional) and a members address book or list to hand out to all members.
- Every group is unique. For some members, this is their only social time and they look forward to coming out. Expect your group to experience “ups and downs” in terms of attendance and enthusiasm. Having a phone committee responsible for keeping in touch with members will help keep the group going.
- As a group leader, make sure you are not overwhelmed with potential needs, tasks and responsibilities. Break your jobs down **and ask the Lung Association** to help you along the way.
- Most importantly provide an inviting atmosphere where people can express themselves in a safe and empathetic environment.

# 3. STRUCTURE

- How often the support group will meet is usually determined by the need of the group. Most groups find that once a month from September to June works well for most members, however, some groups opt for quarterly meetings instead. The preferred day of the week is often determined by the leader along with the other group members, although it is also heavily influenced by the availability of the location.
- The time of the meeting should best fit the group – for many people, late morning or early afternoon works better for driving.
- The length of the meeting averages 1 to 1.5 hours. It may include listening to a speaker (if available), socializing, sharing information & resources as well as other activities suggested by the leader and group members.
- The group can suggest topics of interest and the leader will choose an agenda and a topic for each meeting. Ideally, depending on the size, the group might also have a back-up leader or co-leader, a treasurer and a secretary.
- The role for a secretary could be to send out get well, anniversary, birthday and condolence cards. The cost could be covered by club fees, if applicable. A treasurer could manage the finances.





- Establishing a phone committee and/or e-mail database can help a leader keep in touch with group members.
- Some larger groups organize a committee to call and visit sick members to let them know they care and to help support them through a difficult time.
- There are no “rights or wrongs” when establishing the structure of your support group. Many different factors play a role in what the end product will look like. As long as it meets the needs of the members and everyone feels comfortable with it, then it will be successful.



*“If you are starting a support group, don’t expect to get the response immediately; sometimes it takes time and persistence.”*

*-Brenda C.*

# 4. PROMOTION

It is important to spread awareness about the meetings in order to recruit members. Some suggestions include:

- Create a poster outlining the dates and times of the meeting as well as the contact information. The Lung Association can help you with the template for your poster.
- Prepare a letter or an e-mail that describes the group and outlines the pertinent details.
- Write a short description of the group and have it ready for any opportunities that may arise.
- You can approach a local journalist and they may write a feature story on your group!



*“Don’t give up what you enjoy. Do it slower, but do it.”*

- Bruce E



## Ways to promote your group:

- 1 Ask your family doctor, respirologist or pulmonary rehabilitation leader to contact their lung patients via mail or e-mail
- 2 Place posters at the following locations:
  - Hospital (respiratory therapy department, pulmonary function lab, bulletin board)
  - Doctors' offices
  - Pulmonary rehabilitation clinics
  - Senior's centres
  - YMCA/YWCA
  - Fitness centres
  - Churches
  - Bulletin boards (grocery store, variety store, library)
  - Local public health unit
  - Staff rooms of local corporations
  - Contact Lung Association for ideas and to help you with the poster!
- 3 Free listings
  - Cable TV may list your event for free on their community channel.
  - Local newspaper (e.g., SNAP) - most daily & weekly newspapers have "what's happening this week in the community" sections.
  - Local radio and television station events page.
- 4 Use the computer
  - Email, Facebook, Twitter
- 5 Word of mouth

# 5. TOPICS OF INTEREST



*“ I start my day doing breathing exercises, always with pursed lips. ”*

-Lorraine L.



## Possible Topics for Guest Speakers

- Air pollution and other irritants
- Breathing techniques and body positioning
- Caregiver support
- Chronic disease and depression
- Computer tutorial
- Dealing with stress
- Energy conservation and fatigue
- Healthy lifestyle
- Home security and safety
- How to improve your memory
- Importance of exercise
- Insurance (health, travel, life and home)
- Lung Diseases - risk and prevention
- Lung Diseases - symptoms, diagnosis, treatment
- Lung Diseases - how they affect lungs
- Management plan
- Managing and preventing flare-ups
- Medication and inhalation techniques
- Preparing for your future (will, power of attorney, funeral arrangement)
- Proper nutrition
- Quitting smoking
- Secretion clearance and cough techniques
- Sleep issues and CPAP
- Stress management
- Supplemental oxygen
- The importance of pulmonary rehabilitation
- Travel issues
- Travelling with oxygen
- Updates in research

# Potential Guest Speakers for the Topics Outlined

As a suggestion, speakers should talk for no more than 30 minutes, allowing for a question and answer period at the end of the presentation. It is preferable to have the speaker at the beginning, not the end of the group meeting.



## Here are a few ideas for potential speakers:

- Acting club/music/choral group/voice teachers
- Addiction counsellors
- Audiologists
- Community Care Access Centres
- Canadian Mortgage & Housing Corporation (air quality)
- Dietitians (meal plan, supplements)
- Fire departments
- Funeral home representatives (preparing for your future)
- Guests from non-profit health care organization such as:  
LANS, Heart and Stroke Foundation, Canadian Diabetes Association, Arthritis Society, Osteoporosis Canada
- Home care oxygen company
- Home security suppliers
- Insurance agents (medical, travel, life, home)
- Internet trainers



- Life skill practitioner (dealing with loss)
- Lung transplant recipients
- Medical doctors
- Occupational therapist (home safety, bathrooms, kitchen)
- Paralegal/legal services (wills, powers of attorneys and other issues)
- Personal accountants/financial planners
- Personal support worker (<http://www.psno.ca/>)
- Pharmacists
- Physical education instructor
- Physiotherapist
- Police
- Psychiatrist or psychologist
- Public Health (TB, air quality)
- Pulmonary rehabilitation leader
- Red Cross
- Respiratory therapists
- Respirologists
- Social workers
- VON (Victoria Order of Nurses)
- Yoga/Tai Chi/Laughter Instructors

**Note:** As part of a support group, it is also important to allow time for members to share their issues, challenges, and stories with others. This will allow members to get to know each other and have fun while also learning different ways that others manage their condition.

# Who are the LANS Lung Health Ambassadors?

This is a group of dedicated individuals with or without a lung disease who help to raise awareness of COPD and other lung diseases in NS. Our team of Ambassadors have met with their provincial members of parliament regarding government funding for COPD programs, or assisted with forming new lung disease support groups. They have been featured in The Lung Association newsletters and resources, and have answered the call for television and radio interview opportunities. They are also quoted throughout this booklet!

The Lung Association is always seeking new Lung Health Ambassadors to represent their region. These individuals need to be enthusiastic about sharing information on lung disease in their community. They can be part of a respiratory rehabilitation program, a maintenance exercise program, support group, or they can be acting on their own.

*“If you dream it, you CAN do it. My dream was to get an exercise program started and we did.”*

-Bev B.





When you can't breathe, nothing else matters™

**The Lung Association of NS provides lung health information and support.**

- Asthma • Chronic Obstructive Pulmonary Disease (COPD)
- Healthy Air • Health Care Professional Education • Research
- Smoking Prevention and Cessation • Tuberculosis

For more information about lung health, how to start a support group, assistance with your new support group or to reach one of the Lung Health Ambassadors, call the Nova Scotia Lung Health Information Line at 1-888-566-5864 or visit us at [www.lung.ns.ca](http://www.lung.ns.ca)

Also find us on:



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