



## **ATA Support Group Leader “Help Book”**

If you are interested in starting a tinnitus support group, the following pages provide helpful information on how to start, organize, recruit and run a successful tinnitus support group. It also gives advice on meeting topics and helpful ways to keep people coming back to your group time and time again!

Topics include:

- ☞ Starting a Tinnitus Support Group
- ☞ The First Meeting
- ☞ Ideas for Meeting Topics
- ☞ Finding Guest Speakers
- ☞ Suggestions for a Successful Meeting
- ☞ Promoting Your Group
- ☞ Different Jobs for Different Support Group Volunteers
- ☞ Being an Active Listener

Questions?

Contact Katie Fuller, Director of Support at (800) 634-8978 x 220 or [katie@ata.org](mailto:katie@ata.org)

## The First Meeting

So you've decided to start your own support group and you're exciting about hosting regular meetings for people who have tinnitus and their friends and families...

**First things first:** *make sure you have a location to meet.* Consider using rooms at public libraries, hospitals, colleges, churches, synagogues, recreation or senior centers, etc. Some large businesses - banks, for example - also have meeting rooms available. Many of these rooms are free to nonprofit groups, but reservations usually must be made in advance. If you book a room and your plans change, call and cancel as soon as possible. For your safety, we discourage in-home meetings.

**Next up:** *publicity.* Make sure you have submitted your meeting information to the [American Tinnitus Association \(ATA\)](http://AmericanTinnitusAssociation.org), your local newspapers and television stations, tinnitus community message boards, social networking pages and other appropriate venues. You will receive phone calls or e-mails from people who have heard about the group. Be sure to have meeting information and location directions handy when replying to people. And keep track of telephone numbers and e-mail addresses so you can remind people about the second and third meetings.

**On the day of the meeting,** arrive early at the location to double check the room's configuration, lighting and temperature.

**For the first meeting,** be prepared to meet for the fully allotted time. Whether one person or 50 attends, stick to your agenda to make sure the most important items are discussed. Consider the sample agenda below when deciding on how to structure the first meeting.

Most importantly, before your first meeting, *relax.* You are volunteering your time and energy to help people battle a common problem and you've provided a forum and a reason for people to share. Even if everything does not go exactly as planned, you are making a difference in how people relate to each other and their tinnitus.

## Sample First Meeting Agenda

### I. Welcome and Introductions

Introduce yourself and why you started the group. Are you a healthcare professional with a keen interest in tinnitus? A volunteer who has learned how to cope with tinnitus and wants to help others learn to do the same? A spouse who has a personal connection to helping people with tinnitus? If you are not a healthcare professional, *be sure to let people know that you cannot give medical advice.*

### II. Meeting Frequency

Should you be meeting quarterly, monthly, semi-monthly? Some groups meet monthly on a school-year schedule, with summers off. Discuss what will work for you and other participants.

### III. Meeting Structure

Guest speakers can help make group meetings informative and useful, but having time to share and talk as a group can help build your community. Talk to people about what kinds of features they'd like to see in each meeting. Some groups have a "book club" approach where they discuss research articles or the latest issue of [Tinnitus Today](#). Other groups are sure to always incorporate thirty minutes for going around the circle and talking about how the past month has been for each person with regards to their tinnitus. Other groups have a guest speaker each and every time. Talk about people's expectations for the meetings.

### IV. Group Guidelines

For the first meeting, discuss what will make the meeting a safe, welcoming place for people to share and participate. Some groups go so far as to create rules for discussions. For example, is confidentiality important? Should you have a rule against interrupting? Help people to feel like they have some ownership of the group and how it is run.

### V. Meeting Content

Discuss what kinds of topics people would like to learn about at each meeting. Keep notes or pass around a sheet where people can write their suggestions. Alternately, start a jar where discussion topic ideas can be kept and pulled out at the end of each meeting to help start planning for the next.

### VI. Tinnitus: "What's Working for Me This Month"

End on a positive note. While people should be given a forum to discuss the challenges they're facing, they also should leave with something new or beneficial to try or consider. Ask people what's worked for them this month, what they've tried with good results, how they've improved their sleep or how they keep their spirits up. Even serious, hard discussions can be highlighted with a positive outlook.

## **Ideas for Meeting topics**

Having a formal topic for each meeting can help form a tight agenda while giving structure to the group's conversation. Here are a few ways to find out which topics interest your group's participants:

- Ask people to submit a **questionnaire** during the first meeting.
- Ask participants to fill out little slips of paper to put into an "idea jar"
- Include a **column for suggestions on the sign-in sheet**
- Hold **brainstorming discussions** to gauge interest in different topics
- And encourage people to **make requests** if they have something on their mind

Meeting topics can also correspond to the type of guest speakers you invite. For example, a dentist might naturally feel compelled to speak about temporomandibular joint disorder (TMJ), while a psychologist might choose to speak about depression. Local experts can be an easy and informative way to discuss complex topics without too much research on your end.

### **Some suggested meeting topics:**

<ul style="list-style-type: none"> <li>• Acupuncture</li> <li>• Allergies</li> <li>• Biofeedback</li> <li>• Cognitive Behavioral Therapy</li> <li>• Coping Strategies</li> <li>• Depression</li> <li>• Diet/Nutrition &amp; Vitamins</li> <li>• Drugs that help/drugs that hurt</li> <li>• Electrical Stimulation</li> <li>• Habituation</li> <li>• Hearing Aids</li> <li>• Herbal Remedies</li> <li>• Hypnosis</li> <li>• Job Concerns</li> <li>• Masking</li> <li>• Medical &amp; Surgical Intervention</li> </ul>	<ul style="list-style-type: none"> <li>• Meniere's Disease</li> <li>• Noise Levels</li> <li>• Personal Thoughts/Moods</li> <li>• Relaxation Techniques</li> <li>• Research</li> <li>• Sound Therapy</li> <li>• Sleep Problems</li> <li>• Temporomandibular Joint Disorder (TMJ)</li> </ul>
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## Finding Guest Speakers

Guest speakers are one of the biggest draws to any meeting. But finding people to speak can be a challenge. Who makes a good guest speaker? Where do you find someone? How do you ask a professional to speak?

### Look to a variety of professions

Doctors, audiologists and hearing aid specialists all make excellent candidates. But guest speakers don't need to be tinnitus authorities. Experts from a variety of professions can have interesting and relevant information to share. Consider inviting nutritionists, psychologists, chiropractors, naturopaths, cognitive therapists, biofeedback specialists, hypnotists, massage therapists or others.

### Use your connections

When looking for a guest speaker, don't go it alone. **Take twenty minutes during a meeting to gather suggestions from the group.** Who do they know that may be willing to speak? A doctor? An acupuncturist? Discuss the best way for the members themselves to do the asking. Professionals will be most receptive to speaking when they are approached by someone they know. Another great way to connect with speakers is at hearing health events. Conferences are often affordable, informative and a wonderful place to meet experts from a wide variety of fields. **Don't forget to [contact ATA](http://ATA.org).** We are always available to answer questions and provide additional resources. We have listings of providers for each region of the United States, many of whom are willing to donate their time.

### Offer information with your introduction

When you approach someone new, consider first writing an introductory letter or e-mail that formally introduces your group. Including an article about tinnitus and the expert's specialty may add to their interest in speaking. When you call, explain who you are, a bit about your group, why you are interested in having them speak and what benefit they can derive from speaking to your members. Some professionals may not be very familiar with tinnitus, so be ready to explain basic tinnitus information, and why their specialty is relevant to people with tinnitus.

Guests should be agreeable to donating their time and should understand from the beginning that their visit is a service, *not an opportunity to sell their product*. Keep in mind that your group will probably be responsible for your speakers' travel costs if they are coming from out of town. Sometimes professionals have their staff set up their meetings and public appearances. If you don't know the speaker, it's good to talk with them at least once before the meeting - unless you like surprises!

# Suggestions for a Successful Meeting

## Format & Structure

- ☞ Invite a variety of guest speakers to the group. Doing so encourages diversity, dialogue and openness to other people's opinions and experiences. It also helps take pressure off of you to serve as an expert on all subjects. While support group facilitators can have impressive knowledge about tinnitus, many are not healthcare professionals. A professional perspective can deepen the dialogue.
- ☞ Encourage attendees to invite their family members, friends, colleagues and neighbors. People with tinnitus need and deserve to be understood. Inviting those people closest to tinnitus patients can prove educational for tinnitus patients' supporters. Plus, by inviting people without the condition, you can discuss how to prevent tinnitus.
- ☞ Place **sign-in sheets** near the entrance to the meeting room so that you can collect contact information for people, which will help with promoting future meetings. Have space on the sign-in sheet for people to suggest topics they want to discuss.
- ☞ Talk to group participants about good **meeting length**. You want meetings to be long enough to give everyone, including guest speakers, an opportunity to contribute, but not so long that people will fade or lose interest.
- ☞ **Have an agenda**: doing so will keep you on task and use your time effectively. You can also track topics that come up but don't get discussed because of time, saving them for the next meeting.

## Communication

- ☞ Establish **group rules** to help make the meeting a safe place to communicate and share. For example, you may decide as a group to set aside thirty minutes each meeting for general discussion, or to give each member of the group five minutes to speak. Work with your group to discover how to make all attendees comfortable communicating.
- ☞ Don't feel as though you need to be the full-time source of information. When asked for answers by a group member, say, "Let's ask the group."
- ☞ Speak in the first person - **tell your story** - and encourage other members to do so, if they feel comfortable.
- ☞ When group members are interrupted, step in immediately and ask the interrupters to allow the speakers to finish their thoughts.
- ☞ **Turn complaints into a task** for the group by asking for ideas or solutions. Let participants who complain know they are not alone, but also that there are solutions too.
- ☞ **Encourage**, but do not pressure, quiet members to speak.
- ☞ Notice when a topic has been finished and **summarize** it for the group.

- ☞ Repeat questions or main points for those who are hard of hearing, and occasionally ask the group if they are all able to follow the conversation.

## Atmosphere

- ☞ Quickly take care of disturbances that bother others—like someone smoking, interruptions from people not attending the group or a faulty sound system.
- ☞ Pay special attention to the needs of those in the group who are hearing-impaired.
- ☞ Choose a location that has good acoustics so that people aren't straining to hear the conversation.

## Logistics

- ☞ Set up a group telephone or email network so that people can contact each other between meetings.
- ☞ Promote your meetings in local community calendars, both online and newspaper-based. Invite local health reporters to attend.
- ☞ Make contact with a local psychologist or counseling hotline. Some participants may be distressed enough to need professional counseling. Have the therapist's name and number on hand to share with people in need.
- ☞ Have your next meeting's location, topic and time ready to announce at each meeting.

## Promoting Your Group

Each support group is responsible for promoting upcoming meetings. Often, this task is completed by the group facilitator, but some groups have a well-organized volunteer structures, complete with one person who takes on this role before each meeting. Ways to promote the group include:

- ☞ Calling (800) 634-8978 x220 or, emailing Katie Fuller, at [katie@ata.org](mailto:katie@ata.org) to have a reminder sent out via e-mail to people in the ATA database who live in your metropolitan area.
- ☞ Posting a meeting on [Meetup.com](http://Meetup.com).
- ☞ Adding a message to various online community message boards for people with tinnitus.
- ☞ Hanging up fliers in local health care clinics, libraries, musical instrument stores and grocery stores.
- ☞ Sending an announcement to local newspapers for inclusion in their calendar of events.
- ☞ Sending a press release to newspapers, television and radio stations, and local magazines for free coverage (see below for sample)

### Sample Press Release:

Today's date

Publicity Coordinator's name, address and telephone number  
Contact Person

FOR IMMEDIATE RELEASE

PORTLAND, ORE. - The Greater Portland Tinnitus Support Group will hold its monthly meeting on Monday, October 1, 2007, from 7:00 p.m. to 8:30 p.m. in the community room at the Chestnut Hill Library. This event is free and open to the public.

Tinnitus is the perception of noises in the ears or head when no external source is present. The Greater Portland Tinnitus Support Group will offer the latest treatment information, coping and stress reduction techniques, and encouragement and camaraderie to help combat this debilitating condition. While there is no cure for the over 50 million Americans who experience tinnitus, there are many different treatment options available.

A small donation is accepted at the door to help cover the costs of refreshments. The Greater Portland Tinnitus Support Group meets the first Monday of every month at the Chestnut Hill Library. For more information, contact the Group Leader [insert name] at [insert Group Leader's telephone number].

## Different Jobs for Different Support Group Volunteers

A supportive group environment can offer great relief to people who are troubled by tinnitus. From a practical standpoint, though, a support group takes time and effort to facilitate. Group facilitators are encouraged to find volunteers to help with group tasks. Asking for help accomplishes many things:

- ☞ It lightens your workload
- ☞ It helps tasks get completed more quickly
- ☞ It provides the group with one or more “back-up” leaders in case of time conflict, vacation, or illness
- ☞ And it gives others a sense of ownership and responsibility toward the group.

The following are some suggested support group “jobs” and associated tasks. Don't be limited by this list, however - wherever you need help to make your group successful, ask! Also, some groups hold elections to staff different positions. Decide with your group what works best, and be flexible as your group progresses - informal volunteer schedules might work in the beginning, but as your group grows, you may need a more formal leadership structure.

### Group Leader:

- ☞ Finds the meeting place
- ☞ Plans the meeting's agenda
- ☞ Coordinates guest speakers
- ☞ Leads the discussion
- ☞ Asks attendees to help out with group tasks
- ☞ Encourages group members to become supporters of the American Tinnitus Association
- ☞ Communicates with [ATA](http://ATA.org) whenever questions or concerns arise
- ☞ Sends [ATA](http://ATA.org) updates (copy of the minutes, newsletter, etc.) to let us know how the meetings are progressing
- ☞ Is the telephone or e-mail contact for the group in the [ATA Support Network listings](http://ATA.org).
- ☞ Assists members in getting to know one another
- ☞ Keeps the meeting focused
- ☞ Fosters an atmosphere of trust and mutual support
- ☞ Listens carefully and with sensitivity
- ☞ Maintains an environment of safety for all members by an agreed-upon definition of confidentiality
- ☞ Tolerates differences
- ☞ Helps group members deal with conflicts as they arise
- ☞ Does not dominate or intimidate or allow others to do so
- ☞ Keeps the members pursuing a positive approach to their tinnitus
- ☞ Group leaders are also encouraged to delegate above tasks when appropriate

## **Greeter:**

- ☞ Welcomes people at the door and helps them locate restrooms, coat racks and refreshments
- ☞ Reminds people to sign the roster
- ☞ Introduces attendees to one another

## **Refreshment Coordinator:**

- ☞ Organizes volunteer schedule for snacks
- ☞ Makes reminder calls to snack volunteers before the meeting
- ☞ Use group donations to purchase snacks - if the group decides to use funds in this way
- ☞ Sets up refreshment area
- ☞ Keeps necessary supplies on hand

## **Secretary:**

- ☞ Takes notes during the meeting
- ☞ Handles group mailings or e-mails like meeting announcements or newsletters, if applicable
- ☞ Writes or edits the group's newsletter

## **Librarian:**

- ☞ Coordinates lending library of books, brochures, CDs and DVDs at the meetings
- ☞ Keeps track of items that are checked out; reminds borrowers to return materials
- ☞ Discuss useful books, CDs, DVDs or articles at the meetings

## **Publicity Coordinator:**

- ☞ Places group fliers on local community bulletin boards.
- ☞ Designs the group's meeting notices
- ☞ Sends press releases to the local paper, radio stations or television stations

## Being an Active Listener

Active, effective listening is a good habit to learn. It promotes positive communication between people and helps maintain order in the group setting where many people may want to speak.

When we listen, we bring to a conversation our opinions about and our ability to understand the subject matter. Speakers have their own opinions and levels of understanding, and they may also have anxiety about speaking in front of a group. Overcoming these challenges to become a committed participant in a dialogue is at the heart of any active listening exercise.

There are always external factors when listening in an active way. There's the speaker, the subject about which he or she speaks, the mediums involved in the presentation and the overall environment. For example, if you're standing in a crowded airport terminal, paying close attention to the speaker is going to be challenging no matter how engaged you are in the discussion. If you're right below an air conditioner vent, you might not hear as well as you would away from loud noises. Recognize avoidable distractions, and correct them when you can.

The presentation makes a difference in how well you can listen. Is the message delivered using technology, like slides or sound effects? Are concepts introduced incrementally, with examples? This matters especially when subjects are complex. If you're struggling to understand a point made earlier in the presentation, it's hard to be an active listener later in the conversation. While you don't want to interrupt the speaker, wait for a pause so that you can signal that you need to ask a question. He or she will appreciate your interest, and you can expand the knowledge you need to continue the conversation.

Active listening also requires that you suspend or at least minimize opinions, emotions and judgments you may have on the subject. Your opinion is important, but it's also key that you focus your attention on your subject and his or her words. It's better to remain passive while someone else is speaking so that you take in the full scope of what he or she says. This is not to say that what you know about the subject is not relevant - it is! But while you should review what you already know about the subject, remember that you are present to learn what the speaker has to say, not the other way around. Set aside your prejudice and your opinions until it's your turn to speak.

Try to be involved in nonverbal ways. Nod at points of the speech that move you, focus on the person speaking, lean forward to encourage the speaker and signal your interest. The point is to focus on the person communicating.

In a group situation, give the speaker space and time after talking. If you want to ask a question, first express appreciation that the speaker shared, then ask a non-threatening question that builds understanding. In the same way, if you want to make a follow-up point, briefly summarize the speaker's relevant point before sharing your own view. This builds trust and encourages dialogue and, above all, shows you were listening.