

ATA Support Group Leader Guide

If you are interested in forming a tinnitus support group, this guide will provide helpful information on how to establish, run and sustain a successful tinnitus and hyperacusis support group. The following topics will be described:

- Establishing a group (p. 1)
- Sample first meeting agenda (p. 6)
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Establishing a Support Group

This section describes the recommended steps for establishing a new tinnitus and hyperacusis support group.

Form a Mission Statement

Questions?

Contact ATA at
tinnitus@ata.org.

There is no one mission statement for all tinnitus and hyperacusis support groups. You will need to develop one that works for your personal style of leadership, your goals, and the makeup of the people in your group. Current ATA support groups seek to promote education and compassion, with some emphasizing one or the other a little more. We recommend a similar strategy. Education can take a variety of forms. For instance, your group can learn about scientific research into tinnitus and hyperacusis, effective strategies for managing the conditions and/or the reaction to them, or advocacy efforts to support tinnitus and hyperacusis research. Guest speakers and ATA resources can aid in the delivery of information related to these topics. Deciding what kind of support group you're going to be can be tough, and it may not be something you feel you can do prior to the first meeting, without having interacted with other members. However, we recommend keeping it in mind at the very least.

Contact ATA

Before you organize your first meeting, please contact ATA to be listed on the ATA website as a contact person for your area. Be prepared for potential new members to contact you with questions about meeting location,

structure, and content.

Location

Next, make sure you have a location to meet. Consider using rooms at public libraries, hospitals, colleges, churches, mosques, synagogues, temples, recreation or senior centers, et cetera. 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. You may also consider establishing a relationship with a local, non-profit agency that conducts work related to tinnitus, hyperacusis or hearing, and hold meetings at their facility.

Location ideas:

- *Public library*
- *Hospital*
- *College*
- *Recreation center*
- *Religious center*
- *Senior center*

Equipment

Please also ensure that your room is equipped to host presentations. For instance, many guest speakers present using PowerPoint, for which it will be critical to have a projector, screen, and – for the rare occasion that the presenter does not bring his/her laptop – a computer. If presenters choose to Skype into the meeting, or you are planning to watch an ATA Webinar video, then you will also need speakers.

Publicity

Submitting your meeting information to the American Tinnitus Association, your local newspapers and television stations, tinnitus community message boards, and other appropriate venues can help raise awareness for your group. You will receive phone calls or e-mails from people who have heard about the group. 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. (More information on page 13.)

The First Meeting

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

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 (p. 5).

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 knowledge, skills, and stories. Even if everything does not go exactly as planned, you are making a difference in how people relate to each other and their tinnitus or hyperacusis.

Understanding the basics of tinnitus

For the first meeting, please keep in mind that many of the attendees might be newly afflicted by tinnitus, and so may not know much about it. You might consider starting with its definition: tinnitus is the perception of sound in the absence of an external sound source. In addition, many who have suffered for quite a long time still do not realize that tinnitus is a condition of the brain as well as a condition of the ear. Consequently, please be prepared to explain the very basics of tinnitus and the relationship between the phantom sound and the emotional reaction to the sound. ***We also strongly recommend that you refer them to particular webpages on ata.org that you have found helpful and to the American Academy of Otolaryngology's Clinical Practices Guideline for Tinnitus (Executive Summary available at <http://oto.sagepub.com/>), both of which can familiarize them with tinnitus in general as well as potential management strategies.*** There is no need to understand all the nervous system pathways that might underlie tinnitus – guest speakers can serve that role – but having a few basics handy can be helpful for clearing up confusion.

Understanding the basics of hyperacusis

Hyperacusis is generally defined as sensitivity to moderate or moderately-loud sounds. Some people are physically sensitive to sound and may experience pain and/or pressure in the ears during and after exposure to uncomfortable sound. Other people are bothered by certain kinds of sounds and may experience feelings of anger or frustration when exposed to those sounds (e.g., clicking pen, chewing noises). It is not unusual for people who are bothered by sound to use earplugs to avoid being exposed to sounds that make them uncomfortable. Over time, this can exacerbate the problem. Hyperacusis can co-exist with tinnitus, but not every person with hyperacusis has tinnitus. They may, however, experience problems with concentration and mood in the same way that people with bothersome tinnitus do. People with hyperacusis may benefit from reading Jonathan Hazell's article describing hyperacusis, available at http://www.tinnitus.org/Handout%203_DST_jh_oct2002.pdf, or by reading information on the Hyperacusis Network (www.hyperacusis.net) or at the non-profit Hyperacusis Research Limited (www.hyperacusisresearch.org).

Considerations for Group Volunteers

A supportive group environment can offer great relief to people who are troubled by tinnitus or hyperacusis. From a practical standpoint, though, a support group takes time and effort to facilitate. Group facilitators are encouraged to delegate volunteers to help carry out tasks. Asking for help accomplishes many things: it lightens your workload, helps tasks get completed more quickly, provides the group with one or more “back-up” leaders in case of time conflict, vacation, or illness and finally, it gives others a sense of ownership and responsibility toward the group.

The following are some *suggested* support group roles and associated tasks. Don’t feel limited by this list, however – wherever you need help to make your group successful, ask! Also, some groups hold elections to occupy different roles. 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

The Group Leader plays an essential role in developing and maintaining a successful support group.

- Finds the meeting place
- Plans the agenda
- Coordinates guest speakers
- Responds to e-mail or phone queries from new members
- Maintains e-mail list of local members
- Updates local members with meeting information
- Leads discussions
- Encourages members to donate to ATA individually
- Encourages members to help reach the local group fundraising goal of \$100/year (“Establish group guidelines,” p. 6)
- Communicates with ATA (“Collaborating with ATA,” p. 11)
- 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 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 members pursuing a positive approach to tinnitus/hyperacusis

These roles can be filled by more than one individual, or one individual can fill several roles, whichever works better for your group.

- Delegates 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
- Uses group donations to purchase snacks (if the group decides to use funds this way)
- Sets up refreshment area
- Keeps necessary supplies on hand

Secretary

- Takes notes during meetings
- Distributes notes to group mailing list
- Handles group mailings or e-mails meeting announcements or newsletters, if applicable

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
- Discusses 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

Local Liaison

- Investigates promising relationships with local health care providers and/or other groups interested in tinnitus, hyperacusis, or hearing
- Communicates regularly with local groups fitting this description
- Compiles and maintains a list of (group member) recommended local health care professionals

New Member Counselor (outside of meetings)

- Addresses new members' concerns and questions
- Listens carefully and empathetically
- Discusses strategies for coping with tinnitus or hyperacusis

Sample First Meeting Agenda

1. *Welcome and Introductions*

Introduce yourself and say why you started the group. Are you a health care professional with a keen interest in tinnitus or hyperacusis? 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 health care professional, be sure to let people know that you cannot give medical advice.

2. *Determine meeting frequency*

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

3. *Determine 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. Survey 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 or hyperacusis. Other groups have a guest speaker each and every time. Talk about people's expectations for the meetings. Keep in mind too that those expectations might change with the arrival of new members at subsequent meetings.

4. *Establish group guidelines*

For the first meeting, discuss what will make the meeting a safe, welcoming place for people to 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.

It is also ATA's hope that the local groups will be able to help ATA in its fundraising efforts. Even collecting \$100/year from local members can go a long way toward aspects that benefit the support groups; e.g., brochures for members, employee time used to promote local meetings, or more recently, ATA webinar videos.

5. *Determine 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. This could help you form a mission statement if you haven't already done so.

6. *Discuss how to be 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. Others have their own opinions and levels of understanding, and they may also have anxiety about speaking in front of a group. Recognizing these factors is at the heart of any active listening exercise.

Listening does not happen in a vacuum. There's a speaker and the subject about which he or she speaks, but there is also the environment in which the subject is speaking, which often needs special consideration. 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. Ask questions whenever possible, but try to avoid accusatory tones. Demonstrate empathy.

When listening to guest speakers, 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 the speaker 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 remember too that you are present to learn from the speaker, not the other way around. Set aside any bias you might have 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 participated, 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, not only between you and the speaker, but also between the speaker and the audience in general.

7. "What's Working for Me This Month"

Describe the intent to end each meeting 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 has worked for them this month, what they've tried with good results, how they've improved their sleep, how they keep their spirits up, or how they've maintained an active lifestyle despite the tinnitus or hyperacusis. Even serious, hard discussions can be highlighted with a positive outlook.

Sustaining your group: Meeting Topics and Speakers

This section offers suggestions for determining meeting topics and finding guest speakers, key ingredients for sustaining a support group.

Meeting Topics

Having a formal topic for each meeting can help form a tight agenda while structuring the group's conversation. An extensive list of potential topics is provided in the margin on page 9. Here are a few ways to determine which topics interest your group's participants:

Suggested meeting topics:

- Acupuncture
- Advocacy
- Allergies
- Biofeedback
- Cognitive behavior therapy
- Combination devices
- Coping strategies
- Depression/anxiety
- Pharmacological interventions
- Environmental audio tapes
- Group therapy
- Hearing aids
- Hearing protection
- Herbal remedies
- Hyperacusis
- Hypnosis
- Job concerns
- Maskers
- Meditation
- Misophonia
- Neuromonics
- Nutrition & vitamins
- Ototoxic drugs
- Personal thoughts/moods
- Public awareness
- Relaxation techniques
- Relationships with family, friends & pets
- Scientific research
- Sound therapy
- Sleep solutions
- Surgical interventions
- Temporomandibular joint disorder
- Tinnitus Retraining Therapy
- Transcranial direct current stimulation
- Transcranial magnetic stimulation
- Yoga

- Ask people to complete 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.
- Gauge interests with online surveys (e.g., Google Forms or Survey Monkey).
- Conduct brainstorming discussions to gauge interest in different topics.
- 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.

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, acupuncturists, cognitive behavior therapists, biofeedback specialists, hypnotists, massage therapists or others. It helps when potential speakers are located within driving distance of your meeting site, but do not restrict yourself; Skype meetings can serve as alternatives, and every once in a while a potential speaker residing elsewhere may visit your area.

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 the ATA. 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 or hyperacusis 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 or hyperacusis, so be ready to explain basic information (above), and why their specialty is relevant to people with tinnitus and/or hyperacusis.

Guest speakers 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, you might wish to talk with them at least once before the meeting - unless you like surprises!

Knowing your speaker's background is helpful. First, you can use it to draw potential members to the meeting. Second, you can use it to introduce the guest speaker to your group. And third, it will help prepare you and anyone else in the audience for the particular talk that will be given.

Sign up for ATA membership

Finding new guest speakers to attract members can become difficult to the point that you feel you've exhausted the list of local experts. The ATA is the solution to this problem. Signing up as a member or simply for the mailing list will provide you with resources to experts and new content to share with your group.

Suggestions for a Successful Support Group

Format and 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 or hyperacusis, many are not health care professionals. A professional perspective can deepen the dialogue.

- Encourage attendees to invite their family members, friends, colleagues and neighbors. Educating those closest to the people with tinnitus and hyperacusis helps the patients be better understood by loved ones and fosters general awareness for the conditions. Plus, by inviting people without the condition, you can discuss how to prevent tinnitus and hyperacusis. Even pets can attend depending upon whether they are well behaved and your venue can accommodate them.
- 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 require you to use your time effectively. You can also track topics that come up but aren't discussed due to time, and save them for the next meeting.

Communication

- Establish group rules to help make the meeting a safe and positive 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" or "What do others think?"
- Speak in the first person - tell your story if you have tinnitus or hyperacusis - and encourage other members to do so, if they feel comfortable.

- When group members are interrupted, step in immediately and ask the interrupters to please 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 that they are not alone, but also that there are solutions too.
- Encourage, but do not pressure, quiet members to speak.
- 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.
- Ask questions to demonstrate interest.
- Exemplify kindness, compassion, and optimism as best as you can.

Atmosphere

- Quickly address disturbances that bother others, such as someone smoking or a faulty sound system.
- Pay special attention to the needs of those in the group who are hearing-impaired, especially those with hyperacusis.
- Choose a location that has good acoustics so that people aren't straining to hear the conversation.

Logistics

- Set up a group telephone, e-mail network, or online forum so that people can contact each other between meetings. However, do not force everyone to be connected outside of meetings should members want to maintain their privacy. The bcc feature on emails can be a powerful tool in this regard.
- Promote your meetings in local community calendars, both online and newspaper-based. Invite local health reporters to attend meetings if your group consents.
- 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.

Collaborating with ATA

While you are educating and providing support for your local group, ATA is striving to find permanent solutions for everyone with tinnitus and/or hyperacusis. This effort is being undertaken in a variety of ways, including raising money for tinnitus and hyperacusis research, advocating at the federal government level to secure funding for tinnitus and hyperacusis research, and raising public awareness for these conditions.

Although the local groups are distinct from the national organization, they need not be entirely insular. In fact, the two groups can work together in a few ways:

- **Information Sharing.** For example, if a group in Detroit learns a new tinnitus coping strategy that is not known to people outside of Detroit, ATA can serve as a hub to collect information about the promising coping strategy from the Detroit group and disseminate it to the other support groups.
- **Participation in ATA's fundraising and public awareness campaigns,** such as the Jack Vernon Walkathons. Local groups can raise money to send someone representing their community to compete in the race.
- **Develop connections with other tinnitus- and/or hyperacusis-related organizations.** For instance, if you are located in Portland, OR, you could connect with the VA. Any additional ways in which the local support groups can raise funds and awareness for tinnitus will be beneficial for the whole tinnitus community.

Promoting your Support Group

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

- E-mailing tinnitus@ata.org to have a reminder sent out via e-mail to people in the ATA database who live in your metropolitan area.
- Adding a message to various online community message boards for people with tinnitus or hyperacusis.
- 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 next page for sample).

Sample Press Release:

June 20, 2016

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 pm. 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].

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