

**American Tinnitus Association**  
National Headquarters  
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## **Starting A Tinnitus Support Group**

Hosting a tinnitus support group requires a generous time commitment, compassion for others, curiosity about tinnitus, and a strong sense of responsibility. Whether your group meets monthly, every other month, or four times per year, you still must prepare the meetings so that people are introduced to positive ideas, valid information, and helpful speakers. The hard work, however, pays off with better-informed participants and helpful, spirited discussions about tinnitus.

The American Tinnitus Association strives to provide support to our Support Network and help them to be successful. ATA will send an email announcements out to people in your geographic area, help you brainstorm potential guest speakers in your area, and offer regular support to help group leaders on how to sustain and improve their groups.

ATA is committed to its support groups, but the groups remain independent. Many facets of your group are up to you and other participants to determine. The following are several areas where you will want to discuss your goals, your participants' needs, and what you and your group together determine is the most important components of your group.

### **Meeting Places**

To start a group, you first need to find a good place to meet. Consider using rooms at public libraries, hospitals, colleges, churches, synagogues, health clubs, city recreation or senior centers, et cetera. Some large businesses and public buildings also have meeting rooms available. Many of these rooms are free to non-profit 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. ATA discourages in-the-home meetings.

Remember that when choosing a room, ambiance counts. Find a room that has good acoustics, comfortable chairs, and enough space to adequately fit the number of participants. Monitor temperature and lighting, too, so that people are comfortable.

### **Group Participation**

Your group will be more successful if other group members feel responsible for its ongoing success. Ask for volunteers to help with various tasks to help lighten your workload and encourage their sense of ownership. Doing so ensures that many tasks are completed more quickly and can lead to one or more "back-up" leaders in case of time conflict, vacation, or illness. It also encourages taking advantage of people's skills. Some group members might be great researchers, others proficient in newsletter design. And still others might have a public relations background to help get local publicity.

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Remember that number of attendees isn't everything. Some people may attend only once, having gotten the information and support they needed. Others just might not be motivated to attend regular meetings. The important thing to remember is that quality of the meeting matters far more than the quantity.

## **Group Structure**

Groups choose different meeting schedules depending on the needs of the group. Typical schedules are monthly, bimonthly, or quarterly. The best way to figure out how often to meet is to ask participants during your first meeting. See **“The First Meeting”** for more suggestions on querying participants about their expectations for the meetings.

Meeting formats range can range even more. Many groups invite guest speakers to all meetings; other groups invite guest speakers to every other meeting. Groups hold discussions on recently-published books-much like a book club would-or the latest issue of Tinnitus Today. Sometimes, a group member is charged with looking up a specific scientific topic, then presenting back to the group.

A sample two-hour meeting would include a guest speaker presenting for thirty minutes on some topic related to tinnitus, then spending another thirty minutes on questions-and-answers with the audience. The second hour might consist of discussions on new tinnitus treatments or coping strategies group members have recently tried, group experiences with local healthcare professionals, or goals for the next month. See **“The First Meeting”** and **“Ideas for Meeting Topics”** sections for more suggestions.

## **Other Points to Consider**

Some groups request financial assistance from participants to help cover the costs of room rentals (if any), newsletter publishing and distribution, and refreshments. Talk with your participants about this openly, and do not expect to assume all financial burden for running the meetings. A passed hat and sincere request can successfully encourage people to help support the group's success.

Finally, be flexible. If the first meeting place you select isn't the right size or conveniently located for the attendees, look for a more suitable place. If the group would seem to benefit from a looser-or more formal-structure, plan for the next time accordingly. If the materials covered at a meeting didn't meet the needs of the majority of people who attended, choose a new topic and approach for the next meeting. Remember that it's everyone's group - please show your willingness to respond to others' expectations for the group.

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## **The First Meeting**

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

First things first: *publicity*. Make sure you have submitted your meeting information to the American Tinnitus Association, your local newspapers and television stations, tinnitus community message boards, and other appropriate venues. You will receive phone calls or emails 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 email 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—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 health care 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 health care professional, be sure to let people know that you cannot give medical advice.

#### **II. Meeting Frequency**

Should you meeting quarterly, monthly, semi-monthly? Some groups meeting monthly on a school-year schedule, with summers off. 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 to 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

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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.

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## Ideas for Meeting topics

Having a formal topic for each meeting can help to form a tight agenda while giving structure to the group's conversation. To find out which topics interest your group's participants, simply pose a few questions to people. Submit a questionnaire during the first meeting, ask participants to fill out little slips of paper into an "idea jar", include a column for suggestions on the sign-in sheet, or 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, 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:

Acupuncture	Hearing Aids
Allergies	Herbal Remedies
Biofeedback	Hypnosis
Cognitive Behavioral Therapy	Job Concerns
Combination Tinnitus Instruments	Maskers
Coping Strategies	Medical and Surgical Intervention
Depression	Nutrition and Vitamins
Drugs that help/drugs that hurt	Personal Thoughts/Moods
Electrical Stimulation	Relaxation Techniques
Environmental Audio Tapes	Research
Group Therapy	Sound Therapy
	Sleep Problems
	Temporomandibular Joint Disorder (TMJ)

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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 whom they know. Another superb 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 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!

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## **Suggestions For A Successful Meeting**

### **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, many are not health care 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 no 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.

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## 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 e-mail 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.

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## 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:

- Call 800-634-8978, x 219 or, e-mail Lisa F. Hutton ATA's Manager of Member Services, at [lisa@ata.org](mailto:lisa@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
- 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

Publicity Coordinator's name, address, and telephone number

Contact Person

Today's date

### 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].

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## **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. 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 donors of the American Tinnitus Association.
- Communicates with ATA whenever questions or concerns arise.
- Sends ATA a letter, copy of the minutes, or newsletter 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?
- 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 rest rooms, coat racks, and refreshments.
- Reminds people to sign the roster.
- Introduces attendees to one another.

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## **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, pamphlets, and audio and video tapes at the meetings.
- Discuss useful books, tapes, or articles at the meetings.
- Keeps track of items that are checked out; reminds borrowers to return materials.

## **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.

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## **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. 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.

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