



REGISTERED
TINNITUS
SUPPORT GROUP

Starting a Tinnitus Support Group



Table of Contents

The power of tinnitus support groups.....	3
What is a support group?	4
What is the connection between a Support Group and Tinnitus UK?.....	4
Types of Tinnitus UK registered support groups.....	4
What is the role of a support group leader?	6
Do I need any specific qualifications or experience to be a Support Group Leader?	6
Registering with Tinnitus UK.....	7
How Tinnitus UK will support you	7
Support Group FAQs.....	9



The power of tinnitus support groups...

First time people arrive they come in almost fight-mode, very tense and shoulders high, you can almost read their thoughts: 'is this just going to be another let-down being told there is no cure just learn to live with it'. Towards the end people are chatting and many open up about their journey and how it really affects their daily life; they walk away with a smile on their face, relaxed and shoulders about two inches lower.

***Mona,
Southsea Group Leader***

Tinnitus UK gave me hope and saved my life – so now I help save others.

***John, Online Support
Group Leader***

No one without tinnitus understands it, so I find this self-help group extremely beneficial. It helped me in times of great anxiety and worry and to overcome a lot of obstacles.

***Louisa, support group
member***

I contacted my local group, and I believe that this first step was the most important step towards recovery and acceptance. I received a response from someone in the group within 10 minutes. I had been in the depth of despair and that wonderful response gave me hope and strength to believe that I could overcome this.

John, support group attendee

What is a support group?

A Support Group is a group of people with common experiences or concerns who meet to provide each other with encouragement, comfort, and advice. Tinnitus Support Groups are attended by people living with the tinnitus or the people who support them.

What is the connection between a Support Group and Tinnitus UK?

Support Groups are set up as a collaboration between Support Group Leaders and Tinnitus UK. Once a group is established, it operates independently of Tinnitus UK but is expected to adhere to our Code of Ethics. This means that Tinnitus UK will not intervene in the running of a group unless there is a question of the Code of Ethics not being met.

Types of Tinnitus UK registered support groups

Support group leaders and volunteers come from all walks of life and have a wide range of experience when it comes to tinnitus.

Individuals with tinnitus themselves may want to join a support group but there isn't one in their local area; so, they decide to start one themselves with the support of Tinnitus UK.

Similarly, many audiologists and hearing health professionals recognise that their patients would benefit from additional support outside of the clinic and meeting with others who understand what it's like to live with tinnitus. They may decide to start a support group as part of their work or outside of office hours.

There are also many other charities and organisations around the UK that support people with hearing loss and deafness. Again, those who work for these organisations recognise the need for specific tinnitus support and decide to set up a group to meet that need.



In general, support groups fall into four categories, defined by the background of the Support Group Leader:

Leader's Role	About the Leader
<p>Tinnitus UK Volunteer Led</p>	<p>A Tinnitus UK Registered Volunteer is coordinating and facilitating the group.</p> <p>This type of group is ideal for individuals who see a need for tinnitus support in their community and just want to help. These will be people who don't have the backing of the NHS, a private clinic, or other organisation to help them set up and run a group.</p>
<p>Independent Volunteer Led</p>	<p>Typically, someone with tinnitus who wants to give back and help others. They may feel confident in running the group on their own or already have an established group.</p>
<p>Professional Led Not for profit</p>	<p>A hearing health professional or sensory support worker who sees first hand from clients that there is a need for further tinnitus support outside of the clinic.</p> <p>Organised and delivered as part of the local services provision; typically, a local NHS service or charity.</p>
<p>Professional Led Private</p>	<p>A hearing health professional in the private sector who sees first hand from patients that there is a need for further tinnitus support outside of the clinic.</p> <p>Organised and delivered by a professional working in the private sector; typically, a local private audiologist</p>

What is the role of a support group leader?

A Support Group Leader coordinates and is responsible for all aspects of the support group, including adhering to Tinnitus UK's Code of Ethics; a support group can be organised by more than one person.

Duties include things like:

- Booking and managing the venue
- Meeting and greeting attendees
- Facilitating conversations
- Coordinating guest speakers or activities
- Recording and storing information
- Communicating with group members between meetings
- Ensuring all members are supported in a professional and ethical manner
- Ensuring the meeting is safe, supportive, and respectful of all participants.
- Adhering to the Tinnitus UK Code of Ethics
- Regular communication with Tinnitus UK

Do I need any specific qualifications or experience to be a Support Group Leader?

Support Groups are organised by a range of people, but most often people with lived experience of tinnitus or professionals who support people with tinnitus as part of their work. Some experience of facilitating small groups is also beneficial, but having the time and enthusiasm to organise a support group is most important.

Qualities of a support group leader:

- Organised with good time management
- Enthusiastic and motivated
- Friendly, caring, and empathetic
- Good communicator
- Don't have to be a tinnitus expert! Being able to handle challenging conversations
- Able to be objective

Registering with Tinnitus UK

Registering with Tinnitus UK involves sending back a simple form and is completely free. It comes with several benefits for both group leaders and members.

The registration process helps us to provide up-to-date information to anyone who enquires about support or visits our website. It also helps us to keep in touch with local support groups and to share and develop appropriate resources to support these groups and their members.

How to register

All you need to do to register is:

1. Find a venue and set a date for your first meeting (to include in the registration form)
2. Return a completed registration form by email or post:
Email: groups@tinnitus.org.uk
Post: Emily Ducker, Tinnitus UK
Unit 5, Acorn Business Park
Woodseats Close
Sheffield, S8 0TB
3. Agree to follow Tinnitus UK's Code of Ethics for Registered Support Groups

How Tinnitus UK will support you

Support for registered groups

- A start up grant
- A press release sent to local press and promotion on social media
- Invitations to Tinnitus UK contacts with postcodes in your area
- Support group posters and flyers
- Printed copies of Tinnitus UK information sheets and leaflets
- A page on the Tinnitus UK website dedicated to your group
- One guest speaker from Tinnitus UK per year (dependent on availability)
- Contact with your local NHS audiology department (if available)
- Advice on fundraising
- Advice on ideas for activities and speakers
- Discounted places at the Tinnitus UK Annual Conference
- Tinnitus UK Registered Support Group logo to add to your publicity
- Regular networking with other Support Group Leaders
- Free copies of our annual magazine, Quiet
- Opportunity to shadow and learn from established support groups
- Twice yearly check-in with Volunteer & Support Officer and ad hoc support as needed.

Additional support for Tinnitus UK volunteer-led groups

- Background checks for all support group volunteers
- All Tinnitus UK volunteers and events are covered by our insurance
- Some volunteer expenses covered
- Free place at the Tinnitus UK Annual Conference

Training Opportunities

- Free place on our Tinnitus Adviser Training Course – we hold a few spaces on each course date for volunteers and support group leaders
- Access to library of webinars
- Support group facilitation training
- Shadow other support groups, particularly online



Support Group FAQs

1. Who can I ask for support?

The Volunteer and Support Group Officer is the first point of contact for any requests for support.

Please contact groups@tinnitus.org.uk and your query will be directed to the appropriate person.

Also, in your area you probably have organisations with responsibility for helping local voluntary and community groups. To find the nearest one to you, go to: <https://www.navca.org.uk/find-a-navca-member>

2. Where should we meet?

Finding an available venue which is accessible and cheap (or free) can be a challenge. Your hospital Audiology Department might be able to provide a meeting room somewhere in the hospital. Alternatively, community centres, church halls, libraries and even local pubs are all worth considering. Let us know if you are struggling and we might be able to help produce a list of venues to consider.

3. What should I look for in a meeting venue?

Accessibility is essential to ensure your meetings are open to all service-users. It is also important to consider the acoustics and availability of a hearing loop in the room as those with hearing loss and tinnitus may struggle to follow conversations. Finding the perfect venue is unlikely. If your meeting place is comfortable, accessible, and affordable for the group, you can meet pretty much anywhere.

4. What about meeting in my home?

You should not hold Support Group meetings in your home. Our goal is to support you to safeguard yourself and your members: if something happened in a private rather than public setting, such as an accident, this could have repercussions on you or on Tinnitus UK. It would also be difficult to maintain appropriate boundaries when having people come to your home.

5. When should we meet?

The truth is: it depends. Weekday evening meetings tend to attract a good cross section of people, if you give people enough time to get home from work; and dark, cold winter nights may lead to lower attendance. Meetings at weekends work well for some Support Groups, although often clashes with

other commitments. Personal commitments may mean numbers fluctuate. Daytime meetings during the week tend to attract people of retirement age.

If you know some people who may be interested in attending your group, it might be worth asking them what their availability looks like. Unfortunately, you can't accommodate everyone's needs, but you can try and cater to the majority. What this looks like will also depend on the demographic of your local community.

6. Should I organise a programme of events or speakers?

The purpose of a Support Group is to provide a space for people to share their own experiences and advice, so it isn't a requirement to offer speakers. However, a programme of events or speakers is useful because it creates momentum and could make attendees more likely to come back. It's also a way to promote your group and attract new members. If the group meets monthly, we recommend having a minimum of six months scheduled in.

7. How should I plan the meetings?

Every group is different. You may find that you plan a particular meeting, but on that week the attendees want to discuss a different topic or require more time to share. We have a sample meeting plan which you can use if you would like to have a starting point. You want to strike a balance between having enough structure to keep the time constructive, but flexible enough that attendees have time to talk and share their experiences. Follow the 80/20 rule: attendees should be talking for at least 80% of the time. Having some sort of plan will also enable you to facilitate discussion, especially if you have an attendee who is dominating conversation.

8. Where can I find guest speakers?

You can approach your local audiology department, high street hearing centres and local yoga, mindfulness, and relaxation practitioners. If you are trying to contact specific people, please get in touch with Tinnitus UK and we may be able to connect you.

9. Do I need to be IT literate?

You do not need to have comprehensive IT skills however it will be helpful to have a basic knowledge, particularly with email. Tinnitus UK will correspond with you via email; we also host training and quarterly support group leader meetings remotely online. Support group leaders often utilise social media to promote their events, however this is not essential.

10. Do I need to be on social media?

Not necessarily, but social media is a great way of letting people know about the group. For instance, there are often community groups on Facebook where

people post about local events and support as well as groups specifically for people with tinnitus. If you aren't comfortable with social media yourself, there will probably be someone in the group who is, so they could share information on the group's behalf.

11. Do we need a bank account?

Unless you are intending to fundraise for the group or pay for guest speakers, a bank account isn't necessary to start with. It's fine to ask for a contribution towards venue hire or refreshments, if you can account for money coming in and going out.

12. Do we need insurance?

As a group providing direct support to individuals, it's a good idea to protect yourselves with insurance in the case of any injury or damage arising from the activities of the group (e.g. a slip or fall by someone attending a meeting / fundraising event or damage to the premises where the group meets)

For more information about starting a support group contact:

Emily Ducker
Volunteer and Support Group Officer
EmilyD@tinnitus.org.uk
0114 250 9933

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