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**British Tinnitus  
Association**



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# SOURCES OF MUTUAL SUPPORT FOR TINNITUS

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**This information leaflet outlines the ways you can get support from other people with tinnitus to help you manage your own tinnitus successfully.**

Many people say they benefit from being in touch with other people with tinnitus. Tinnitus can be an isolating and lonely condition - by getting in touch with other people with tinnitus, it can be made less so. The BTA recognise this and we facilitate a number of ways people with tinnitus, their families and friends, can gain mutual support in addition to the help and advice available from the BTA and medical professionals.

## **Tinnitus support groups**

Local tinnitus support groups regularly help thousands of people. For those experiencing the fear and anxiety that often accompany the early days and months of tinnitus, the

support group can be a lifeline. That anxiety can sometimes have been made worse by unhelpful advice from friends, family or even some medical professionals who are not specialists in this field.

Here is a selection of comments made by people attending different groups throughout the UK:

**“You realise that you are not isolated, this makes you feel less alone.”**

**“It’s great to share ideas on how to live well with tinnitus.”**

**“I walked in there that night defeated by tinnitus, and I left knowing it was nowhere near as debilitating as I had thought, and that it can be lived with.”**

**“It makes you focus on the condition and you realise how well you are dealing with it.”**

**“Empathy; unless you suffer you do not have any perception of what it is like, doctors do**

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**not always understand tinnitus.”**

**“After attending group meetings or speaking to our groups contact on the phone, I feel more confident about my condition.”**

**“I find the group sessions very useful. It is good to share experiences, thoughts and feelings. I feel encouraged and I actively try to deal with the feelings that my tinnitus brings. I try to incorporate the advice from the therapists and the suggestions from other group members.”**

We are currently working hard to expand the network of tinnitus support groups. To find your nearest tinnitus support group, you can find the most up-to-date details on our website at [www.tinnitus.org.uk/find-a-support-group](http://www.tinnitus.org.uk/find-a-support-group) or by calling our helpline on **0800 018 0527** or emailing [info@tinnitus.org.uk](mailto:info@tinnitus.org.uk). If there isn't a group in your local area, we will take your details and explore the feasibility of supporting the setting up of a new group.

## **The BTA forum**

[www.healthunlocked.com/bta](http://www.healthunlocked.com/bta)

The BTA forum is an online discussion site where people can hold conversations in the form of posted messages. It differs from online chat in that the messages are archived and remain on the site. This means that messages are searchable, so you can see if someone has already asked your question, for example, or has mentioned a particular topic.

Our forum contains many posts, often tagged with a particular topic. Within a forum's topic, each new discussion started is called a thread, and can be replied to by as many people as so wish. A sense of virtual community has developed within our forum, thanks to the

regular users.

Our forum is moderated – that is, there is someone checking all the messages to ensure they meet the House Rules, that the space is free from spam (advertising) and that it is a polite, constructive place for discussion. The moderator ensures that posts comply with the rules and that everyone is supportive of each other. The moderator can warn or ban members who behave inappropriately if necessary, but that very rarely needs to happen. The moderator often points forum users in the direction of relevant BTA resources, such as information leaflets on a particular topic. However, we are unable to answer specific medical questions.

Users have to register with the forum (the instructions are on the forum) and can then log in to post or read messages. Any registered person can post, read, or comment on messages.

Forums have a special set of jargon associated with them; for example, a single conversation is called a “thread”. If you want to check any definitions, the Wikipedia page on Internet forums is a good place to start.

There are other forums related to tinnitus available. Two of the most popular are run by Tinnitus Talk and Action on Hearing Loss.

## **Facebook**

[www.facebook.com/britishtinnitusassociation](http://www.facebook.com/britishtinnitusassociation)

Facebook is a social networking service and website. Users must register before using the site, after which they may create a personal profile, add other users as friends, and

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exchange messages, including automatic notifications when they update their profile.

We have a "Groups" page which people may "like" and if they click on "show in newsfeed", they can see posts from us automatically. Otherwise, people click on our page to visit from time to time.

Posts are made by the BTA but any user of Facebook may like or comment on them, or share them to their own feeds. We use Facebook mainly for publicising our work, but occasionally for sparking discussion. People can send messages to the BTA through Facebook, either publically by commenting on a post or privately through the messaging function but again, we are unable to answer specific medical questions.

Posts can be images, sounds, video, links to websites – not just text.

## Twitter

[www.twitter.com/britishtinnitus](http://www.twitter.com/britishtinnitus)

Twitter is an online social networking service and micro-blogging (very brief journalling) service that enables its users to send and read text-based posts of up to 140 characters, known as "tweets".

Unregistered users can read the tweets, while registered users can post tweets through the website interface, SMS (text message), or a range of apps for mobile devices.

Users can group posts together by topic or type by use of hashtags (words or phrases prefixed with a "#" sign). Similarly, the "@" sign followed by a user name is used for mentioning or replying to other users. To repost

a message from another Twitter user, and share it with one's own followers, the retweet function is symbolised by "RT" in the message.

Whilst most posts on our feed are made by the BTA, we do retweet other's tweets (and they retweet ours). We try to reply to every comment and question although we are unable to answer specific medical questions.

## Other sources of support

The BTA can offer help and advice to people with tinnitus, their family and friends. Our friendly and experienced team can offer support via our freephone helpline **0800 018 0527** or [info@tinnitus.org.uk](mailto:info@tinnitus.org.uk)

**Quiet** - members of the BTA receive a quarterly journal called *Quiet*. Many members say that they gain a lot of benefit from reading about other people's experiences in the magazine. If you would like to join the BTA, do contact us on **0800 018 0527** or you can join online at [www.tinnitus.org.uk](http://www.tinnitus.org.uk)

Support from the BTA or from other people with tinnitus is not a substitute for medical advice. Details of how to access tinnitus services are available in our leaflet *Tinnitus services*.

## Alternative formats

This publication is available in large print on request.

## For further information

Our helpline staff can answer your questions on any tinnitus related topics on **0800 018 0527**. You may also find our website [takeontinnitus.co.uk](http://takeontinnitus.co.uk) helpful.

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## BTA publications

Our information leaflets are written by leading tinnitus professionals and provide accurate, reliable and authoritative information which is updated regularly. Please contact us if you would like to receive a copy of any of our information leaflets listed below, or they can be downloaded from our website. \*available in Easy Read

- All about tinnitus\*
- Balance and tinnitus
- Complementary therapy for tinnitus: an opinion
- Drugs and tinnitus
- Ear wax removal and tinnitus
- Flying and the ear
- Food, drink and tinnitus
- Hearing aids and tinnitus\*
- Hyperacusis
- Ideas for relaxation without sound
- Information for musicians
- Musical hallucination (musical tinnitus)
- Noise and the ear
- Otosclerosis
- Pulsatile tinnitus
- Relaxation
- Self help for tinnitus\*
- Sound therapy
- Sources of mutual support for tinnitus
- Supporting a child with tinnitus in the classroom
- Supporting someone with tinnitus
- Taming tinnitus

- Tinnitus and disorders of the temporomandibular joint (TMJ) and neck
- Tinnitus and sleep disturbance
- Tinnitus and stress
- Tinnitus services\*

### Leaflets for children:

- Ellie, Leila and Jack have tinnitus (for under 8s)
- Tinnitus (for 8-11 year olds)
- Tinnitus (for 11-16 year olds)
- Ellie, Leila and Jack and me have tinnitus activity book (for under 8s)
- Tinnitus activity book (for 8-11 year olds)
- Tinnitus activity book (for 11-16 year olds)

We are a registered charity and currently receive no government funds to support our work. The production and distribution of this leaflet is subsidised by kind donations from our supporters.

If you would like to help us to support others with tinnitus please consider making a donation online at [justgiving.com/bta](https://www.justgiving.com/bta) or by sending a cheque/postal order to the address at the foot of this leaflet. Thank you on behalf of the UK tinnitus community.

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### British Tinnitus Association

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Email: [info@tinnitus.org.uk](mailto:info@tinnitus.org.uk)

Helpline: **0800 018 0527**

Website: [tinnitus.org.uk](https://www.tinnitus.org.uk)

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