Promoting tinnitus awareness

British Tinnitus Association

For the duration of Tinnitus Awareness Week (4–11 February), the British Tinnitus Association (BTA) will be promoting better tinnitus awareness. Known to be one of the most common health problems facing people in the UK today, tinnitus affects a staggering 10% of the population, and in 1% of adults, tinnitus can have a major impact on all aspects of everyday life (BTA, 2010).

Defining tinnitus

The word tinnitus comes from the Latin word for ringing, and refers to the perception of sound in the absence of any corresponding external sound. Completely unique to the individual, noises may apparently be heard in one ear, in both ears or in the middle of the head. In addition, it can be difficult to pinpoint the exact location of the sound. The noise may be low, medium or high pitched, there may be a single noise or two or more components, and the noise may be continuous or occasional. Ringing, whistling and buzzing are common sounds that are heard, but complex sounds may also be reported.

While for some people, the experience of tinnitus is short-lived or mild in its severity, for others tinnitus can be very distressing and can significantly affect daily life, giving rise to issues associated with sleep, concentration and mood.

Better tinnitus awareness

Tinnitus is experienced by people of all ages, and it is the aim of the BTA to educate everyone in order to generate better tinnitus awareness. By providing information and advice through the confidential freephone helpline, website, in-house magazine (*Quiet*) and Facebook, the BTA is able to support hundreds of people each week by helping them learn to cope with the condition. The BTA works to ensure that as many people as possible are informed about tinnitus and the support services that the BTA provides. The BTA also advises medical professionals across the world.

During Tinnitus Awareness Week, the BTA aims to educate those who are exposed to loud music, whether this is via a personal music player, at home, at a public concert or at a nightclub, in order to highlight ways in which tinnitus may be prevented. BTA chief executive David Stockdale commented on this:

> **'It is vital that people are made aware of the dangers of exposure to loud noise in order to prevent a dramatic increase in the number of people experiencing the condition in the future. We all get just one set of ears and we need to look after them.'**

Hope for a future cure

There is currently no cure for tinnitus, but the BTA is instrumental in funding important clinical research to find one. The charity is currently funding research at the University College London (UCL) Ear Institute in London, and the BJHCA spoke to Dr Roland Schaette, the BTA's senior research associate at UCL to find out more. He said:

> **'At the moment, we are closer than ever to finding a cure for tinnitus. During the past decade, tinnitus research has made tremendous progress, and we have learned a lot about the mechanisms that are involved in its development.**
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> **'A very significant part of this progress has come from a switch of perspective. Although tinnitus can be triggered in the ear, the processes that keep it going and make it a problem are in the brain, so tinnitus can now be approached from a neuroscience perspective. This broadened scope has successfully attracted the interest of brain researchers.**
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> **'The picture of the mechanisms that lead to the development of tinnitus has become much clearer. Thus, I expect that the puzzle of how tinnitus arises will be solved within the next decade, and that this will lead to true targeted tinnitus treatments.**
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> **'Even though, in the UK alone, there are more than 1 million tinnitus sufferers, it is difficult to obtain funding for research. Therefore, the number of research groups that focus on understanding this condition has remained relatively small. Funding from the BTA thus makes a huge difference, and has helped to establish new research into how tinnitus arises and how it might be cured. We have managed to provide new evidence of a common mechanism for the development of tinnitus with and without apparent hearing loss, providing an important piece to the puzzle of its genesis.'**

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British Tinnitus Association (2010) About the BTA and our services http://tinyurl.com/48zw9bm (accessed 25 January 2011)

Further information

Freephone helpline: 0800 018 0527
www.tinnitus.org.uk

iStock/drbimages

Pulsatile tinnitus: a different tune

Emma Greenwood—Founder of whooshers.com

Millions of people around the world suffer from tinnitus—a perception of sound in the ears or head when no external sound is actually present. The sound is often described as a ringing in the ears, and currently there is no cure. However, the sound I hear has another characteristic that distinguishes it from the more common or 'regular' form of tinnitus. It is in sync with my heartbeat, which means that I hear a constant whooshing, pulsing and heartbeat-like sound. This rare type of tinnitus is known as pulsatile tinnitus (PT). PT is the perception of a rhythmical noise that is synchronous to the patient's heartbeat. It is not a condition—it is a symptom of an underlying condition that sometimes warrants careful and specialized attention. Some PT sufferers hear sounds on one side of the head, whereas others hear it on both sides or 'all over' the head. Unlike common tinnitus, underlying causes of PT may be found and even remedied. The list of possible underlying causes, which range from benign to serious, identifiable to unknown, and reparable or too risky to repair is quite long and crosses over many medical specialties.

Therefore, it is unfortunate that the awareness of PT is lacking. When I replaced tinnitus with PT on intake forms, few doctors went beyond a typical tinnitus evaluation. It was first insisted that I had the 'ringing in the ears tinnitus' and one doctor even told me there was nothing he could do and that I must 'live with it', even before a single diagnostic test was carried out. Furthermore, one practitioner told me he thought I might be 'crazy' and suggested that I seek psychological counselling about the 'sounds I think I hear'. Most of them looked at me blankly when I mentioned PT.

This is not surprising, since a reference to this relatively small subset of tinnitus sufferers is often missing from articles, conversations and curricula in medical schools about how to recognize a patient with tinnitus. There are exceptions, however typically, if mentioned at all, PT becomes a footnote. And to make matters worse, there is an abundance of misinformation about PT online.

It was only when one doctor put his stethoscope to the back of my head and was able to hear the heartbeat-like sound, that I began to see validation. More doctors began to hear it too, and after a myriad of tests, the cause of my PT was determined. However, discussions regarding how to treat the rare underlying cause continue. Therefore, PT sufferers often feel isolated. We cling to tinnitus associations, groups, websites and articles, even though the guidance and commiseration is not specific to cases like ours. Some of us attend tinnitus support meetings and complain about what we hear, oblivious to the fact that what we hear is different from what regular tinnitus sufferers hear.

To help fill this void, soon after the cause of my PT was determined, I launched whooshers.com — an online information and support forum for PT sufferers. The response has been incredible. Among other features, the site includes links to clinical journal articles written by health professionals that highlight PT cases in which the underlying causes were identified and remedied. I encourage patients to discuss these cases with health professionals, and I specifically discourage self-diagnosis.

Some of the words patients use to describe PT are whooshing, swooshing, humming, blowing, hissing, and squealing. PT sounds like blood rushing through a vein. As described by members of the whooshers.com community, PT may sound like:

- 'A heart beating in a hollow tunnel with a flat echo'
- 'The ultrasound of a heartbeat turned up really loud'
- 'Crickets to the beat of the heart'
- 'Someone marching in deep snow'
- 'Hearing a baby's heartbeat during a sonogram'
- 'Blood or crushed glass flowing in a vessel and pulsating'.

There are variations of the above, and individuals can have a difficult time imagining some of these sounds that are different from their own. I can certainly understand how they may seem to someone who doesn't experience PT. However, the sounds are very real, and the stress and anxiety they cause cannot be overstated. Tinnitus is terrible to live with, and sufferers of all kinds should be embraced. We all need and deserve more than the unhelpful (but common) 'live with it' branding by some in the clinical community. A conversation that lasts more than 2 minutes goes a long way.

As a whoosher, I urge that PT sufferers deserve special attention and advocacy, especially at initial evaluations. The growing whooshers.com community encourages PT sufferers to find advocates who understand PT, recognize its long list of possible causes, have the patience to consider possibilities, and provide coping techniques in the meantime. With great numbers of health professionals out there, sufferers of PT don't receive enough attention. On behalf of PT sufferers everywhere, I invite more of you to learn about our cases and help us, because we need and deserve advocacy and support.

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