



Cambridgeshire Tinnitus Support Group

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No. 92

NEWSLETTER

September 2008

21st
CELEBRATION BUFFET LUNCH

12.00 for 12.30 pm

Saturday 13th September 2008

*Arundel House Hotel, Chesterton Road
Cambridge CB4 3AN*

Deryck Baines will talk about his
adventures as the "Itinerant Tinnittee"

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This year we are officially celebrating 21 years as a group (I believe the exact anniversary was in fact April, but our celebratory lunch is in September so you must forgive us). I hope you enjoy Avril's reminiscences over those years - they give a good insight into why the group exists - to help people who have tinnitus cope with their condition, particularly those to whom it is a recent problem. Avril wrote a similar article to celebrate our first ten years, which included the following comment: "Looking back there is definitely more awareness than ten years ago, more research is going on and more than a glimmer of hope that in the not too distant future many of us might benefit from treatment of one sort or another." We may not yet have reached that prophetic point, but with the pace of relevant research increasing and the current multidisciplinary collaboration between the professionals, who would wager that the dream of a successful treatment is not too far away. As the outgoing BTA Chairman, Dr Ewart Davies, recently wrote: The clouds of mystery about the cause and mechanism of tinnitus are slowly rising, and I am still optimistic that an effective pill will become available in the not too distant future." Amen to that.

REPORT OF JUNE MEETING – "Tinnitus Therapies & more"

Ruth Pollard

Avril welcomed 21 members, informing them we had a Naturecore Relaxation 'sound masker' machine at the meeting for anyone to borrow and trial. It had been donated by David Baguley in order for the members to evaluate its effectiveness. She then introduced our speaker for the day, Ruth Pollard, RNID Tinnitus and Audiology Information Officer, whose articles have appeared in the RNID publication *oneinseven*.

Ruth began by explaining her role in the RNID, and informing the group about the Tinnitus Helpline* which can be accessed by phone or e-mail. She explained that the word 'tinnitus' came from the Latin word 'tinnire' meaning to ring. She explained that the causes and triggers for the condition can be many and varied...ear infections, loss of hearing, Ménière's disease, injury to the ear, acoustic neuroma (tumour on the auditory nerve) stress, noise above 85 decibels from concerts, clubs and machinery.

She also mentioned medication, which led to a discussion amongst the group as to their own personal experiences. Diuretics and aspirin were seen as possible irritants and Ruth suggested alternatives should be sought via G.Ps. Anti-malaria drugs and Quinine in tonic water, originally put in to combat malaria, have been found to aggravate tinnitus. The use of mobile phones was touched on, but Ruth was unaware of any research proving or disproving any connection between mobile phone use and increased tinnitus.

Our speaker stressed the importance of the hearing pathway and tinnitus with research showing that the ear was one part of a more complex analysis of the part that the brain plays in tinnitus, particularly the auditory cortex, limbic system and the autonomic nervous system ('flight or fight'). Due to where we hear the sounds, people can learn to use auditory filters which filter out unwanted sounds in our ears or heads. This is the same mechanism that we use to respond to our own child's crying or at a cocktail party to hear only the person speaking to us.

Ruth referred to an experiment where volunteers, who had no hearing problems or tinnitus, were placed in a completely sound proof room for 5 minutes. 94% stated that they heard ringing, buzzing or whooshing, which the researchers felt indicated that tinnitus may not be totally cochlea-related but be in the brain all the time and filtered out. This was referred to as Habituation (accept, tune out, filter out). At the lowest level it does not bother a person, at a different level a person does not react because they filter it out and don't hear it. However, it has been found that profoundly deaf people experience tinnitus, thus concluding tinnitus is not solely ear-related.

Much research has been done into Habituation Therapy, as to where the signal comes from – aetiology (the study of causation); drug treatment; rTMS (repetitive transcranial magnetic stimulation) where implants have been used to control magnetic stimulation; foods like caffeine/alcohol/cheese which stimulate areas of the brain, and with alcohol, the balance mechanism of the inner ear. Complimentary therapies have also been trialled with no evidence to elevate one therapy above others, although a holistic approach to restore balance and calm the body from a state of alertness to relaxation is thought helpful to relieve tinnitus.

The talk was very helpful and Ruth finished by reiterating the process for getting help from your GP followed by referral to the ENT clinics but also left giving contact details to get personalised help for specific problems. Avril then closed the meeting by thanking Ruth for her interesting talk and the promise of lunch as she had been good enough to come up from London on a Saturday.

*Tinnitus Helpline: 0808 808 6666

E-mail : tinnitushelpline@rnid.org.uk

Report by Patsy Deller



Our beginnings

The Tinnitus Clinic at Addenbrooke's Hospital was started by David Baguley in 1985, and in February 1987 the Cambridgeshire Tinnitus Support Group (CTSG) was founded with the help of Ivy Court the Head of the Lipreading Department at that time. The group got off to a good start with presentations by Mr. David Moffat, Consultant ENT surgeon of Addenbrooke's, and Mr. David Wiggins of the BTA.

In the first news sheet David Baguley said: "there are many ways in which people with tinnitus can help themselves – with relaxation techniques, with support for each other, and in understanding their tinnitus. The new Support Group will provide a focal point for all these things and more. Please support it, a Group of this kind is only as strong as the support it receives."

It made sense in the beginning to work with CAMTAD, the Cambridge Campaign for Tackling Acquired Deafness. CAMTAD was founded in 1978 and runs Volunteer Training Courses once or twice a year. Every Training Course has included a morning's lecture by David Baguley about tinnitus and the whys and wherefores of coping. Over 101 current volunteers now have enough insight to guide people with tinnitus in the right direction, and the strong links and consistency of their office presence has been of enormous help to CTSG. CAMTAD's Hearing Help Sessions operate all over Cambridgeshire with one weekly session in Cambridge City, 23 monthly sessions in the surrounding villages and ten quarterly sessions. Recently two CTSG members volunteered for CAMTAD Training to support a new branch in Huntingdon. In addition whenever CAMTAD attends exhibitions, CTSG information is on display with literature for handing out.

Our Aims

The Group's main aims are, as they were, to support new members through introductory literature, counselling and providing meetings and speakers with expertise relevant to tinnitus and general healthcare. We also acquire and distribute the current literature from the BTA, the RNID, and other Support Groups such as Hull and Birmingham. Members can also try



THE BOWEN TECHNIQUE BEING DEMONSTRATED TO OUR MEMBERS BY ELIZABETH HUGHES - SEPTEMBER 2007

out various equipment on loan and borrow books from our small library including the latest, 'The Consumer Handbook on Tinnitus' by Richard Tyler, donated by David Baguley, who has written a chapter on Hyperacusis.

Committee People

Our current Treasurer, Mary Wright, took over the books in 1994; Joan Kowalski and Deryck Baines were with us very early on, and Deryck has only just resigned after many years of finding speakers and reporting on talks. Alan Yeo was elected Membership Secretary in 1992 and in fact edited Newsletters 12 - 14 in 93/94 before John Cammann took over. John helped me with the CAMTAD Exhibition in 1994, designing and manning the CTSG stand – CAMTAD held week-long Exhibitions in 1988, 1992 and 1994 bringing together all the voluntary and statutory groups and service providers; they were a real showcase for people with hearing-related problems in Cambridgeshire. John was so impressed that he then volunteered for the CAMTAD volunteer training and became a reliable and trusted volunteer; the monthly Hearing Help Sessions in his home village of Linton benefited enormously by his new found knowledge of hearing aids and specialist equipment. John and I took on the organisation of the Exhibition in 2003 to celebrate CAMTAD's 25th Anniversary. This was another week-long event in a large

community church in the centre of Cambridge city, but John became ill and was unable to attend and see the results of his work. Alan and other committee volunteers stepped in and their support saved the day. John had edited Newsletters 15 to 65 and attracted a great deal of appreciation for the content and presentation - his death in January 2004 left a huge gap in the CTSG. Once again, Alan Yeo, now retired, stepped in and is the current Newsletter editor.

My involvement was from the outset; I was secretary to Ivy Court and as Organiser of CAMTAD and having experienced tinnitus from childhood along with ear disease I actively welcomed the gathering and exchange of information with others; the benefits are reciprocal. On my total loss of hearing in January 2006 until my self-funded cochlear implant in November of that year the only noticeable change was the removal of my name from the BTA records, as telephone contact for CTSG. Alan once again restored the balance, and now we are back to normal again.

Events

CTSG have been represented at every opportunity over the years with our personal advisors taking their display screens, hand-out literature and personal equipment to library exhibitions, volunteer opportunity events and charitable promotions.

We welcome the BTA Awareness Days and organised a whole day of events in 2006.



TINNITUS AWARENESS WEEK 2006 - PATRICK DUNLOP FROM THE LOCAL BUDDHIST CENTRE SHOWING US HOW TO "RELAX AND HELP OURSELVES"

We had two very successful events this year, one in the centre of Cambridge and the other at Addenbrooke's Hospital, complete with the BTA banner on each occasion.

However, there is no doubt at all that our best effort to date was the Study Day held in March 2005; following the success of the 2003 Exhibition for CAMTAD I wanted to do something similar focussing on Tinnitus, and was very pleased when David Baguley suggested a Study Day in memory of John Cammann. Alan and I met with David many times over 12 months to plan this event which saw over 100 people attend from all over the country, and was the fore-runner of other Study Days.

Meetings

Our bi-monthly meetings are held on Saturday mornings and we have welcomed some excellent speakers on the alternative therapies; members of the medical profession on ear health, relaxation, balance and dizziness, and we have practised T'ai Chi, Sound Therapy and Feldenkrais and more. However our most helpful meetings are our Self - Help discussions which we try to hold at least once a year. Five members have undergone the excellent BTA Counselling Course and the shared experiences on these occasions make for invaluable support - we even manage to down mulled wine and mince pies at the November meeting; Xmas can come early at CTSG! We are also fortunate to be able to call on David for regular reviews of the tinnitus scene and he has made 12 such presentations over the years.

The Future

I am pleased to say that 21 years later we are still active, with good attendances at our bi-monthly meetings - if anything there is a greater strength in the Group of late, with some new faces with fresh ideas coming onto our committee. We have at last persuaded David Baguley to be our President, and future committee meetings are to be held at Addenbrooke's Hospital. The future of the CTSG is looking bright!

Avril Dring



The Sound of *Summer*



Experts are often asked: 'Will flying make my tinnitus worse?' and 'What if my tinnitus flares up while I am away?' — all valid questions for those who have tinnitus, or hyperacusis.

Hyperacusis describes a reduced sound tolerance level and an increased sensitivity to sound. Everyday sounds may be perceived as too loud, uncomfortable or even painful.

One thing that people with tinnitus and hyperacusis may share is a susceptibility to shy away, or withdraw from sound.

Both can be counterproductive as they can lead to a further increase in sensitivity.

Take flight

Many people plan a holiday to escape the stresses of daily life. But anxious moments can crop up during a holiday — even before it's begun.

Allowing plenty of travel time to the airport, rail station or ferry terminal and checking in early can get you off to a stress-free start. Tinnitus or hyperacusis needn't stop you from flying to your chosen destination. Some people who have tinnitus report being less aware of their tinnitus on a plane because cabin noise (such as air conditioning or passenger chatter) acts as a subtle distraction.

Others may feel the need to wear earplugs during the flight because of the engine noise; however, by reducing your exposure to environmental sound your perception of tinnitus can increase.

Additionally, when you take them out after the flight, you may feel more sensitive to sound. Earplugs may be more helpful later in your holiday to protect your ears from exposure to louder noise (such as watching a live group). If you normally wear hearing aids, you should keep them in during your flight as, the more background sound you are picking up, the less obvious your tinnitus may be. Sitting further away from the engines may be beneficial.

As long as your ears are in good health, flying should not pose a risk to your ears.

Making the most of in-flight entertainment systems may also create a welcome distraction from your tinnitus.

Self-help

If you benefit from using sound enrichment at home, there is no reason why you cannot continue to benefit while you are away. There are a number of products on the market that are easily transportable. For example, RNID's travel alarm clock is small enough to carry in your hand luggage. You can attach headphones to listen to a variety of soothing sounds including rain, or white noise.

If you prefer listening to music, you could carry an MP3 or portable CD player. Keeping the volume just below that of your tinnitus may be the most beneficial. If you are worried about disturbing other people in your room with background noise, you could use a 'sound pillow'.

If you forget to take something along with you, or experience tinnitus for the first time while you are away, there may be things in your room that could

help distract you from the sound — such as an electric fan or air conditioning unit.

Local noise

While away, you may be exposed to unfamiliar noise, such as the sound of children playing if you are staying in a family resort. This may cause a problem if high-pitched sounds make your tinnitus and/or hyperacusis worse. If this is the case, it may be better to choose a quieter resort. But remember that background sounds can be a helpful distraction, so make the most of any new ones.

Relax and unwind

Stress and anxiety may make tinnitus worse; so, it might be helpful to have a number of relaxation strategies on standby to combat any possible increase in your tinnitus/hyperacusis while you are away. There are six different relaxation exercises in our Tinnitus and relaxation factsheet that you may find helpful. Taking a holiday may be an ideal way to relax and unwind. Deciding not to go away on a well-deserved break could have a negative effect, as it may leave you feeling low or frustrated. Sometimes, a little sunshine, or change of scenery, can give us a perk and lift our spirits. This, in turn, may benefit your tinnitus. [The information given in this article is not medical advice and, by providing it, RNID undertakes no responsibility for your medical care.]

(This article was adapted from *oneinseven*)

[See also BTA factsheet: Flying and the ear - <http://tinyurl.com/5qp82c> - Ed]

Education? The following are some more genuine Qs & As from GCSE exam results:-

Sociology: Q: What guarantee may a mortgage company insist on? A: To buy a house, they will insist you are well-endowed.

Biology Q: What happens to your body when you age? A: When you get old, so do your bowels and you get intercontinental.

Q: How are the main parts of the body categorised? (e.g. Abdomen) A: The body is consisted into three parts - the brainium containing the brain, the borax containing the heart and lungs, and the abdominal cavity containing the five bowels - A, E, I, O and U.

Q: What is the fibula? A: A small lie

SNIPPETS FROM RNID

• Subtitles praise - RNID held a Commons reception in May, co-organised with the broadcaster and the National Deaf Children's Society, to celebrate the BBC reaching 100% subtitling across its seven main television channels. Their chief executive, Jackie Ballard, congratulated the BBC on its achievement but said more needs to be done to address background noise, which is a big issue for many hearing-impaired people. Andy Burnham, MP, Secretary of State for Culture, Media and Sport called on other broadcasters to work towards 100% subtitling.

PS: RNID Trustee The Rt Hon Malcolm Bruce, MP, tabled an Early Day Motion in April congratulating the BBC on its success. So far, more than 100 MPs have signed the motion.

• Tiny hearing device launched - A new type of hearing aid that can be worn for 24 hours daily and up to 4 months at a time has been launched in the US. The Lyric, which fits right inside the ear canal just a few millimetres from the ear drum, is said to be the only hearing aid that is completely invisible when worn. Users can wear it when they sleep and shower. The tiny device is currently only sold in a few clinics and has to be put in place by a doctor. RNID's Senior Audiology Specialist, Angela King, said: "It is great news that companies are now recognising the need to design comfortable trouble-free hearing aids that also give a more natural sound quality."

• Implant guidance - RNID have been helping the National Institute for Health and Clinical Excellence (NICE) to evaluate the benefits of cochlear implantation. NICE is expected to issue guidance soon and it is hoped that the recommendations will ensure people who are unable to access a cochlear implant because of funding restrictions, would now be able to do so.

• Call for new drug therapies - RNID's biomedical team visited San Diego in June to attend Bio2008, the world's largest biotechnology conference. Their aim was to raise awareness of the vast commercial opportunities that exist for medical treatments for hearing loss and tinnitus. They also warned the biotechnology industry that it needs to invest in drug therapies to protect hearing against side effects of one of the most common types of chemotherapy, Cisplatin. The platinum-based drug causes damage to the inner ear and can result in hearing loss, balance problems and tinnitus. Each year, hundreds of thousands of cancer patients are at risk of permanent or permanent hearing loss because of the side effects.

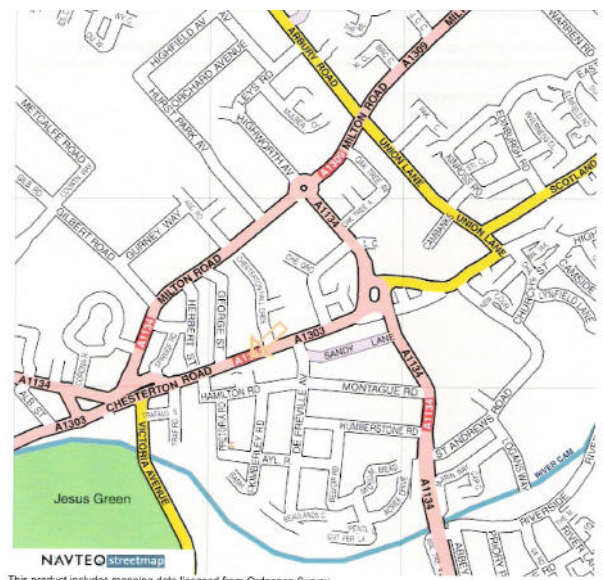
Please remember

This is your newsletter and all comments, letters, contributions or editorial copy relevant to tinnitus or CTSG, or anything you think maybe of interest to our members would be very welcome. Please send to :-

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LOCATION OF ARUNDEL HOTEL



CONNECTIONS

CTSG is an independent organisation, associated with Cambridge CAMTAD and Addenbrookes' Audiology Department. We receive no financial support other than from members subs, sales and donations. The major part of our income pays for the production of the Newsletters and the postage to members, plus our affiliation to BTA. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG or CAMTAD.

**Our next meeting is on 15th November when
Dr Terry Buffin will be our speaker**