



CHESTERFIELD & NORTH DERBYSHIRE TINNITUS SUPPORT GROUP

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Newsletter

Edited by Audrey Carlin

Conference 2015 Edition

REPORT FROM CHESTERFIELD TINNITUS SUPPORT GROUP CONFERENCE ON 25TH APRIL 2015



Over one-hundred people attended the Winding Wheel in Chesterfield on the 25th April 2015 for our Conference,



(above) Lindsay, Joanne and Audrey

(below) Joy, Gail, Joanne and Muriel



the purpose of which was to reach out to those people who are unaware that help and support is available to them as well as to keep our own members informed about current research, appropriate pathways to ENT and audiology, stress management and an update of what we, as a support group, can offer. Brett co-chaired the Conference with Lindsay.



CLAIRE ROBERTS, AUDIOLOGIST/HEARING THERAPIST, CHESTERFIELD ROYAL HOSPITAL

Claire has been a Hearing Therapist at the Royal Hospital for many years and she spoke about their work with tinnitus patients. Claire talked about the pathway to their services, specifically for people who experience tinnitus. Patients whose presenting symptom is tinnitus would normally be referred to Ear Nose & Throat (ENT) before being referred to Audiology so that their symptom can be thoroughly investigated and a medical opinion provided. However, they have a One-Stop Clinic so if your GP refers you on to this service you would normally be seen by ENT and Audiology on the same day. Claire then went on to explain how they help patients with tinnitus. They allow the patient up to 45 minutes to talk about their experience of tinnitus and how it impacts on their life. Claire said that,

even very mild hearing loss tends to exacerbate the experience of tinnitus and that's to do with the fact that when you have got a hearing loss your hearing system is working hard to hear and can be driving up any sensation of sound you happen to be hearing in your head and ears.



(above) Claire, Jodie and Debi

One rewarding aspect of their work with tinnitus patients is that they are finding that providing patients with digital hearing aids helps them to manage their tinnitus much more effectively. Claire added that they discuss sound enrichment and distraction techniques but if a patient is struggling with tinnitus then they may benefit from more in-depth therapy (Rational Emotional Behavioural Therapy) provided by one of the specialists within their team.

Claire went on to say that the position regarding the private sector is that they provide audiology services for the fitting of hearing aids. However, they do not get involved in helping and supporting people with tinnitus. Therefore, if you are needing help with tinnitus it may well be Chesterfield or another NHS hospital in this area, for

example, Kings Mill Hospital or Royal Derby Hospital.

Finally, Claire spoke about the long-term relationship they have had with our group over the last 30 years and particularly the importance of peer support that we can provide.

PROFESSOR DEBORAH HALL
Professor Deborah Hall, Director, Research Lead (Tinnitus etiology and management), Research Lead (Sensorineural plasticity and rehabilitation) at the Nottingham Hearing Biomedical Research Unit.

Prof Hall gave some background about the funding structure for medical research in the UK. The National Institute of Health Research use funding in strategic ways and one of the ways they spend their funding (almost £1bn per year) is in biomedical research units; there are currently



Prof Deb Hall with David from the BTA

20 across England. Each one targets a specific area of health that the government has identified as causing a major burden on healthcare on the British population and there are a number of different topic areas but hearing loss and hearing related problems is one of the key priority

areas that the government have actually identified. It affects a lot of people, 10 to 20 per cent of adults are affected by hearing related problems but as yet there is no cure for tinnitus.

Nottingham Research Centre, established since 2008, is a very important centre for hearing research because it's the main investment from the government in hearing research. There is a lot of research into tinnitus at the moment, some of which is focusing on trying to actually measure tinnitus, through brain imaging, to work out what causes it. Some of their understanding of tinnitus is that it's related to hearing loss and they think it is something to do with the way that the brain interprets the sounds that the ear is sending to the brain. They are also looking at how tinnitus affects other things such as concentration, memory and attention, working with psychologists to get a better understanding of this. A big part of their work is running clinical trials and setting them up to evaluate interventions. A PhD research student is currently using functional magnetic resonance imaging and has found that there is a link between the hearing brain and other parts of the brain that are responsible for generating the tinnitus sound. For some people who find their tinnitus very distressing, recent research has found that parts of the brain involved in representing emotions links them to how they perceive the sound. There is a very complex network involved in the tinnitus condition and they can see this when they look in some of the very

small structures involved in processing emotions.

Finally Prof Hall said that over the last few years there has been a lot more interest from the pharmaceutical industry about potential compounds that might be beneficial for hearing loss and also for tinnitus. Autifony Therapeutics, recently published in the Press, have a compound that they believe might help reduce the effects of age related hearing loss that affects



the high frequencies and tinnitus. Prof Hall has been working with them and they have managed to get funding from the government to run a clinical study. They have recruiting centres in Sheffield and Nottingham but the trial is looking for people who have hearing loss related tinnitus but have not actually been experiencing tinnitus for very long - less than 18 months. They want people in the early stages of tinnitus and they have a trial for 4 weeks to evaluate whether it makes a difference.

*[We are on NBRUH's mailing list so we receive their newsletter and will always let you know about any new research that is taking place. Several of our members in the past have been involved with their research projects]
(Audrey)]*

MURIEL LASCELLES, THE GROUP'S AMBASSADOR

Muriel Lascelles, who was first introduced to our group at our 2013 conference, spoke about her tinnitus journey. Muriel was diagnosed with



tinnitus 2½ years ago and at that time was trying to live life with tinnitus as well as dealing

with all the other problems associated with tinnitus. She encountered rapid and huge weight loss, a feeling of isolation, was constantly in a state of anxiety and could neither eat nor sleep. Every day became a challenge for her as to how she would get through that day and even bedtime would fill her with dread. It was taking over her life, she declined invitations and the thought of going on holiday was unthinkable. Having been told by the medical profession that she had tinnitus and there was no cure, she was starting to go down the dark road of despair until she was introduced to our support group in February 2013. That is when things started to change for her. She took away advice and help from our conference to start the process of managing the condition. She began to realise there is life after tinnitus. Muriel went on to attend our group counselling workshops and learned techniques for managing the condition and she can now reflect on so many things, which she says is thanks to our support group, in helping

to bring her to where she is today – living life to the full and loving every minute of it.

Muriel said she no longer gets stressed over the smallest of things, something she learned at the workshops, and now deals with, and reacts to, difficult situations in a totally different way.

Muriel now supports our group and has been instrumental in our attending Patient Participation Groups (through first introducing us to her own surgery's PPG) to spread the word that when patients are diagnosed and the doctor has to say that sadly they can't help, they can signpost patients to a support group. She has also been happy to talk about her tinnitus journey, having done so to the NHS governance meeting when the members of the Board were in attendance and most receptive to hearing how our support group had helped Muriel to get her life back on track.

In conclusion Muriel said that, by telling her story, she hoped this would help those newly diagnosed and those still struggling with tinnitus, to know that help and support is available to them.

JOANNE GORDON, TINNITUS GROUP CO-ORDINATOR

Joanne Gordon, the group's Co-ordinator spoke about the work of the Support Group and the ongoing help provided through regular newsletters, one-to-one lay counselling either by telephone or at the office, meetings,

coffee mornings and afternoon teas at various venues which provide a relaxing



atmosphere in which to meet and talk. Following on from the group's successful lay-counselling workshops, Joanne gave an overview of what can be expected at the workshops which will be starting again at the beginning of September. The workshops are for 2½ hours, one per month over a period of 4 months, so if anyone is interested in taking part, please contact the group as soon as possible as places are limited.

LINDSAY KNOTT – CHAIR



Lindsay Knott, Chair of the Group told of her own personal journey. Lindsay's tinnitus had started in January 2013. As she lives in Nottingham it was a year later before she found out about our support group. Lindsay subsequently joined and took part in the lay-counselling workshops which she found very helpful, together with the ongoing support we offer. Lindsay talked about how difficult it had been until she contacted our group, where she was given time and understanding and was not dismissed. She talked about the hope and encouragement she was given and the friends she has made. Lindsay said that our workshops have helped her to

understand "her" tinnitus and how she reacts to it. She also said that our group had enabled her to access better NHS support and the feeling that, as part of our group, she is not alone as we offer consistent and ongoing support.

Lindsay finally added that, although at times life is hard, we do have an option. Either we don't do anything at all or we embrace life and do new things. She added "I do believe that's the only way I get through my tinnitus experience at the moment, to keep living and improving my life."

FRANCES GOODALL OF INTEGRAL THERAPY

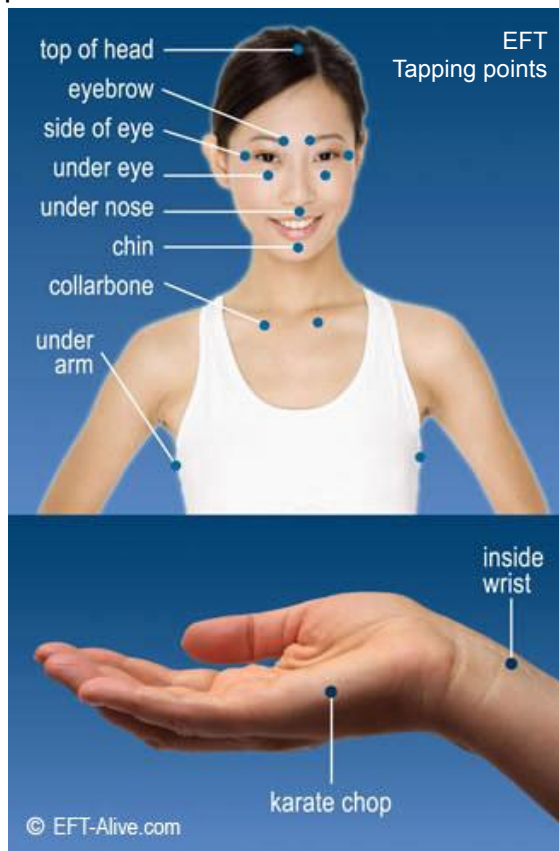
Finally Frances Goodall spoke about stress management. Frances knows



what it is like to have a condition that affects your lifestyle as she suffered with CFSME in her early twenties. Frances' talk was about stress and trauma and how it can affect the body and mind, following on with creating more positive experiences through music, mindfulness or Tai Chi.

When living in a state of stress it tires out the system and modern life doesn't teach us to live in a calm way so we have to find it for ourselves. Part of the brain that is called the amygdala (which is the emotional part of the brain) can become over-activated, resulting in the fight or flight response.

Neurological conditioning is where every experience is recorded in the subconscious mind. If you can find peace and



acceptance that's always the first stage, although it's very natural at first to feel frustrated and sad about it. It's a very natural and human response to challenges but ultimately if we keep reacting in that way it can perpetuate stress and perpetuate the conditioning in the brain which can perpetuate the sound.

Symptoms exist when we're suffering but how we respond to those symptoms is what we can start to change. Frances concluded by talking about Emotional Freedom Technique (EFT) which involves tapping points which, although it looks unusual, has been proved to help many people around the world with different issues.

MINDFULNESS by David James Lees

The afternoon session was more practical with break-out sessions for people to experience Tai Chi and Mindfulness. David James Lees led the Mindful Meditation, something that has been part of his life for nearly 40 years.

Mindful meditation is about learning to focus your mind and that can be very important for people whose tinnitus is intrusive. When you hear tinnitus your mind will automatically focus on the sound which makes it worse. It's like throwing petrol on top of a fire! The more you focus attention on it, the more intrusive it becomes – thus a negative vicious circle builds up. The vicious circle of stress and anxiety can be helped by Mindful Meditation.

David told of his own story as a profound stutterer as a child. When after 10 years on medication and trying



speech therapy it all failed, he was discharged and so had to come up with something himself. Someone suggested meditation to him and he was so desperate that he went along

to a Buddhist centre where firstly he was taught how to breathe properly which is very important in Mindful Meditation.

Over the years he has learned that he can control his mind. However, even 40 years later he has to be mindful – mindful of his breathing, mindful that his mind doesn't run ahead because that's when he stutters. That's what the Chinese call the mischievous monkey that swings through the trees and runs away with you and that's really what meditation can help you with. You can do Mindful Meditation wherever you want to. It's about being in control of your mind. David then took everyone through a session for 30 minutes. The clear message from David was that you should continue with your Mindful Meditation in order to maintain its positive effects on managing your tinnitus well.

In the other break-out room people were experiencing Tai Chi (before moving on to the mindful meditation).

TAI CHI by David Hall

Tai chi, also called tai chi chuan,



combines deep breathing and relaxation with slow and gentle movements. Originally developed as a

martial art in 13th-century China, tai chi is today practised around the world as a health-promoting exercise.

While there's scope for more rigorous studies on tai chi's health benefits, studies have shown that tai chi can also help people aged 65 and over to reduce stress, improve balance and general mobility, and increase muscle strength in the legs.

Tai chi is characterised by its slow, graceful, continuous movements that are gentle on the joints and muscles. Done correctly, you'll find that the tai chi poses flow smoothly from one into another. Many movements are completed with bent knees in a squat-like position.

Tai chi energises the whole body and gives you more chi, the energy that makes you feel alive, well and vital.

Tai chi has been called moving meditation. Moving meditation is very useful because if you can learn to meditate while moving then you can bring meditation into every movement that you do in life.

JOANNE'S SPONSORED RUN – MANCHESTER 10K – 10th MAY 2015



Joanne and her husband, Simon, successfully ran the Manchester 10K in May, in which thousands of

runners took part. Joanne's time was 54 minutes and Simon's 43 minutes. Thank you to everyone who sponsored Joanne, raising £120 for our group.

MAY DAY – 4TH MAY 2015

First of all thank you to everyone who donated to our May Day Stall,

including ladies of the Knit & Natter Group run by Tracey of



Image & Colour Emporium, Chatsworth Road, Chesterfield, who are always supportive of our group. Also to our members and friends who also made donations to us. Also thank you to Dr Bethell from whom we loaned the tombola drum.

Joy (pictured with Muriel in their bumblebee outfits which attracted a lot of attention) collected so many items that we also took over another stall which helped with our success on the day. It was nice to see some of our members who came along to say hello on a sunny but breezy day. As usual it was a lovely atmosphere and everyone enjoyed themselves.

Gail joined Muriel and Joy in running the tombola and can be seen helping a customer.



Philip and I ran the other stall. Philip

(pictured) helping two customers.

Nearly £400 was raised on May Day so thank you to everyone.



I took up an offer by a young man to take me for a ride on a



tandem around the market stalls. Such fun!!!



And the band played on!