

CHESTERFIELD & NORTH DERBYSHIRE TINNITUS SUPPORT GROUP



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Newsletter: Edited by Audrey Carlin

November/December 2019



Joanne

BRITISH TINNITUS ASSOCIATION CONFERENCE AT GOLDSMITHS UNIVERSITY, LONDON



Audrey and I attended the BTA Conference over the weekend of 12th to 14th September, arriving there on Thursday 12th for the Networking event that evening.

It was also quite exciting for us, as Audrey was introduced as one of the Vice Presidents of the

BTA and her photo was shown on a large screen in the first plenary the next morning; she was made very welcome by delegates at the Conference. Audrey says she is honoured and privileged to be asked by the BTA to be a Vice President and looks forward to fulfilling the role to the best of her ability.

We were also introduced to the new President, Tony Kay, who is Head of Audiology Services at Aintree University Hospital and whom we have previously met at one of the BTA's Information Days. We also spoke to Sandy Grimes who is the other Vice President, having been in that role for a year. Audrey has known Sandy for many years. Sandy has been an Audiologist in the NHS over 30 years. Audrey is the first non-medical person to fulfil this role but she has 35 years of experience of tinnitus and is a founder-member of our support group since its Inception in 1984. She has always been committed to helping and

supporting people who experience tinnitus.

BTA Gold Standard Award

We were also one of the first groups to receive the BTA's Gold Standard Award for Tinnitus Support Groups, along with gold badges in recognition of the service we offer to people needing our help and support.



Work of the BTA

The first plenary was an update of the work of the BTA and was given by David Stockdale, Chief Executive. He has now been in post 10 years and in that time, the BTA have made huge progress in supporting people and supporting research initiatives.

The BTA aim to create a world where **'No one suffers from Tinnitus'**. A sentiment we wholeheartedly agree with. They aim to do this by making progress in key areas:

- Finding a cure
- Managing Tinnitus
- Delivery of services
- Information and prevention

The BTA have recently revised their statistics from 1 in 10 people experiencing Tinnitus to **1 in 8**. This means 13.2% of adults in the UK live with tinnitus. Therefore, the tinnitus population is set to increase by 500,000 over the next decade.

As well as offering support through their magazine—'Quiet', website and helpline, they also organise Information Days.

Booklet of the BTA Conference

Audrey and I have copious notes from the conference weekend and we are going to collaborate in order to develop an informative booklet about the event as there were numerous speakers talking about a variety of subjects that we are sure will be of interest to you.

Joanne

“EQUINOX 24” - GOAL SETTING by Joanne

First of all thank to everyone who sponsored me for the Equinox 24 Run, the final total raised was £210 for which we are very grateful.

Goal Setting

I set a goal on the sponsorship form of 50k although in my head I wanted to match my total of last year which was 80k. This is 8 laps in 24 hours. Unfortunately, training hadn't gone well. I had fallen in May and had to go to A&E for



stitches which weakened my knee. Trying to get back to training too quickly meant I had put pressure on other parts of my body and pulled a calf muscle which took several weeks to recover. This is why I felt I needed to officially set a lower target of 50k.

However, I still believed (secretly) I could reach my 80k target.

Day 1

The day came around and myself and my husband (Simon) stood on the start line at 12 noon. It was a very hot day and the course has a number of hills. One called 'That Hill' which is renowned because, although relatively short, it is very steep. Things didn't go well because after 2 laps I had a problem with my foot, which I managed to resolve. However, a combination of the hot day and not enough time between laps 2 and 3 meant I was forced to walk lap 4 as I had a headache and felt nauseous. I decided I would have to finish for the day whilst my husband continued onto a 5th lap. Last year I had run 5 laps before retiring for a rest overnight. Disappointed I went to bed.



Day 2

I awoke with renewed energy, headache and nausea gone. I re-evaluated the plan for taking on nutrients. If I wanted to match my achievement of last year I would have to run another 4 laps (25 miles) with a limited break. There was barely enough time to complete the required 4 laps before the end of the 24 hour deadline but I set my goal and knew, with refreshed energy, that I could do it!



Wet through but pleased to have done it!

The second day was cooler but with some torrential rain which made the course difficult to navigate. Nevertheless, I am pleased to report I finished my 4 laps in time, making the total 8 laps (80k – 50 miles in 24 hours).

Conclusion

I think there are some things to take away from this experience. That some days are not good days but we can re-evaluate our goals; this should not be seen as failure. Also, we can show determination and strength when we listen to our bodies and feel in a good frame of mind.

Joanne

INSPIRATIONAL STORY—BELIEF

My name is Clare and I work in the DAST office in administration



and project support but I also get involved with the Chesterfield & North Derbyshire Tinnitus Support Group admin work. I have two boys, Aaron and Noah and they are both extremely artistic and musically talented. Aaron was diagnosed with Autism when he was six years old but he has not let his diagnosis define him. Although he has some difficulties, he has not let these hold him back. Aaron is currently studying

for his 'A' level exams and one of his subjects is Art. For one of his main pieces, he chose to paint one of his cats, 'Micah'. Aaron has aspirations to work in music production in some way,

as he loves all kinds of music genre. He has taught himself to play the bass guitar and has recently passed his Grade 6 music exam in bass guitar with a distinction. I have always encouraged Aaron to aim high, and if obstacles appear we try and find a way for him to leap over them. His determination is such an inspiration to me and others.

‘The greater danger for most of us lies not in setting our aim too high and falling short, but in setting our aim too low, and achieving our mark.’ (Michelangelo)

Clare

Aaron Griffiths, Micah, Oil paint on MDF:-
This piece was painted, from an image of one of my cats, named Micah. I chose to use an angle as if the viewer were looking down upon the cat, while he is laying on his side. I chose to photograph this pose as it signifies that he wants to be petted, and therefore is making himself vulnerable because he trusts his owner not to hurt him. I feel that the angle that the photo was taken further perpetuates this sentiment, as it has a large amount of space around the cat, giving the idea that the world around him is larger than him. I feel that this shows the feeling of needing to take care of your pets, especially powerful for those who you are sentimentally attached to. I felt the need to make this painting more accessible to both other people and to me by not including my hand, which was originally going to be part of the composition, for the sake of allowing the viewer to imagine that they, themselves, could be the one standing over the cat, and therefore would be able to more fully imagine the feeling of responsibility and even fear for the safety of said pet.

This is a copy of Aaron's submission for his 'A' level Art

REPORT FROM SEPTEMBER MEETING

We had a very good social event at The Badger where Jane Birkin came along to give us a talk about the work she does as PLOD Manager. PLOD stands for:

P = Police

L = Link

O = Officer

D = Deaf (people)

In 1978 Jane, as a young Police Officer, was based in Shirebrook. During those days Jane said she experienced some funny moments. She recalled her time in Shirebrook with affection “it was a good community; nice people who respected the uniform .”



One night she had a call to help one of her colleagues, a Policeman, who was in Shirebrook where 60 youths were causing a rumpus on Alder Way. There weren't many police officers around at the time to help and so Jane, who was on foot, went along to help her colleague. When Jane arrived on the scene, she respectfully asked all the youths to go home as they were keeping people, including babies, awake. They immediately obeyed her request and went home. On another occasion she approached two girls on Patchwork Row who were pushing a pram. Suddenly the pram came 'sailing' past Jane, who grabbed it before it went into the road. The girls were laughing and Jane was about to tell them off when she glanced into the pram. No baby! - it was Guy Fawkes in the pram so they all ended up laughing.

On another occasion she was walking in Shirebrook on her own when she suddenly heard a “ticking” noise. She immediately thought it was a bomb and felt very scared. When she walked to the left, it got louder; when she walked towards the centre of the road, she could just hear it. She went to the left again and discovered it was a lamp post ticking.



(Shay is usually behind the camera but on this occasion we ‘copped’ him)

Jane left the Police Force after 7 years when her son was born. At the time there was no flexibility for women so she had to leave. Eventually she applied for a job as a Researcher in Derbyshire, working for 23½ hours a week. As part of the job, they wanted Jane to talk to Police about deafness so she went around all the police forces to see what they offered for deaf and hard of hearing people. Jane went around the country interviewing all the staff in charge to find out their commitment to the deaf community.

Derbyshire has the highest number of Deaf and Hard of Hearing people in the country proportionate to the population and they are the only police force to have achieved the prestigious Action on Hearing Loss ‘Charter Mark’ year on year.

Four years’ ago Jane became the PLOD Manager and works in the new building at Ripley where there are about 100 people.

They also work closely with the Derbyshire Fire & Rescue Authority and the Police and Crime Commissioner, all of whom share the same building so they have strong working relationships.

What do you get if you cross a Comedienne, a Neuroscientist and a Monk?

A Fabulous Night Out!

We all know that laughter is the best medicine and that Mindfulness can help with stress and anxiety. Hence, the night out to see Ruby Wax at the Pomegranate Theatre present her new book “How to be Human” was like a double dose of the best therapy.

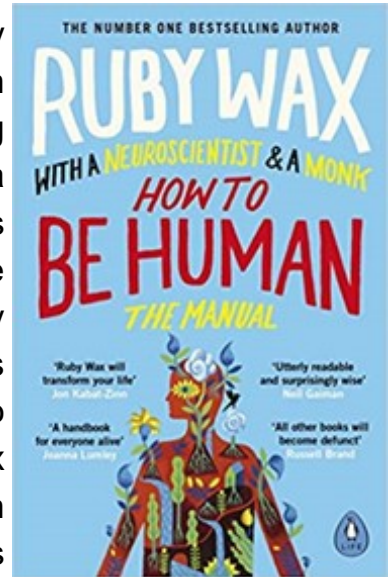


Ruby Wax

The first half of the show was Ruby on her own. Ruby Wax is not only a successful comedienne but she also holds a Master’s degree in Mindfulness-based Cognitive Therapy from Oxford University. Ruby did talk about her battles with depression and her family history of mental illness, which was aired on the popular TV Programme “Who do you think you are?” However, this was served with a double helping of comedy, as Ruby discussed the topics in her book including Evolution, Emotions, Relationships and Forgiveness. Her enthusiasm, humour and energy was infectious.

How to be Human

After the interval, Ruby was joined by her co-authors, Neuroscientist Dr Ash Ranpura and Practising Monk Gelong Thubten. Although the set-up was like a chat show with Ruby asking questions of both Ash and Gelong, it was like three friends meeting for a chat. The diversity of the three people was evident as was their rapport, although the monk had to turn away at one point, as Ruby Wax joked about how every time Ash mentioned a neurological term, she was getting a little over excited!!



Self Compassion and Acceptance

Gelong Thubten talked about Mindfulness. He too suffered from depression and on a 4 year retreat, he learnt to accept his state of mind. He eventually realised that he should not be fighting how he felt or beating himself up but be treating himself with love and compassion. Self-compassion is important in mindfulness.

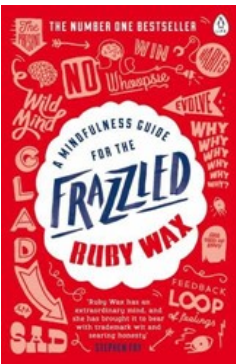
Mindfulness

Meditation or Mindfulness can be done for as long or as little time as you have available. Gelong talked about acknowledging thoughts whilst concentrating on deep breathing. Also that the mind will wander; recognising this and then bringing yourself back to deep breathing. As with any new learning, the importance is training yourself and practising. Your mind will wander at first but you will get better at concentrating on your breathing if you continue to practise. Mindfulness will help

anyone suffering from stress, anxiety and depression as well as tinnitus and can be helpful in the management of chronic pain.

Finally

The final part of the show allowed the audience to ask questions. One person asked how she could support someone suffering from depression. We often talk about the effects of Tinnitus on family members and I think that this was a really interesting question to ask.



It was the neuroscientist who answered but not from his medical knowledge but from his heart. He has a friend who suffers from depression (Ruby) and he says what is really helpful is when she tells him how she is feeling, if she is suffering on that day. He can then behave accordingly and treat her with understanding and compassion. If the person doesn't say how they are feeling, others may not be aware of this and their behaviour may not give the right messages.

Mum (Audrey) and I really enjoyed the evening out; it was both informative and a really good laugh.

Ruby's earlier book – 'Frazzled' can be purchased at the British Tinnitus Association for £8.99. <https://www.tinnitus.org.uk/shop/a-mindfulness-guide-for-the-frazzled>

SAFE AROUND SOUND

When we produce our booklet about the BTA's conference we will also include information about

“Safe Around Sound”

You can take part by completing a short survey on social noise in everyday situations. Web address as follows:

www.surveymonkey.co.uk/r/safearoundsound.

For more information look on the BTA’s website

Staying Safe Around Sound

TALK BY DR ASMA ELARBED, PhD Student, NIHR Nottingham Biomedical Research Centre/ University of Nottingham

Asma Elarbed came along to our meeting at Monkey Park to talk to us about the research she is undertaking.

Is there any relationship between tinnitus and stress?

Asma Elarbed is looking for the relationship between tinnitus and stress. Currently it is not clear whether tinnitus acts as a stressor, or stress leads to or makes tinnitus worse. At the NIHR Nottingham BRC (University of Nottingham) PhD student, Asma, is conducting research to answer this question. She is measuring “cortisol” which is an important human hormone that is released by the “adrenal gland” in response to stress.

She is comparing the level of cortisol (from hair sample from the base of the hairline at the back of the head) in people who have tinnitus with those who do not have tinnitus and before and after tinnitus starts. This will tell her more about the biology of tinnitus. She is also looking at issues that relate to stress and tinnitus, namely depression, anxiety, memory and attention, to determine how all these factors relate to each other.

The reason the hair samples are taken from the back of the head is because ultra-violet light (sunshine) can affect the results so they don't use the rest of the hair.

Asma asked us to define stress – some of the answers were – anxiety, worry, pressure. For some people it is something they have in their lives over which they feel they have no control.

Stress can cause changes in blood pressure and heart rate. However, we are all different and the same situation doesn't



have the same stressful effect on everyone. For some, tinnitus starts when they are going through a stressful event. To date, out of 10 participants only 4 have shown an increased level of cortisol from the tests taken from the hair samples which means 6 are not affected by the cortisol. More people are needed to carry out tests in order to complete the research. Asma is still collecting data

and needs to recruit more people to take part. They also wish to recruit healthy individuals to take part in the study to compare their results with people who have tinnitus, so if you have a family member who would like to take part, please contact Asma as follows:-

asma.elarbed@nottingham.ac.uk

Looking at events in life, stress can be as a result of life changes. Cortisol can be measured in the blood and saliva but for the purpose of this research, in order to measure the cortisol over a period of time, hair shafts are taken. Cortisol is higher in the morning and lower in the evening, its purpose is to start the

day with energy.

Cortisol is produced from cholesterol in the two adrenal glands located on top of each kidney. It is normally released in response to events and circumstances such as waking up in the morning, exercising and acute stress. Cortisol prepares the body for a fight-or-flight response by flooding it with glucose, supplying an immediate energy source to large muscles.

Cortisol functions to reduce inflammation in the body, which is good, but over time, these efforts to reduce inflammation also suppress the immune system. Chronic inflammation, caused by lifestyle factors such as poor diet and stress, helps to keep cortisol levels soaring, wreaking havoc on the immune system. Long-term stress and elevated cortisol may also be linked to insomnia, chronic fatigue syndrome, thyroid disorders, dementia, depression, and other conditions.

Asma talked about the fact that stress is subjective and so too is tinnitus. Also the TFI (tinnitus functional index) and the fact that this too is subjective and self-reporting. There is always a correlation between if someone has high level of tinnitus and high level of stress.

There are some types of tinnitus such as tinnitus-related Meniere's and tinnitus-related Acoustic Neuroma which will not be used for the study as it is strictly to do with tinnitus-related stress. The study finishes in March 2020, after which Asma said she will return to update us, along with visual aids to help our understanding of this study.

NATIONAL POETRY DAY – LAUNCH OF OUR POETRY BOOK

Forward Arts Foundation is responsible for National Poetry Day, an annual mass celebration of poetry that unites people throughout the UK in the enjoyment, discovery and sharing of poems. This is celebrated every year during October and coincidentally we launched our Poetry Book entitled “Distraction” at the beginning of October. Next year’s National Poetry Day falls on the 3rd October 2020. Our Poetry booklet is on sale for £2.00 per copy

to raise funds for our group.



There are a variety of poems written by our poetry group and many people are buying them for stocking fillers for Christmas.

Sarah read a quote recently and thought it might be nice to include in our Newsletter.

“So when people say that poetry is a luxury, or an option, or for the educated middle classes, or that it shouldn’t be read in school because it is irrelevant, or any of the strange and stupid things that are said about poetry and its place in our lives. I suspect that the people doing the saying have had things pretty

easy. A tough life needs a tough language – and that is what poetry is. That is what literature offers – a language powerful enough to say how it is. It isn't a hiding place. It is a finding place."

Jeanette Winterson – "Why Be Happy When You Could Be Normal?"



I agree with this as William Henry Davies, who wrote beautiful and meaningful poetry, had a tough life as a hobo for several years and yet wrote "Leisure" which is one of my favourite poems:

Leisure

What is this life if, full of care,
We have no time to stand and stare.

No time to stand beneath the boughs
And stare as long as sheep or cows.

No time to see, when woods we pass,
Where squirrels hide their nuts in grass.

No time to see, in broad daylight,
Streams full of stars, like skies at night.

No time to turn at Beauty's glance,
And watch her feet, how they can dance.

No time to wait till her mouth can
Enrich that smile her eyes began.

A poor life this if, full of care,
We have no time to stand and stare.

THE HEALING POWER OF SCENT

Taking care of yourself is an integral part of your wellness . Complementary therapies can be helpful in managing stress. Using essential oils from plants, flowers and herbs to assist your body's natural healing abilities, aromatherapy can energise you, or encourage you to relax, depending on which oils you use.

It is always better to go to a registered Aromatherapist. Louisa Pini explains: "Aromatherapy has such a powerful effect because it taps into our limbic system. This part of the brain that deals with emotions, memories and stimulation, and can even influence hormonal responses. She adds, "Once inhaled, essential oils can stimulate memories, moods and feelings." An Aromatherapist will take your medical history and create the right blends to support you, often offering relaxing aromatherapy massages. Be sure to tell them about any medications you're taking and speak to your GP before trying any new forms of therapy.



Lavender oil has wonderful sedative properties and is recommended to help you sleep. It has a calming and soothing scent and a recent study in Turkey revealed that lavender essential oil increased quality of sleep and reduced anxiety levels in patients.

"Another lovely oil that can be suitably warming with winter on its way is sweet orange oil" says Louisa Pini. "It's pleasant, sweet scent is gently uplifting and combines well with bergamot for a powerful mood enhancer."

[Extracts from "Happiful"]

FESTIVAL OF CHRISTMAS TREES AND TALK BY DAVID TIDESWELL ABOUT GARDEN BIRDS

We look forward to seeing you at our festive event on **Friday, 29th November**. This will commence at 10.30 with warm drinks and mince pies or scones, after which David Tideswell will give a talk about Garden Birds. At 12.30 for those who wish, we will walk across to the “Crooked Spire” to see the beautiful display of Christmas Trees. **Booking is essential; form enclosed.**

CHRISTMAS CONCERT : FRIDAY 13TH DECEMBER

We can promise you a wonderful evening of Songs from the Shows performed by “Peak Performance” of which Debi Alvey (one of our Senior Specialist Audiologists) is one of the lead Soloists. There will be light refreshments and a Seasonal Raffle so come along and join us for a relaxing evening of entertainment. **Tickets £7.00 each. Booking form enclosed and we will send you the tickets on receipt of your payment.**

AGM & CHRISTMAS ENTERTAINMENT: WEDNESDAY 18TH DECEMBER 11.00 TO 13.00 The Badger, Brockwell Lane.. After the AGM we will continue with entertainment from within our group. The usual lovely food will be served by The Badger together with mince pies.. **Booking is essential (booking form enclosed)**

STAYING WARM AND HEALTHY BY HELEN CARTER

Wednesday, 29th January 2020 at The Badger, Brockwell Lane 11.00 to 13.00

You will find this very interesting and informative as she gives lots of tips and advice and a pack of helpful information.

Booking Form will be enclosed with the next newsletter in the New Year.

**OUR CHRISTMAS WALK : FRIDAY 20TH DECEMBER
AT HOLLINGWOOD HUB, WORKS ROAD, HOLLINGWOOD,
CHESTERFIELD, S43 2PF**

Come along and join us for our Christmas Walk

We will meet outside Katey's Coffee Shop (Inside Hollingwood Hub) at 10.30 am. (Form enclosed so we know who to expect). At the end of the walk, we hope you will join us for a hot drink in the coffee shop. Joanne's mobile phone number is on the booking form and please let us know if you would like a lift to **Hollingwood Hub**. [Photo is from our 2018 walk at the canal]

