

Date: 4 December 2009
Meeting: Tinnitus Meeting
Client: WNDA – David Baguley
Notetaker: Belinda Sewell

Please note this is not a verbatim record

Welcome first and good morning and thanks for coming. This is the WNDA Tinnitus Support Group support meeting. I welcome David Baguley and we are very pleased to have him here. We arranged different dates for him to be here. The loop is on and if not working let us know. The palantypist is here too. I'm sorry about the issues with the technology again.

There will be a break half way through too during which there will be pens and paper at the back for you to write out any questions, which is often easier for you to write down than for David to ask the audience.

Teas and coffee during the break too.

Welcome to David.

David: Thank you Rachel and I'm delighted to be here. We have many holidays in this area and on Friday we have a busy clinic at Addenbrookes so it was nice to come here instead.

For the first 45 minutes we will have slides and a walk through what we currently know and then a break and Belinda can rest her fingers! Then we will have questions and end around 11.30 or 11.45.

With the questions, I can't treat you in a crowded room like this so they have to be general, which I am interested in.

When you hear a talk about Tinnitus its very important that you understand the background of the person giving the talk. A surgeon talks of surgical causes for Tinnitus and what can be done, which we will cover later.

A psychologist talks of emotions and distress and an audiologist, like me, talks of hearing which you have here today.

I have been at Addenbrookes since 1995 which is an inspiring but also exhausting place to work. When I started David Hardy and David Moffit were very important. David Hardey was president and now retired and David Moffit is an ear surgeon and currently there still. They sat me down on a Friday afternoon with a beer, when you could drink on Friday afternoons still, and said I should choose a special interest in my career. I thought it might be Tinnitus and after another beer they asked if I was sure, as nothing could be done as people with Tinnitus will cry and you won't be able to help them. It's a shipwreck for your career.

I'm very obstinate, and I thought that is very interesting. Why are people with Tinnitus in such trouble, some of them. Why are they so distressed and nothing can be done about it!

I set myself in that direction and run the Audiology department and I have daily clinic and are very busy – that is based at Addenbrooke's which you know how it looks like. I also have pictures of car parking spaces which are not extinct!

We will go through the auditory system and how it works well. Look at definitions of Tinnitus, old and new. Look at causes of Tinnitus which will be important for some of you and what therapies are available for Tinnitus. Let's break the idea today that nothing is available in terms of treatment which I don't believe.

I want to look at breaking news to a truly effective therapy for this symptom.

Let's look at the auditory system. Don't worry about the science on the slide. When we focus on the inner ear, here, we call it the cochlea which is the Greek word for sail. For Tinnitus and general hearing we miss the point. The ear is attached to the fantastic brain. For each nerve between the two there are three that go in the opposite direction, and at one point there are five. That is interesting as you think the pathway goes from ear to brain but there is a

controlling route to the ear and they are important mechanisms. Hearing is two way and complicated. It processes sound and is dynamic.

My ear is doing something different in this quiet stage compared to the time during the break when it will be much noisier.

Let's go on tour round the hearing system and look at the important structures for Tinnitus. We have a lovely structure for the ear and you can move it. One in ten humans can move their ears unlike dogs and cats. We can't use that to localise sound.

The canal is a resonant cylinder and we like to see what sound is in there. The ear drum you can see is a thin membrane you can see through and is translucent and is 3 cell thick. It plays sound down into the ossicles and they are the smallest bones in the body. They take sound from the ear drum across the cochlea to the middle ear which is full of ear, ventilated through to the throat through this tube here which pops open when you fly, or sneeze or swallow. The tube gets blocked in some children resulting in glue ear.

Sound then passes to the cochlea which changes the sound into a pattern of brain energy over 8 octaves with a resolution much smaller than two keys on a piano and very very small. It's a stupendous job that its doing.

Here is a picture of a human inner ear. You see the cochlea here and behind the semi circular canals of your balance organs so we can gauge planes in space and balance.

Here is a picture of Corti who was the first person to accurately describe the inner ear structure. Here is a guinea pig inner ear with an extra turn and they hear better than humans. Here is the basilar membrane and you see rows of hair cells. Here is a cut through the organ, the centre and an inner hair cell and three rows of outer hair cells. We will talk about that shortly.

The inner hair cells are the closest to the centre connected to the ear to the brain. In normal hearing there are 3,500 and they don't regenerate but in birds and other animals they do. We lost that skill

when we became mammals and we hope to get back to that regeneration.

There you can see the hairs that sit on the hair cell.

There are three rows of outer hair cells from brain to ear and they vary in length. Here you see the hairs in a guinea pig again, bunched together.

There was debate about what the hair cells did for a long time. you see round the side of the cell there are lots of funny things inside them called mitochondria which gives the cell energy and there are more than you would expect. So the cell needs a lot of energy and that was a clue as to what they did.

(Rachel can you remove the purple on the screen please)

as the membrane move with sound vibration the connection opens to allow the cell to fire. That is the mechanism and we are down to a resolution of thousands of a millimetre.

(We have a technology gremlin. In an old gym at one talk in Venezuela the technology failed completely and at one point a dog came down to listen to me!)

Rachel: sorry everyone. Technology isn't our strong point!

Comment: You should just have switched it off as if you unplug it, it doesn't like it at all.

Let me show you the cells.

You can see the little cell there. In the laboratory its played an electrical signal. Watch the top of it.

Playing "Round the Clock" rock music to it. The cells move and its extremely interesting – sensory cells that move and its fascinating!

Let's quit while ahead. That is how the brain controls the ear – it allows the outer hair cells to move focussing the sound in the inner ear allowing it to focus on the sound.

The sound enters the spinal cord then and part of the brain listens hard to new things, sound in space and if it is moving.

Then sound and vision are brought together and further in sound and meaning but at a low level is the vigilant system and this is the clue as to what hearing is actually for. I ask people and they say for talking, which is lovely but we have only talked for 50,000 years and Chimps have the same ear and don't talk much and Guinea pigs don't talk at all. Hearing is our danger detection sense, always on and listening for warning sounds. Like a burglar on the stairs and asthmatic children. If you see how fast adrenalin is released to a sound – seven thousandths of a second.

I talked to the guys in the laboratory to build a machine that can recognise sound in that time period, and they can't do it.

This is the big heart of understanding Tinnitus because those life saving mechanisms are part of Tinnitus and cause deep seated distress and reaction that many people have. This is a fundamental block of your Tinnitus understanding and why it affects you.

Definitions – this is the first one from 1693 and is in the library at Cambridge. They thought it was blocked air, moving the ear drum.

There have been other definitions in history. Top left is a tablet from ancient Babylon and text books found there mention Tinnitus – one 7 times. It was thought to be insects fighting in the ear or a bad spirit whispering. Babylonians tried to use incantations to drive the spirits out.

On the Right is Hypocrites who mentions Tinnitus in terms of medical illnesses and the start of thinking of it as a disease of the ear.

Pliny of the Ancient Romans was interested in Tinnitus too. a recipe for it was dissolved opium in red wine which made people feel better about Tinnitus – you hardly noticed it!

The main treatment in America is Xanax which is a tranquilliser and very strong.

At the bottom right is Toynby and wrote one of the first text books and suffered from Tinnitus and died inhaling ether and chloroform and he died from that. the first Tinnitus martyr!

This is our best definition – as on screen. McFadden 1982

I disagree on some aspects of this as some people don't hear it centrally but from externally. That is probably the best working definition we have.

What are the medical causes? Going from the outside in?

- Having wax in the ear
- Having a pea sprouting in the ear
- A hole in the eardrum
- Middle ear fluid
- Dislocating the small bones
- Disease of the middle ear

A lot of the conductive causes can at least be stopped by surgery or medicine.

Middle ear – disruption of the ear cells can ignite Tinnitus. A hearing loss that effects the middle ear can have Tinnitus associated to it with other diseases of the middle ear.

Common to have a scan looking at the nerves and looking for benign tumours which we do carefully at Addenbrooke's.

Presently a lot of research looks at what happens to Tinnitus in the brain and the idea that losing some hearing down here can cause the brain mechanism to ignite Tinnitus on the way to the brain and where you do your thinking.

One cause you may not know of, is that it can be caused by magic! It appears in each Harry Potter book and he gets it when people are

rude to him or is very stressed. He has a spell that can cause Tinnitus but not cure it! They get a buzzing in their ears. The British Tinnitus Association are writing to J.K. Rowling for support!

Who has Tinnitus? A third of the public will say they do. One in ten have it longer than 5 minutes at a time. 1 in 20 have it badly, and 1 in a 100 have it severely.

Between 2-4% have been to a hospital about Tinnitus.

What about the Tinnitus experience. Some hear more than one sound. Women are more likely to talk about it as they are more sensible about visiting their doctor.

More people have it when older and I'm interested in Tinnitus in children

More people have it with a hearing loss.

Why is it trouble? Here is a famous quote from a 1970s Tinnitus pioneer. In his view chronic pain, balance problems and then Tinnitus, in that order, is what are the worse things that can happen to someone.

In 1990 two researchers sent a questionnaire on Tinnitus to a research group. Most answers said it affected their general health, hearing and depression and insecurity and apprehension etc.

That is interesting. There are two Tinnitus facts that are hard to explain as paradoxes. If you take people with no Tinnitus and put them in a silent room some of them will hear buzzing, whistling etc. What proportion would you think that is?

Comment: 30%

Comment: Much more than that

David: 94.5% was the highest measurement and most is around 80%. So we have activity deriving from our inner ear which isn't a surprise, but normally we don't hear it.

If you measure how loud Tinnitus is, which is hard to do, in 80% of people it comes out as if it was quiet. 10 decibels or less which is a whisper. But people are very upset with it. The modern theory is that the inner ear signals are picked up by the danger detecting brain areas, paying it a lot of attention and making it more sensitive to the Tinnitus and causing the agitation and upset that many people at the clinic talk about.

This was brought together by Jastreboff and Jonathan Hazel who now lives in North Norfolk and they have both been on holiday together recently at North Norfolk.

Jastreboff drew modern ideas together and suggested could be ignited in the middle ear but detected in the danger detection area causing an emotional response in another area of the brain. It's a compelling way to look at Tinnitus.

He also described that when the brain is faced with a sensation input that it doesn't read as trouble, it filters it away. Its called habituation.

Hundreds of thousands of nerve fibres are triggered when you first put your shoes on in the morning but you don't feel them later in the day.

On my train journey I saw lots of houses near the tracks but those living in them, filter the sound away over time.

This is at the heart of Tinnitus therapy. If we make it understood, less clear and less likely for the brain to react to it, it will stop listening to it.

How might we do this in a clinic? With the habituation based approach they reduce the anxiety and fear and use relaxation therapy to break the link with Tinnitus and agitation.

We use sound to reduce the starkness of Tinnitus. You need a decent fitting of a hearing aid, or sound generators that produce a soft sound in the ear to reduce the Tinnitus signal.

To use the sound of rain/or the ocean to reduce the starkness of the Tinnitus and allow people to get to sleep more easily and get back to sleep more easily.

This device has a waterfall sound which for older people, the sound may be a disaster!

There are some words used for therapy that might confuse you!

Tinnitus retraining therapy is a way of habituation therapy along with others.

There is a treatment called neuromonics which will be launched next year – a way to listen to music to reduce the sound of Tinnitus and will be pushed hard privately at a cost of £2-3,000 which is only as good as the treatment you could get for free at the Q.E. hospital.

Psychology – cognitive behaviour therapy is another treatment with Tinnitus benefits. Norfolk is leading the East of England in this therapy to be attached to each G.P. practice and should be more readily available in the next few years.

Which treatment works best? You can't do placebo testing but based on research in 70-80% of people there is an improvement and Tinnitus isn't so much a problem. They hear it but aren't troubled by it.

I want to look at the opportunities for self help which is often as good as seeing a therapist.

Sleeping better

Watching caffeine intake

Getting up and going to bed at the same time

Relaxation therapy

Sound enrichment – quiet sound in your environment like radio, fan, etc. Sitting in silence isn't good.

Getting an informed clinical diagnosis.

Everyone can have access to treatment, firstly at the doctor, or the hospital or somewhere big like Addenbrooke's. Clear commitment

from the Department of Health and there are now clear services available for people.

The British Tinnitus website is a good place for support.

There is a clear understanding that different groups must work together i.e. Audiologists etc. There is clear evidence they are now collaborating and no longer competing.

We can image Tinnitus in the brain which is exciting and we can see the structures involved and how they work and how it influences the brain which we can change.

Drug trials are extremely interesting. The first British one with Glaxo Smith Klein has just ended in Cambridge and people are taking experimental drugs with the idea of turning Tinnitus down. That is very exciting for me and I have done lots of work getting the big drug companies involved. It won't be me and my laptop on a kitchen table solving this, but big drug companies and they are excited as it's a huge market and some of them are broke, and so they are motivated.

Using digital technology to treat technology is also exciting breaking news.

We will have a break and then answer your written questions.

Tinnitus is an enigma still but there is a pace for exciting innovative research and I'm more optimistic now of reasonable therapy to turn the sound down or off and I wanted to share that with you

15 minute break and then questions. If there are no questions there won't be any answers.

QUESTIONS AND ANSWERS SESSION

www.rnid.org.uk

David: Let's continue and engage until 11.45 when Belinda's fingers will be worn out and the projector will have died, and my throat will be sore.

Great to see so many interesting questions and to see what is on your minds. Laurence McKellar and I are writing a self help book on Tinnitus and that is my Xmas holidays project.

Q: Someone asked where they could get a sound generator from?

Answer: We prefer you get them from a clinic with someone explaining how best to use them. Julie Simmonds is here from the Q.E. clinic who is an expert on this. And someone to be sent too. you may find the road to Julie or myself isn't clear and the RNID website is best to use. You can see it in glorious purple on the screen.

Comment: That looks like .mid from here and it isn't.

David: No its r n l d.

Q: Role of alcohol and Tinnitus

Answer: if you look at the alcohol effect on Tinnitus its different to what we used to think especially thick drinks like sherry and port. Now we say for a third of people it makes no difference, for a third it makes it much worse and for the other third it makes it much better, which is the group we worry about! We did a tutorial group for new audiologists and mentioned alcohol and its use. If people are agitated it's a short term solution and relaxation techniques are more effective.

Q: Any link with diet and Tinnitus?

Answer: we said red meat, curry, chocolate, caffeine and all the good things in life effected Tinnitus. We sat down and looked at the list which is long and bad to do as there is no evidence. Even the issue over caffeine may be wrong with no link. If someone drinks 8 double espressos resulting in a whirling head there may be a link! Also with wheat but generally there isn't a link. For those finding alcohol makes Tinnitus worse, people should be sensible in general about consumption.

Q: General prognosis?

Answer: there is conflicting evidence here. With increased hearing loss with age, there is danger of increasing Tinnitus trouble if you don't do anything about it. If you get your hearing aid attended to, it might improve. Also old age may mean a bit of isolation, depression and unhappiness which can lead into Tinnitus too. you will hear your Tinnitus more and not feel great, so there are links there.

However research says that in general people with Tinnitus get better over time. a Medical Research Council in the mid 80s asked 30,000 people about their hearing including Tinnitus resulting in a huge amount of data. They then went back in the early 2000s (20 years later) about their hearing and Tinnitus. One in ten people had trouble. Wonderfully they were different people and those reporting it in the 80s no longer had it. For the people reporting it in the 2000s it was a new condition. So you really may be able to filter it out and over time there may be improvement hopes for some of you

Q: Somatic Tinnitus

Answer: For these people that clench their teeth, smile broadly, their Tinnitus can change dramatically. People paid more attention to this over time. Robert Levine in Boston did a big study on how Tinnitus changed when you did these movements and how many people got Tinnitus by doing them. If you don't have Tinnitus then in 60% you can induce it temporarily. So there is something in the muscles in the head and neck related to hearing. Remember the chap in the corner that can move his ears here.

For a horse, they move their ears forward and back and there is a link with hearing and location. We have that link still but don't use it much. When we clench our teeth it can push up the Tinnitus that is already there.

TMJ dysfunction is the joint at the edge of the jaw and in the West we carry a lot of stress here and there may be a link in some people with Tinnitus and this. We have a good link with the jaw clinic sending people along with Tinnitus and seeing if we can help. Relaxation therapy is particularly helpful with this.

Q: Someone had dizziness etc and is it linked.

Answer: yes and no. dizziness means imbalance and vertigo is a swirling. If it's a new symptom go to your doctor please. For some people hearing and dizziness and Tinnitus go together with Meuniers disease. Its lower frequency and louder and more intrusive associated with falling to the floor and vomiting and humiliation as people think you are drunk. We do specific sound therapy in these situations. If you have balance issues, please talk to your doctor.

Q: Drug called amitriptyline

Answer: this is a very old fashioned drug used for depression and now for facial pain too and good for getting people to sleep. Tinnitus sufferers can benefit it and if it helps neuralgia which is a burning sensation on face nerves, it may help hearing nerves and make Tinnitus less intrusive. There is a signpost there but the research needs revisiting.

Some depression drugs have a Tinnitus role. If you have Tinnitus and depression and the depression is treated, you will feel better about Tinnitus and that is a very good pathway. Or you can have cognitive therapy and other treatments. If you have depression due to your Tinnitus its worth exploring.

Prozac and its cousins may help people with Tinnitus who aren't depressed. California/Swedish research looking into this currently and is cutting edge research.

Q: Tinnitus as a side effect of other drugs i.e. blood pressure drugs

Answer: Tinnitus is cited as a side effect of many drugs. If you feel a drug you are taking is lifting up your Tinnitus go and see your doctor to look in the "book of words" and then use their common sense.

Quinine is good at stopping night cramps but causes Tinnitus. We then have to decide which is worse. Often people say they have a sound generator and will stick to the drug as they don't want the night cramps back. Common sense rules the day.

Q: Does atmospheric pressure change Tinnitus?

Answer: I think it does. Not in everyone though. Some patients can map their Tinnitus against the barometer. Ear pressures can change with atmospheric pressure. Some treatments put excess pressure into the ear canal and benefits some people but we don't know way and we are discussing doing research there. Its very interesting and a clear research line in future.

Q: Why does my Tinnitus sound like far off music?

Answer: One of my first ever Tinnitus patients was a lovely lady but in real trouble as she could hear Elvis Presley! She didn't like him as she was sick of it. There is something called musical association like "wooden heart", "happy birthday" and this often happens at stressful times like funerals and then "Abide with Me" stays with them. We have to be careful as its in the area where a psychologist should be involved.

One of my medical students who has just qualified is lovely and we looked at all this area over the summer and wrote it up. Its probably a subset of Tinnitus and worth mentioning to your doctor as specific things can sometimes be done.

Q: Hearing aid hasn't helped Tinnitus – what's next?

Answer: if we say hearing aids help 60-70% of Tinnitus sufferers, then 30-40% won't be helped. You can try setting the hearing aid up differently which do clever things now and filter out sound and can learn. We can tell how often you wear them by plugging them into our computers – big brother is watching!! We used to do it sneakily by looking at battery use. One packet of batteries annually means you aren't wearing it every day!

Sometimes a Tinnitus sufferer may need two programmes though. One allows the background noise to come up which is good for Tinnitus and allows soft sound. We are looking at specific tuning for Tinnitus.

Also there are new devices coming out and should be more widely available soon. It combines a hearing aid with a sound generator.

They were poor in the past and hard to maintain. A new digital device is being trialled in Cambridge which may help.

Q: My Tinnitus gets worse when I remove my hearing aid.

Answer: Don't take it out until bed time and have your sound generator already on so you don't go from sound to quiet to sound. So move across into sound when you can. that is common sense.

Q: How can you talk to a child about Tinnitus?

Answer: It is hard. At a primary school if we asked how many had Tinnitus, a lot would put their hands up to please you. What is Tinnitus? If you ask them what their favourite colour is before break time they would say blue and it would be red by the end of play time. life is hugely fluid and that is part of the joy of being a child. So you have to use children language and be careful to ask the question in several ways and talk about monster/crisp packet noises and things like that.

A third of adults said they had Tinnitus at some point and 1 in 10 it was troublesome. For children its just the same. That should not surprise us. Its rare for an adult to say it started as a child though. We think that over time the process of habituation is more effective. Their brain is more plastic and can change more easily to deal with Tinnitus and there are benefits there.

Q: Hyperacusis – hyper sensitivity of hearing

Answer: These people can't bear to be near the Hoover or washing machine, and aren't just male! There is some debate on how common it is – about 2% of the population and higher in autism. With Meurrier's disease its separate. Hyperacusis can occur after head injury, as one person here, and there are sound therapies that can help here too.

Q: Will hair cell regeneration ever happen?

Answer: Let's go back to a slide here. Ok. Here is the picture of the outer hair cells that have movement and are the most fragile. If

deafened by toxic drugs/noise the outer hair cells are damaged first. They are packed in by supporting cells. Interestingly at a point in embryology they were precursive cells and some grew to be supporting cells and some hair cells. People are working on taking supporting cells to trigger them into growing into hair cells. Getting the precursive cell to do this. We have got to the stage where you can convince a supporting cell to grow into a hair cell but it isn't connected to anything. The next huge challenge is to get the nerve to grow to the supportive cells and be used where they are.

I want to look at the inner ear like a prefabricated house. If it cracked it was done for and you had to knock it down as you could not fix it to hold its strength. The inner ear is like that with inner tensions within it. People are saying a broken cochlea is like a broken prefab. You may be able to get a cell to grow into something different but it won't help much.

I'm sure that when I retire we won't be much further in that area.

Any questions?

Q: Can Tinnitus be caused by meningitis?

Answer: Yes by both types - either it being toxic to the ear or from the medication to keep them alive. Care has to be taken.

Q: Could facet joint injections in the spine cause it?

Answer: Not seen that, but joints are linked to hearing so it is possible.

Q: If you want to get involved in research through the trials how do you do that?

Answer: We are currently building links with clinics like Bedford and Kings Lynn and want a network of support and communication. Also through the British Tinnitus Association who are a fine organisation and who advertise their drug trials.

So we are done. Happy Christmas to you all. I hope the talk helped and I hope I haven't upset anyone. If so, let me know, or your G.P. know, and I wish you well.

Rachel: I hope you found that useful and thank you to David and its been beautiful. We will have notes at the office from the typist so ask me if you want them and I will send them to you.

David mentioned the RNID and the products you can purchase for Tinnitus and you can take one from the office today.

The West Norfolk Tinnitus Support Group meeting is held here monthly for you to get together and get advice on the first Friday of every month between 10-12 so do come along for further advice.

Thank you to David and all for coming. Have a good afternoon.