



AMNET NEWS

AMNET IS AN EASTERN COUNTIES, SELF-HELP GROUP OF FORMER AND NEW ACOUSTIC NEUROMA AND MENINGIOMA PATIENTS AND CARERS, BASED IN ADDENBROOKE'S HOSPITAL, CAMBRIDGE UK

Spring 2009
Issue 45

Raising money for Brain Tumour UK and Brain Tumour research

We welcomed Peter Davison to our Christmas meeting to talk to us about his cycle ride from Land's End to John O'Groats undertaken in May during 2008. Peter last spoke to us in April when he described his planned trip so we were very pleased to welcome him back to tell us how it went.

His trip has so far raised over £11,000 and the money is still coming in including a donation of £100 from Amnet which was presented at the meeting.



*Presenting a cheque for £100.
From left to right Peter Davison,
Chris Richards and Joanne See*

Editorial

Dear All

Welcome to our Spring newsletter – although as I write this there is rather a lot of snow around. Hopefully we will see the signs of spring before too long.

For this edition we have some entertaining and interesting articles. Peter Davison's arduous ride from Lands End to John O'Groats may have inspired me to get on my bike but then I remembered that I tend to fall off bikes – I need a lot more practice. For those of you who helped me with my research project or remember me writing about it a couple of years ago, there is an article taken from a similar project carried out by Debra

Lamb an AN patient from Manchester. However where I was concentrating on experience post surgery she was talking to people about diagnosis and making decisions about treatment. Allan Hughes' article describes what it is like to be in the 'Watch and Scan' programme. I would welcome similar articles describing your experiences in relation to acoustic neuroma. It does not need to be long and I would be very willing to help anyone who does feel the desire to write something but is not sure how to go about it.

Meanwhile we will continue to look forward to the spring and summer and I hope to see some of you at the meeting on 28th March.

Regards

Next Meeting

Our next meeting will be held on **Saturday March 28th 2009** in the Boardroom at **Addenbrooke's Hospital**. The doors will open at 13.00hrs and our speaker will be **Peter Lawrence** who will speak about his journey towards making a decision about treatment of his acoustic neuroma.

Peter Davison - Peter's REALLY Arduous Ride



Peter was diagnosed with a brain tumour in 2005 and received treatment in the form of surgery, radiotherapy and chemotherapy while he was working in Singapore. He is now based in the UK. The idea for his trip came from learning about the number of young people who die from brain tumours and how it is an ignored topic in government sponsored medical research. He talked about the concept of '**Average Lost Life Years**' (the **ReALLY** of the **title**) which highlights the cost of brain tumours in terms of the lives of young people who have brain tumours and who either die or have severely diminished quality of life. Peter decided to do his bike ride to highlight the lack of support for brain tumour research and to support Brain Tumour UK.

Preparing

Peter described how when he last spoke to us he was still waiting for his bike to arrive – he was being provided with one by Dawes, but they had been waiting four months for components to arrive from Taiwan so they agreed to give him a different bike but he then only had a month to practice.

As he was getting ready to set off on his journey he started to get media interest in his trip. He described how this escalated after an early morning interview on Radio Cambridgeshire culminating in an appearance on BBC's Look East programme and newspaper coverage in the Cambridge Evening News. The BBC persuaded him to take a video camera with him to film parts of the trip and kept in touch with his progress. He was a little concerned about the extra weight provided by the camera, microphone, and digital tapes but gamely carried it and filmed parts of his journey and the people he met along the way.

His journey began with a rail journey to Penzance where he had a First Class ticket while his bike travelled in the van. He felt he needed to make the most of the opportunity to travel comfortably as this would be the last chance for three weeks.

Setting out

His first day travelling from Penzance after a commemorative photograph at Lands End was done in a howling gale and pouring rain and there were floods in Redruth. While cars could not drive through the five inches of water he was just able to get through on his



Setting off at Lands End.

bike. This was a rather daunting start to his journey but he reached his Bed and Breakfast where a very helpful landlady washed and dried all his kit and he managed to get a meal in a local pub, even though it was flooded.

Fortunately this was the last rain he experienced for 10 days as the wind changed from Southwest to Northeast so it was a head wind that he had to ride into but at least it did not carry any rain. Devon on his second day presented rather different problems – large hills and badly signposted lanes which resulted in rather a lot of extra miles.

South Coast

He was accompanied by various friends and family along the way and one of his brothers rode with him on his motor bike along the south coast. One of his tasks was to

scout out cafes where Peter could stop and take on some of the 6000 calories he needed each day to keep cycling. Peter found that he often met people in these cafes who were interested in what he was doing, then often told him tales of how brain tumours had affected their friends and families and pressed £5 notes into his hand.

Peter planned his route to take in detours to places where he was able to put his case and obtain some media interest. His first stop was the **University of Portsmouth** where there is a centre for research into brain tumours. One of the things he noticed here was that all the equipment that was used in the laboratories had plaques indicating where the funds to buy the equipment had come from and they were all individuals, families or charities. Very little government money is available for brain tumour research because it affects such a small number of people in comparison to other cancers.



Meeting Jim Paice MP at the Houses of Parliament.

Houses of Parliament

A day later Peter reached London and went to the **Houses of Parliament** to talk to his MP Jim Pace, to put his case for funding for research into brain tumours. At this time Senator Edward Kennedy was diagnosed with a brain tumour which while unfortunate, did raise the media profile for the cause of funding for brain tumour research. That evening was spent with trustees from BTUK in a pub watching Manchester United win the European Champion's league.

On leaving London Peter's next stop was in **Welwyn Garden City** at the headquarters of **Scherring Plough** the pharmaceutical company who produce a drug called Tamsolamide which is used to treat recurrent and high grade brain tumours. Peter had been given this drug in Singapore and it had been efficacious and well tolerated. There is a campaign to make this drug more available in this country and Peter's visit was an opportunity to raise some publicity about this and it resulted an article in the Sunday Times.

Cambridge

In Cambridge he called in at the **Cambridge Cancer Help Centre** and was joined by his younger brother who was also cycling. They rode together for two days from

Cambridge to Warrington where his brother retired having had enough. By this time Peter was having trouble with his knees. His leg muscles had been weakened by the high doses of steroids given after his surgery and he was now needing to take regular doses of ibuprofen to continue. He was joined by another friend on a motor bike and continued into the Lake District from where he was accompanied for the rest of the journey by his wife in a car.

Heading North

Unfortunately 15 miles into the next day he found his knees would not cycle any more and had to stop. As he had appointments in **Edinburgh** his wife drove him the 130 miles to Edinburgh where he met with some academics and a brain tumour support group. He was very disappointed that he was unable to cycle this section but having obtained medical advice he increased his doses of ibuprofen and was able to continue.

The last part of the journey through the Scottish Highlands was much less stressful as he had no further appointments, the weather and scenery were glorious and he was able to take enough painkillers to continue. It was more 'fun' whereas the earlier part of the ride had felt like 'work'.

Throughout the journey he was followed by Radio Cambridgeshire who rang him every couple of days and reported on his progress.



Snow in the mountains in May.

We would like to acknowledge Peter's fantastic achievement and thank him for coming to tell us his story. I have also included some pictures of his ride.

Peter was disappointed that he was unable to complete the whole journey on his bike and is planning to return to the Lake District next year, with some family and friends to complete the 130 miles he missed. We wish them luck!

Acoustic Neuroma: how does the experience of diagnosis and making a treatment choice impact on the patient?

A study by Debra Lamb

Some of you will remember that a couple of years ago I carried out a research project talking to members of AMNET about their experiences in relation to acoustic neuroma. My emphasis was on how people had coped following surgery. Last year Debra Lamb a qualified practising counsellor and acoustic neuroma patient herself carried out a research project exploring the way a small group of patients made decisions about treatment following a diagnosis of acoustic neuroma. This is a summary of some parts of her dissertation.

Her study recorded the stories of eight people including herself and aimed to explore the experience of this group in terms of diagnosis, explanations of options, evidence of shared decision making, emotional support from medical staff and whether they had received any counselling support. She was also interested in the support and resources mobilised by the patients themselves.

As many of us are aware a diagnosis of acoustic neuroma comes as a great shock to most patients who are often then faced with having to make a difficult decision about what treatment option to take. Recent Government policy has encouraged patients to be more involved in decision making in relation to their health although the degree to which individual patients wish to be involved in these decisions is variable. The availability of information on the internet has also increased patient's knowledge, while sometimes also increasing their anxiety.

Debra interviewed seven volunteers who were recruited through BANA and became her co-researchers. There were four men and three women aged between 34 and 54 who had experienced different size tumours and different treatment experiences. Each one was interviewed in their own home and related the story of their diagnosis and treatment which Debra hoped would illuminate their lived experience and the process by which they made their decision about treatment.

Diagnosis

Through her unstructured interviews Debra first examined the initial recognition of symptoms. Some of the group members considered that they had been suffering symptoms for quite a long time and had not attached any importance to feelings such as fullness of the ear, dizziness and tinnitus. A visit to the doctor was sometimes prompted by an unrelated problem and the long standing problems were mentioned in passing. Some were surprised that the symptoms were being followed up while others had been aware of 'something wrong' for some time. The resulting tests including the MRI scan were quite unsettling, especially as it was frequently not clear why a particular test was being carried out. When the diagnosis was made everyone suffered some shock and bewilderment although some were relieved that the condition was not 'life threatening'.

Most of the group felt they needed information and this was not readily available. Information was obtained from a variety of sources including BANA and the internet. Using the internet as a source of information produced mixed results. Being well informed about the condition sometimes made the relationship with doctors a little more strained, but for others the information produced fear.

There was also the suggestion that doctors do tend to promote their own treatment and this can be confusing for patients. Surgeons told patients that surgery was the best route while radio-surgeons promoted Gamma Knife, so patients felt they were caught in the middle and finding it difficult to make an informed decision. There were comments about the doctors 'appearing like God'.

Making the decision

Factors that influenced the decision making were varied. For Debra herself it was the opportunity to discuss the surgery with a sympathetic secretary and the opportunity to have the surgery done quickly through private treatment. For others, research on the internet that suggested that unsuccessful Gamma Knife treatment may result in difficulties for later surgery, led to a decision to opt for surgery. The risks of surgery seemed too great for a couple of members of the group and they opted for the Gamma Knife, one person followed professional advice from a family member and the other was put on a 'watch and wait' programme.

The degree to which this group felt they had shared in the decision making also varied. Most of them felt that the professionals had provided information although in some cases this was seen as quite biased towards one treatment. However most of them felt they had made their own decision after discussion with friends and family.

In the difficult time between diagnosis and treatment what helped people most was information and this came from various sources. Some found BANA and others who had also had a diagnosis of acoustic neuroma a useful resource, and family and friends were also very supportive. While spiritual convictions supported a couple of the group, for others the need to feel some control over their situation was of great importance.

Attitudes and emotional support

Attitudes to the acoustic neuroma varied along a continuum from an acceptance of the tumour and treatment to a need to have control over it and most strongly a negative desire to be rid of the tumour.

Some of the group were disappointed with the degree of emotional support received during their treatment. There seemed to be little evidence of support from the clinical team (apart from for one patient who had Gamma Knife treatment) but people drew on their own support networks both external and internal.

My own experience of the illness had fuelled both my curiosity and passion into discovering whether there was a shared commonality in our experience of diagnosis and making a treatment choice.

The findings illustrate how the diagnosis of Acoustic Neuroma impacted on us and how we immediately began to mobilise our own resources to cope with our illness, especially in the light of there being very little written information available at the point of our diagnosis.

As patients diagnosed with a potentially life-threatening condition, the study revealed how we navigated our paths through the dilemma over which treatment option to take. It also highlighted the factors involved in our decision making process and how our attitudes may have played a part in shaping our final decisions.

Any shared-decision making with the medical professionals in charge of our care seemed to centre on our need for reliable medical opinion, although the different treatment options were only explained to half of us. Where circumstances allowed, we seemed to reach the decision ourselves after conducting our own research, talking to family and friends and, in many cases, following our gut instincts. This study revealed how most of us took control over our illness and ultimately made the decision about treatment for ourselves.

In line with recent literature about the impact of the internet on the patient becoming informed about their illness, the study revealed how the internet, for most of us, became the primary source of information. Often, this was the way we discovered BANA which allowed us to access impartial information and support. Becoming internet informed often became a factor in influencing our choice of treatment.

Research Aims – *One of my aims and hopes for this research study was to portray the lived experience of a person receiving the diagnosis of Acoustic Neuroma and highlight the dilemma involved in how to proceed in the period following it. As a result of using the heuristic approach in my research, my findings have*

As counselling is Debra's professional background she asked the group whether they would have found counselling helpful. Some of them felt they would, but did feel the counsellor should know something about their situation.

Overall the group were quite positive about the future although for some hearing loss was an issue and for those who had not undergone surgery or for whom the tumour had not been totally removed there is a feeling of ongoing uncertainty.

I have taken Debra's own words from the conclusion of her dissertation which I feel outline her thoughts and findings clearly.

been naturally unfolding and enlightening. Through the telling of their stories, participants' voices can be clearly heard in this study, offering insight into the difficulties experienced by Acoustic Neuroma patients. Often these voices are demanding a say in the practical treatment of their condition. In terms of our emotional care, half of us would have welcomed the opportunity of counselling had it been offered as part of our standard patient care.

SOCIAL AND PROFESSIONAL IMPLICATIONS

Social Implications – *Although still relatively rare, the incidence of Acoustic Neuroma in the population is rising (ANAUUSA, 2008). This is judged to be due to advances in MRI scanning, not just on patients experiencing symptoms, but also during incidental scanning. This study showed the important role of the GP in achieving as early a diagnosis as possible, thereby enabling patients to have more treatment choice and successful treatment outcomes. BANA are currently in the process of writing to GPs across the country to raise their awareness of the symptoms which point to Acoustic Neuroma, especially since within the next two years, they will be able to request MRI scans directly without going through a hospital consultant.*

Professional Implications - *The study would suggest that there is a need for impartial written information about Acoustic Neuroma to be available and given to patients at the point of their diagnosis. As already mentioned, not all newly diagnosed patients join BANA. The reason for this is not clear. However, if information about the existence of BANA was given to a person at diagnosis by their Consultant, this would enhance patient choice.*

One of the aims of the study was to investigate whether counselling has a role in the patient's experience of Acoustic Neuroma. Since half of us felt that we would have benefited from counselling, this supports the idea that counselling could play an important role for some Acoustic Neuroma patients in the period following diagnosis.

Taken from:

Debra Helen Lamb (2008) 'Acoustic Neuroma: how does the experience of diagnosis and making a treatment choice impact on the patient?'

A dissertation submitted to the University of Manchester for the degree of Master of Arts in Counselling Studies in the Faculty of Humanities

I asked Debra if she had any further thoughts she would like to add to this and I have printed her reply opposite.

Most of my research participants contacted me again after they received a copy of my dissertation and felt participating was a cathartic experience. I'm left feeling that in spite of all the good work BANA do, the supporting information is not getting fed through by Consultants at the time of diagnosis, which really saddens me. I'm also left with no doubt at all that what patients need most is early impartial information and the right to have a say in their treatment.

Patient viewpoint on 'Wait and Scan'

I was sent this account by Allan Hughes describing his experience of being diagnosed with an acoustic neuroma and being in the 'Watch and Scan' programme. It is good to hear from someone who is looking for the positive slant on his experience.

When I was asked to write something about being on the "Wait and Scan" protocol, from a patient's point of view, it made me think

[a] Did I actually **have** a point of view?

[b] If so, would it be of any use to others?

[c] Could I write about it objectively?

Well, the answer to [a] is "Yes" but the answers for [b] and [c] will have to come from the reader.

I know that I **DO** have a point of view, but not thinking about my situation very often is one of the strategies I have developed to cope with my condition. That doesn't mean I take it (the neuroma) for granted, but to spend all day, every day, dwelling on what might happen and what I should do (i.e. to have the operation or not) is very counter-productive.

I have probably had the condition for about 10 years, but it was diagnosed 4 years ago. My G.P. picked up on the fact that I had severe tinnitus in only one ear and my E.N.T. consultant in York (a former registrar of Mr. Moffatt) sent me for an M.R.I. Scan which confirmed it. When my G.P. told me that I had a brain tumour, it took a bit of getting used to, but the more information I was given (including that from AMNET), and the support and reassurance from my consultant, the more I got used to the idea that my world was not coming to an end.

I came down to Addenbrooke's more than 2 years ago and was assessed and put on the database. Both elements were re-assuring because the initial assessment advised me to wait and see (although I was offered the operation if I wanted it) and the fact that I was on the database meant that I would not be unknown to the clinical team (history wise) if my condition suddenly deteriorated and surgery was necessary.

In the spring of 2008, I was invited (with hundreds of others) to take part in the study being conducted by Mr. Simon Lloyd on patients like myself. Despite it involving a lot of travelling and an overnight stay, I immediately said "Yes", because apart from wanting to put something back into a service that has served me wonderfully well, it was also another opportunity to garner more information from an expert, and have a third opinion that managing without surgery was appropriate and advisable. Next to getting married and being ordained as a priest, it is probably the

biggest decision that I will have to make. The journey and the consultation was time well spent.

The perspective I have of being on the programme is definitely one of a lay-man and for that reason I would never proffer an opinion to anyone else who is in the same position. You must take the advice of those directly responsible for your clinical care, not just because they are highly qualified and vastly experienced, but because no two conditions can be exactly the same and because we all have different pain thresholds and management strategies.

I can think of not one negative of the situation in which I find myself. I don't relish the 45 minutes in an M.R.I. Scanner, but even that is bearable with a few meditation/relaxation techniques and a good C.D. (I know that when I reach track 9 then I am nearly ready to come out!). I feel I am lucky to be scanned, but am always apprehensive for 3 weeks until the results are known. This is probably the only time I think of my condition (apart from odd painful episodes), hence my unusual start to this article.

The greatest positive is the fact that you feel a part of the hospital set up, even though you may be hundreds of miles away. You also know that the team are only a phone call away. This feeling of well being is helped greatly by publications and communications from AMNET which augment clinical support, whilst in my case, my consultant here is always helpful, and my first port of call. To reciprocate, I let him use me as a "patient" for students who have to examine me and take a history, before attempting a diagnosis as part of a viva voce, so he keeps a regular check on my progress and is a major source of consultation should I have a bad patch.

I hope that I can manage without the operation but knowing that Mr. Moffatt alone has performed over 1000 procedures, along with the knowledge and expertise of all the staff, makes me realise that although such a procedure is major surgery indeed, it is also, in a way, becoming routine. That fact alone makes it worth being on the protocol, because the longer you are on it, the more habituated you become to possibly having the procedure, and thus, the less anxious you become.

Allan Hughes January 2009

postbag



I received this letter from Jean who would very much like to hear from others - if you would like to get in touch with her or have some suggestions that may help, please contact me and I will pass on your details .

Peterborough

I would like to give you a brief summary of what has happened to me. This has now become unbearable and I would like to communicate with fellow sufferers of acoustic neuroma.

My tumour was first diagnosed in 1986 when I was in hospital recovering from a hysterectomy. I was moved to another hospital (the Queen Elizabeth Hospital in Birmingham) and an acoustic neuroma was diagnosed. I underwent surgery for removal of this. However the neurosurgeon was unable to remove the tumour totally due to it's position but he did not think it would grow again. I had seven glorious years and then on a routine check was told the tumour had grown to almost it's original size – needless to say my husband and I were devastated. The following week I again underwent surgery for removal of this tumour but again due to it's shape and position this was not possible. I did not get on too well after this operation and became incontinent and my gait was unsteady. Yes, you've guessed it – three months later I had to undergo yet another operation to fit a peritoneal shunt. I also had to have several stitches in my right eye and a gold weight was fitted.

Following this I was sent to the Hallamshire Hospital in Sheffield where I underwent Stereotactic Radiosurgery (some 14 years ago). This so far has prevented any further growth of the tumour. Of course I have regular MRI scans and am really carefully monitored.

Of course (as is usual I believe) I lost my hearing in the right ear and had some facial palsy and my right eye was affected. I recently had an operation on this and now have little sight in this eye. Nevertheless I have managed pretty well!

However, (whether it's advancing years) I have now become very deaf in my left ear and suffer very badly with tinnitus and become extremely giddy.

These symptoms have almost destroyed my quality of life – **HELP** I would very much appreciate letters from fellow sufferers of acoustic neuromas letting me know of their experiences and any tips!

Yours sincerely

Jean Grove

Would you like to join AMNET?

We provide

- Telephone contact with past patients, who understand what you are going through, and have time to listen
- A regular newsletter for members, with information about developments in treatment and living with acoustic neuroma.
- Regular meetings, providing the opportunity to listen to expert speakers and meet other members
- A library of resources, which can be hired by members
- A detailed website, at www.amnet-charity.org.uk

If you would like to join AMNET and support our work please complete the form below and send a £15 annual subscription to:

AMNET

The Old School House, The Green
Old Buckenham,
Norfolk
NR17 1RR

Name _____

Address _____

Postcode _____

*Tel _____

*Email _____

(* optional)

Treatment Date

Watch and wait _____

Surgery _____

Radiotherapy _____

Gamma Knife _____

I enclose a Cheque/Postal Order for £15 for my yearly subscription to AMNET.

FORTHCOMING MEETINGS

Our next meeting will be held on Saturday March 28th 2009 in the Boardroom at Addenbrooke's Hospital. The doors will open at 13.00hrs and our speaker will be **Peter Lawrence** who will speak about his journey towards making a decision about treatment of his acoustic neuroma.

The following meeting will be our AGM on Saturday 18th July 2009. Our speaker will be Diana Farragher who is a physiotherapist specialising in treatment of facial paralysis.

AMNET Advisory Panel at Addenbrooke's Hospital, Cambridge

Mr David Baguley MSc MBA
Principal Audiological Scientist

Kate Burton
Consultant Radiographer in Neuro - Oncology

Jean Hatchell
Clinical Nurse Practitioner

Melanie Jackson
Skull Base Nurse Practitioner

Mr Robert Macfarlane MD FRCS
Consultant Neurosurgeon

Mr David Moffat BSc MA FRCS
Consultant in Otoneurological and Skull Base Surgery

Ella Pybus
Co director Meningioma UK & Trustee of BTUK

Mr N J C Sarkies MRCP FRCS
FRCOphth Consultant Ophthalmic Surgeon

BANA Booklets

BANA has produced some booklets which may be of interest:-

A Basic Overview of Diagnosis and Treatment of Acoustic Neuroma

The Facial Nerve and Acoustic Neuroma

Headache after Acoustic Neuroma Surgery

Eye care after Acoustic Neuroma Surgery

Balance following Acoustic Neuroma

Effects an acoustic neuroma can have on your memory, emotions, behaviour, executive functioning and energy

All these booklets are available from Alison. There is a charge of £2.00 for all except for the first title.

Contributions

Please consider writing for your newsletter. It can be anything you feel will be of interest to members from a few lines to a couple of pages. It all helps to make the newsletter more interesting.

Email:
chris@richards2113.fsnet.co.uk

If you would like to make a contribution please telephone or email me.

Facial Stimulators

AMNET has some Facial Trophic Stimulators which are available to members for short term loan. There is a charge of £30 at present which includes maintenance and postage. If you would like to know more please contact: **Margaret Allcock on 01493 700256.**

Necessary Note

AMNET News is very appreciative of the opportunity to publish items relevant to the interests of acoustic neuroma and meningioma patients. This includes instances where members of AMNET have experienced relief, improvement, difficulties or otherwise and write to us of their experiences in order to pass on information for the interest and possible benefit of other members. However, AMNET cannot endorse proprietary products or be held responsible for any errors, omissions or consequences resulting from the contents of this Newsletter.

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British Acoustic Neuroma Association (BANA):

Web site: <http://www.bana-uk.com>

Email: admin@bana-uk.com

Telephone: 01623 632143 **Fax:** 01623 635313

Freephone: 0800 652 3143

Address: Oak House B, Ransomwood Park, Southwell Road West, Mansfield, Notts NG21 0HJ

Meningioma UK:

Web site: <http://www.meningiomauk.org>

Email: support-enquiries@meningiomauk.org

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meningiomauk@ellapybus.greenbee.net

(Meningioma UK)

Telephone: 01787 374084

Address: 53 Pine Grove, Brookman's Park, Herts, AL9 7BL

Brain Tumour UK:

Web site: <http://www.braintumouruk.org.uk/>

Telephone Helpline: 0845 4500 386 (10am - 1pm, Monday to Friday).

Address: PO Box 27108, EDINBURGH, EH10 7WS

Royal National Institute for the Deaf (RNID):

Web Site: <http://www.rnid.org.uk>

Email: informationline@rnid.org.uk

Information Line (Freephone)

Telephone: 0808 808 0123

Textphone: 0808 808 9000

Tinnitus Helpline

Telephone: 0808 808 6666 (Freephone)

Textphone: 0808 808 0007 (Freephone)

Address: 19-23 Featherstone Street, London EC1Y 8SL

Cambridge Campaign for Tackling Acquired Deafness (CAMTAD):

Web site: <http://www.copag.members.beeb.net/copmoc/camtad.htm>

Telephone/Textphone/Fax: 01223 416141 (Mon - Fri 09.30 - 12.30)

Address: 8A Romsey Terrace, Cambridge CB1 3NH

Also contact point for Cambridge Hard of Hearing Club and Cambridgeshire Tinnitus Support Group

Changing Faces:

Charity offering support for people with temporary or long-term facial disfigurement problems

Web site: <http://www.changingfaces.org.uk>

Email: info@changingfaces.org.uk

Telephone: 0845 4500 275

British Tinnitus Association:

Web site: <http://www.tinnitus.org.uk>

Email: info@tinnitus.org.uk

Telephone: 0800 018 0527

Minicom: 0114 258 5694

Address: Ground Floor, Unit 5, Acorn Business Park, Woodseats Close, Sheffield, S8 0TB

Entific Medical Systems:

Information about bone conducted hearing aids, particularly for single sided deafness.

Web site: <http://www.entific.com>

Addenbrookes Hospital: Neurology and Skull Base Surgery Unit

Web page:

http://www.addenbrookes.org.uk/serv/clin/surg/neurotol_skullbase1.html

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