



# Unheard Voices: interviews with deafened people

Colin Ellis

Interviewed by Pam Blackman

British Library ref. C1345/23

## IMPORTANT

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**Interview Summary Sheet****Ref no:** C1345/23**Collection title:** Unheard Voices: interviews with deafened people

<b>Interviewee's surname:</b>	Ellis	<b>Title:</b>	
<b>Interviewee's forename:</b>	Colin	<b>Sex:</b>	Male
<b>Occupation:</b>		<b>Date and place of birth:</b>	1945, Harrow

**Date(s) of recording:** 13<sup>th</sup> March 2009**Location of interview:** The City Inn Hotel, Bristol**Name of interviewer:** Pam Blackman**Speech to Text reporter:** Julia Jacobie**Type of recorder:** Marantz PMD660 on compact flash**Recording format :** WAV 16 bit 48 kHz**Total no. of tracks:** 6 **Mono or stereo:** stereo**Total Duration:** 1 hr. 15 min.**Additional material:****Copyright/Clearance:** Open. © Hearing Link**Interviewer's comments:**

**[Track 1]**

*Okay this is Pam Blackman, I am interviewing Colin Ellis. On the 13th of March 2009. Its for the unheard voices project, and we're in Bristol. Speech-to-Text reporter is Julia, okay Colin. Could we start with some facts, your name, date of birth, so we have got it on the record at the beginning of the tape.*

My name is Colin Ashley Ellis, and I was born on the 23rd of March 1945 in Harrow, Middlesex.

*Okay. And your parents occupations? Do you know what they were?*

My father was a milkman, and my mother had worked in the factories during the war. And my father had to leave the milk around to go off to war in the second great war.

*Okay. Would you like to talk about your childhood? A little bit, some of the memories that you...*

Well my first memories of living in this terraced house in South Park Road Ilford, I was 3, 4, and I can remember certain things like going to see my Grandma in a place called Welwyn Garden City which was one of the new towns at that time, and I had to go with my mother on the buses which incurred 5 changes and we went from Ilford to Gant's Hill, Gant's Hill to Walthamstow, Walthamstow to Barnet, and eventually waited for a country bus to take us to Welwyn Garden City. It took us nearly 3, to 4 hours in those days. Then we would stay the night and come home. My grandmother lived in a house alongside the Great North Railway, and I had a bedroom that looked out and saw the steam engines trundling their way all the way up to Scotland.

*How often did you visit your Grandma, you have got a strong memory of it?*

Probably once every 4 months, and that, and then I used to go with my parents to my aunt's place which was called Stamps Farm at Layer Breton in Birch near Colchester, and they had the 70 acre farm that really was the love of my life. And I would stay up there for weeks,

*This would be in the school holidays would it?*

I remember going to school, my first day my mother bought me a lovely red hat. My first school was the Gordon School in Gordon Road Ilford, it was a lovely school. And I made a lot of friends. But my head master eventually left and went down to Sussex, where he retired. And it didn't, I didn't progress any further. Then my family, my grandfather of my father died, in Beacontree Heath Methodist church, and my grandmother died and so my father and mother decided they too would to move Welwyn garden city, because that's where all my mother's family was.

*How did you feel about that, do you remember, you knew Welwyn garden city but it meant changing schools?*

I really wasn't pleased but I didn't have any options. And I had gone to a new school when I was 8, which was really in a tough area of Ilford and was the old seed. And we used to have benches and old desks and I always remember sitting there with this man with a cape, who had this rubber in his hand, scraping the board. My mother had gone back to work and she bought me one of the new fountain, ball point pens which had a spring in it and I sat there one day very bored of his lesson, and I started unscrewing and all of a sudden this pen disassembled it shot up in the air. The next thing I remember was this thing hitting me in the back of the head which was the board rubber which was in them days allowed. And it really hurt.

*So in a way...*

The school was separated it was a boys school and girls school, and in them days you went from 5 until 8, and then 8 to 13, and then 13 and I really was looking up to go to the next one which was a beautiful school up in Ilford, but that time my family moved. I reverted into a different education system which was 5 to 11, and 11 to 16. So I then went to live with my aunt and uncle for a year in their house, and I went to a school called Applecroft School, Applecroft Road, Welwyn Garden City I had some very lovely friends.

*Why were you not with your parents then?*

We was, we moved all the whole family moved, but in them days to get a house in Welwyn Garden City, my father had to work there for a year before you got a house on the development corporation. And he couldn't travel all that distance on a milk round so my aunt very kindly leant us 2 rooms because her children had left so we lived with her for a year. During that we had for a severe winter, and my father being on the milk round served with bronchitis I can remember he was at home for about a month later in bed very poor.

[08:27]

*Do you have any brothers and sisters?*

No I am an only child.

*And it sounds as if your aunt her children were older, so you didn't have many cousins or the same age?*

No I am the youngest, and the amazing thing about it is we still are very close family. My mother's brothers and sisters, she came from a family of 8, and 2 died but she had a very elderly brother, an elderly sister which we went to live with, a younger brother and 2 sisters and then she was the youngest. And they all had one child and as cousins we still meet today.

*When did you leave school?*

Well I was lucky, because of the education I actually passed my 11 plus I wanted to go to Hatfield technical school because I want to go into engineering on the farms and buy farmer but my family couldn't afford it. And then you got chosen like you do today, to go to schools, and I lost out and instead I went too brand new school that opened that year called Welwyn Garden City High School. And then I studied there for 5 years, got my O Levels. My father was very good because he knew what I wanted to do, but he couldn't afford me to go into farming because the family farm of my aunt was so small it could only support their family. So I decided I would go into agricultural engineer, my father found me apprenticeship.

[10:37]

*We can always go back to this stage in your life I just wondered if you want to move on and talk about your adult life. The point at which your hearing loss first appeared?*

Well of course I have had a very full life, and there's a big gap in the middle which took me from agricultural engineering into construction engineering, with big heavy cranes and travelling the world, and then of course moving on from there I got made redundant and went; had my own business. Then I went into 3M, American company which was absolutely the best job I have ever had in marketing for 10 years before being made redundant again. And then at the beginning of that I started to lose my hearing. I noticed my left ear was considerably down, and because I was...

*Can I ask you how old you were then?*

I would be about 45.

*Okay. So that's about 15 years ago is it?*

It would be about 1990. When I went to see the consultants in Windsor he told me that I had a growth on the anvil in my right ear, and that I needed an operation. However, this was in the October, by December I had got a cold which was going round as a virus then, typically you went to the doctors who said sorry, just take the tablets. From three weeks the cold went to flu, you go to the doctors again, and the doctor says sorry, it's a virus that we don't know anything about, keep taking the tablets. Another three weeks and I my head was streaming out with cold I had got a form of meningitis at which time the doctor said oh yes it's serious, I am going to give you some antibiotics, and we're going to give you some nasal medicine of which I did and what consequently happened was that all my head and sinuses in my head were slowly healing, but were congealed with the cold and when I came out of it I lost my hearing in the left ear completely.

*So this was as a result of your GP, giving you the wrong advice basically?*

Absolutely

*But you had already seen a consultant before that, hadn't you?*

Yes I had.

*Were you referred to the consultant? Previously?*

I was lucky because I had for a very good job in 3 M, and I was on BUPA, private medical insurance. And so I was able to get an appointment through my doctors to see him. However I then had to have a scan which at them days cost about £500, and was very rare. And he diagnosed this growth on the anvil which he put down to a family lady's illness I know that comes from my grandmother who was totally deaf, I can remember her not recognising anybody just patting her little dog called Jump. So obviously it was hereditary, but when I went back to see him to tell him that I lost my hearing, in the left ear he would not operate because he said there was 10% chance that if he operated it would go wrong, therefore I would be totally deaf.

*That it would affect the right ear then, is that what he was saying? If it didn't succeed, ...*

If he operated on my right ear and it didn't succeed I would be totally deaf.

*So you initially had a problem in the left ear, and then it moved to right ear as well? Was it the same problem?*

No.

*Was it a result of the virus?*

The left ear is a result of the virus.

[16:13]

*So, how did you feel at this time? Can you remember your feelings? Its quite a sudden loss wasn't it really?*



It was but I had 50% hearing in my right ear I could get on with life I could answer the telephone I could do the computers which were very new to me then. So I got on with my job but unfortunately, in them days 3M were shrinking because of the world trading and I become redundant for the second time in my life which was a bit, because every hundred jobs you went to apply for, you maybe only got 10 opportunities and maybe only three for an interview to get a job.

*Was this in the recession of the 1990s?*

This was 1989, 1990 yes.

*3M was that a company, when you refer to 3M, is that was it the company that you worked for?*

3M UK limited is part of the 3M, American corporation which is one of the top 100 companies in the world, and is an international trading organisation that in invents products and had at that time over 6,000 products from video tapes to scotch pads, to post it notes, to resins, all sorts. In fact were the first people to invent joints for legs or arms and they were had a medical division up at Loughborough which supplied all the hospitals with tapes and various types of adhesives.

*How long were you unemployed for at that time?*

I wasn't. Because my brother-in-law had a business in new Covent Garden flower market, he was going through a very tough batch he had no idea about business management. And was really torn apart and so as soon as I left 3 M, I was donning my overalls going up at 4 o'clock in the morning to help him delivered all the Christmas flowers and baskets around him. And virtually help him manage a business of which he had little idea how to run. Eventually, the people that were chasing him got to know me and I eventually bought into the business with my redundancy money, and we become partners. And we traded up in new Covent Garden for over 10 years, which was a very good time and a very good business at times. But gradually the market began to shrink. Our business began to suffer, and so in 2000, the new Covent Market authority our lease was over, and they demanded an extra 10% for new leases on the land and also the portorage we just said enough is enough and pulled the plot and walked out of them and just closed the business.

[20:38]

*At that time in 2000, how was your health? How was your hearing?*

My hearing wasn't too bad, it was still holding up. But my health, I can tell you, that was the hardest 10 years of my life. Because I was getting up at 2 o'clock in the morning, working up in cold conditions which was not ideal, but was one suited for cut flower when we were dealing with tropical plants, wasn't ideal for us, we wore very warm clothing, but as soon as you went outside you were in temperatures like 30 degrees, which was just made you uncomfortable. And then after going home, I had all the paperwork the management of the business to do, all the money to put away, the bills to do so I wouldn't be getting asleep until 4 or 5 o'clock before I had my dinner then go to bed on a full stomach and quite honestly that really I suppose was the start of the deterioration of my health.

*You travelled up to London each day, where were you living?*

I live in Ascot, have done for over 30 years. And I used to leave at 2 o'clock in the morning, and I was able to employ my younger son at the time, who wanted different way of life and we travelled together. We worked together, which was the most enjoyable part because I was able to teach him about management and about business.

*Okay. Has he gone on to set up his own business since then?*

In 2000 the business began to suffer, and we couldn't really go on the way we were. And so he left and started up his own business, in building and was very successful. And he helped close the company. Then I was at home, so I was able to help him with his accounts and that's on the computers. He went on, he was married, and went on to really get a good business until 2001, sorry October 2000 when we had a phone call to say that his marriage was on the rocks in a big way. This was...

*Shall we have a break? Shall we have a pause? Is that okay.*

[End of Track 1]

**[Track 2]**

*Okay you were telling me about your son had reached a crisis with his marriage, do you want to talk anymore about that?*

Yes I can tell you more because this is a very important part of my life now. We got a phone call to say his marriage was on the rocks, and it was a big sad time. He went off and tried to commit suicide which we didn't know about, it was only my other son his elder brother that got to him and his friend. He was admitted to hospital, but was in such a fury and rage about this that he walked out of the hospital. And we had his 2 sons at the time, because his wife had walked out of him. And left him totally, didn't even know where she was, would not contact him everything. And he did everything in his power to find her including his in-laws. I had to phone my brother-in-law who had a relationship with him, on a sports theme. And he dropped everything on a Sunday afternoon, came across took him out for a curry, and calmed him down. From that point, we were able to turn him round and put him in the right direction and get him away from this horrible thought of him committing suicide. This meant that we and my wife had to have his 2 children to look after, they were 4 and 6. And we had to allow him to go off to work, so that he could earn the money to pay for his mortgage and all the bills. This went on for about 6 months, and it began to work out he tried every way to reconcile with his wife, but she would have nothing of it.

*She didn't want to look after the children? Is that right?*

Yes she completely ignored them, she wouldn't even talk to them this was over Christmas. Something that I believe was a break down in her mental state, which never was investigated or discussed or doctored, but I think she had a mental break down she walked away completely from the whole family unit. What happened then was that we were looking after the children on a basis of Monday to Friday, we would take them to school we would bring them back from school or the people that were looking after the younger one, we would feed them, clothe them, bath them they would stay the night with us and he would call in on his way home from work see them to say good night. And on the 21st of April, he came in after a very exhausting day working at London airport, on a very big project, but which he was quite proud because he was now foreman of the whole project, and he was a bit tired. And he said I am going out, sorry, he got a phone call from a friend of his who was having marriage problems

too, he said sorry I wasn't really going to go out tonight I was tired but seeing as you have got a problem I will come out we can talk. He said night Mum, night Dad, night boys and he walked out the door he said I will see you on Sunday. That was the last time we saw him. Because at 12 o'clock that night, we got a phone call to say that he was involved in a road traffic accident right outside our estate, and that he was probably killed out right. And he was a passenger.

*How old were the children? Still 5?*

They were 4 and 6. And we were devastated. And you see all the stories now, about you should never lose a child, and it brings it home all the time. You should never lose a child. My wife has never got over it, its taken me 7 years really. Our memories are kept a life with those two wonderful boys who now have grown up to be 14 and 12 and have a very loving relationship with us. But we had to bite our tongue, get hold of my daughter in law, on the night that he was killed, to tell her that her husband had been killed in this road accident. We had been notified by my son my elder son, who had he had been one minute earlier, would have been the car that they smashed into as he was going to work on night shift in the post office. So the whole family has been decimated. And we have had to move on and this really is the start of me losing all my hearing.

[06:29]

*Do you think, is it connected? Was it connected?*

At the beginning I didn't think so. But being head of the family I took everything on shoulders. As I say we looked after the boys, we had to gather momentum to bring the wife back into the fold, and we wouldn't release the children. We were at crossroads. At 55, sorry, 56 we were at the crossroads where what do we do? Do we take the boys on to live with us, and bring them up and we were getting on in years, or do we bring the wife back in and their mother and nurture the relationship slowly and eventually hand them back to her? Which is in fact what we did. After some months, 8 months, they went back to their mother, so we had to bite our tongue over lots of things but she has been fairly good in that they come to see us every Christmas, and stay with us, they come on holiday for a week every year, and come to see is nearly every 4 weeks and stay for one weekend. And this we have carried on, and we are so grateful for that. So something good came out of it in so far as their mother returned because

they had not seen her for a while. The only thing that really come at of it they have grown to be two loving boys and I don't think its through really their mother or their step mother, as we look deeper into the relationship of them although they love their mother dearly. But for us, it was the only way of carrying on and seeing those boys. If we had gone against her we would never have seen those boys, they hat been part of are family. Although she has changed her name they have remained my son's sons, and will remain that throughout their life.

*Do they live quite close by?*

Well not really because they live 5 miles away compared to my other son and his family who live just round the corner. 5 miles is nothing in this world.

[09:36]

*No, so at this time, your problem with your hearing, did it suddenly deteriorate? How much hearing did you have at that point?*

I was still the same at this point, and a year after we lost my son, my good wife like all your ladies, was still grieving, and I was doing everything I could to alleviate the problem, so in the February I decided that we would spring clean the kitchen, and I went up a ladder and was hoovering away getting all the dust away, all of a sudden the ladder broke in two. There I was laying on the kitchen tiled floor, blood coming out of my arm, my right arm was broken in 5 places. She was panicking, but fortunately I was awake, and I had been on a St. John's Ambulance first aid course

[End of Track 2]

**[Track 3]**

... so I was able to tell her to ring for the ambulance, tell them I was conscious, that I had broken my arm seriously. Ask them how long they would be, which she did. She came back, put a pillow under my head, tried to move me of which I resisted. My mother-in-law who was living with us at the time, came down and helped and comforted me. Eventually the ambulance came, sat me up right, comforted me,

*You must have been in great pain?*

I was in great pain

*And you were conscious?*

And I was conscious but we have a problem round our way with the local hospital the first thing I said is where are you taking me, I hope its not Wexham and Heatherwood Hospital, it has not got a very good name.

[End of Track 3]

**[Track 4]**

Right, they said no we're going to take you to Frimley Hospital, which was fabulous because it is actually half army and half NHS. And I got there it was all the army staff on duty that day on the Saturday. And I lay on there and they really looked after me. Unfortunately, they were unable to do anything that day and the next thing I knew was that I was in an army ward next to one guy who had come back from Bosnia who had lost his legs, and another one who had jump out a plane and juddered his shoulder and another one who got injuries as well. There were all these guys serving our country and poor old Colin laying there with a broken arm.

*Did that put things in perspective for you?*

It did really. But the treatment I got there from those people was only the best, I can only say that they do look after our soldiers, and I had the best of treatments and they soon put me right. Although I had to have 5 operations to get my arm right, eventually it was put right, and has remained okay until this very day when things have started to get a little bit twisted again. That accident also contributed to the stress that my body was taking, and it was a year later that I noticed that going down the road, in the sunlight, my eyesight started to get a daze and it was like shutting down like a migraine. This happened several times. And we went down to Dartmouth for Easter, I really lost it completely, loss my balance had to lay down for a week, for a day.

*Can I ask you was it your balance that was the problem, or was it your eyesight was deteriorating?*

I had a daze like a white sheet coming over my eyes, and I could hardly walk. My wife thought I was being funny that I didn't want to go shopping I went down there I could hardly stand up. So I came home to our holiday home went to bed and slept soundly for 24 hours before I felt better. Then I began to get the looks from my wife who didn't know really what was wrong with me. This carried on for a couple of months, and then in the April I was watching my grandson play football, I started to lose my balance. My wife told me to sit in the car and watch the game from the car which I did, I lost consciousness, was violently ill, almost felt out of the car. They come running along they propped me up, and promptly took me home.

I couldn't stand up, and I lay on the settee for two whole days, the weekend. If I tried to get up I just fell over, I completely lost my balance. On the Monday I went to see the doctor, and with the help of my wife, and a wheelchair. And the doctor was not my normal I had to see a locum she said "oh dear, you have got a ear virus" and she gave me some steroids. I went back home, with these steroids, lay on the settee, until the Thursday. I still couldn't move. I was violently ill, my wife was worried she called the ambulance. This time, they took me to Wexham Park hospital and I was admitted straight away. I couldn't stand up I lay on the bed. They looked at me they immediately gave me more heavy steroids, and I was on 28 tablets which just went down and up again. And I couldn't sit up. Couldn't see, my head was swirling I just couldn't stand up at all I couldn't get out of bed. They gave me treatment they took me down, scanned me, they gave me the big scan, they gave me hearing tests, but it couldn't hear anything. I was completely deafened.

*What was their diagnosis? Was it that you'd had a virus?*

I was in the hospital for over a week, eventually they took me off of the tablets and I was able to sit up and get up walk round a little bit. They looked at all the graphs, the X-rays everything, they couldn't find anything. The Spanish consultant said to me I think that you may have Meniere's disease. And there's nothing we can do for you here at this moment. I want you to go home, because you're taking up bed space. So I was taken home. And I went back to see him a month later. What he didn't tell me was that on the X-rays was a blur on my head, and when I went to see him he explained that he thought I had got a tumour, he wanted me to see a consultant from a London hospitals. And get a second opinion in the new scanning machine that had been installed at Heatherwood. This took time and I now I am panicking because if I have got a tumour I don't want to be sitting in around I want to know about it. All to we had a few words with the consultant it wasn't long before he came and saw me and took me in and looked at me. And confirmed that it was just a blur on the X-ray plate and I don't have a tumour. This came as great relief to me and my wife although we still didn't know why I lost all my hearing.

[07:56]

*What I am thinking is your wife has obviously been a great support to you?*



Yes she really has a block because after I seen the consultant he sent me back to the audiologist in that a had a young lady who was well up on all the new technologies so she taught me to lip-read. From lip-reading classes from which I went to regularly after 3 months, she said I am going, there's nothing more I can do for you, however I am going to recommend you to go to LINK. And also, I am going to put your name forward to go up to Guys and St. Thomas' for a cochlear implant to see whether it's possible. I didn't know anything about this, or where to go for any help, even to social services or anywhere else. I was a dead end. I didn't know what LINK was, and it was going to take time. But eventually true to the word I got a letter to say come to St. Thomas'. They made no promise on my first day I went back regularly every 3 months and had various tests. In the meantime, I got a letter in the January of 2007 saying that the trust had approved for me to go down and my wife to Eastbourne. The day that we were going on the Sunday, my wife asked was it really essential, but having been told that I was facing redundancy on Friday, from my company, I was really feeling that at my lowest ebb and the feeling that I was going to a nice hotel in Eastbourne and didn't know anything about it, was that I was going to escape from this horrible world.

*This was only a couple of years ago? That your first involvement with LINK? Is that right?*

That's right we went down in March 16<sup>th</sup>, 17<sup>th</sup> I think it was, on a Sunday, and as we got to Eastbourne it was black and cloudy and it was snowing. And we went up into the hotel, we was met by a lovely lady and her assistant and we met another lady who was jovial and also lost her hearing, called Janet Sanderson.

*Janet Sanderson. So Janet helped you a lot I imagine did she on that weekend?*

We sat down to dinner on the Sunday night on a table specially for us, with 5 other couple all with are heads down not talking to each other feeling very sorry for ourselves. I had a young man of ethnic minority sitting next to me, and as I studied body language in 3 M, I noticed that he was only eating with one ahead and he got his other hand down and he was very saddened. And he looked at me said my name is Paul, do you drive? I said yes, my name is Colin yes I am lucky enough to be able to drive do you? He said no. I am too frightened. We went to bed that night, feeling very saddened but optimistic of what we may find. And we went down on the Monday morning, where Jenny Knight sat us down, and explained everything. And for the first time, Janet Sanderson told the story of how she lost her hearing, and which had resulted in

her losing her job, nearly losing her marriage and the real negative parts of her life. This brought home the real identity to me and I knew this was the time when I was going to be very emotional. We finished the talk for lunch, I went straight up to my room and cried my eyes out. Stupid as it may seem as my age but at last I could see I was not a lone. My wife asked me what I was, said I was going outside I needed to be alone. It was snowing profusely I went outside she said wrap up I went out there, crying my eyes out in the cold wind, battling away, I walked down to a hut which housed the seats in summer, and stood behind it and took some deep breaths and eventually walled down on the beach towards the shore. It was really dark, snowing and I am not religious but it was lack somebody said to me look down, look on the beach. I looked down, and there was bright blue shiny pebbles and they were splattered amongst all orange and white ones, and different colours and I couldn't think why we're near the chalk cliffs why blue stones were there. And its just as if somebody said to me, Colin, see these blue stones, they represent disabled people in our community. In front of you is a rare stone, picked up, I picked this saw this stone picked it up and turned it over and on it was two very large chips and the voice said to me, look you see those chips, yes they represent you. You have lost your son, and you have lost your hearing, but you have had a lovely life, you have travelled all over the world, you may lose your job but you have got a lot to offer, a lot of experience, go out and help those disabled people. As I looked at that the sky's opened up the sun came out and it stopped snowing I picked myself up went inside the hotel, saw my wife, gave her a kiss, had a large scotch and that I can tell you is the change of my life. Of which now I have devoted my time to helping others with this disability.

I am going to stop just for a pause for a break.

[End of Track 4]

**[Track 5]**

*There's two things I would like to ask you out of what you have just said, are you now religious is one question, as that moment changed the way you look at the world?*

I wouldn't say I am religious, I certainly have walked on the borders of it. And was interested with Methodism, and my whole family has been, but like all of our generation, I didn't have the time or the what can I say, the will to go regularly to pray. But, I did go to church at Christmas time, and during harvest festival and when I had my business up in Covent Garden, supported them with Christmas trees and fruit and vegetable and festivals and we had the most glorious of festival. But not really, I wouldn't say we go through it although we got to the ceremony of marriage and deaths and births and that. So this came as a real shock but on my desk at work, somebody had given me the story about Jesus walking across the sands that had got to me in a way that this was really my story, and I can't explain it, I could tell you that the weather changed, have still got those stones, and its my story and its my way forward in getting over this disability and helping everybody and anybody that comes and asks for help.

[02:25]

*Could you describe a typical day now, when you are, how much time you give to charity work, you know you're no longer working are you?*

Well, although being 63 with disability there is still discrimination out there in the market place, and all to I have got a degree in marketing, and a lot of experience, people look at me with my disability, and turn me away from the jobs. Although I have applied for a job, really nobody wants me. And so, I have devoted now all my whole time to being semi-retired and helping the charity. 18 months ago, I was asked to go and form a new club, called the Bracknell Deaf and Hard-of-Hearing Club which had been formed by four members, I put a lot of weight behind it, and now we have nearly 30 members on a regular basis come in every 2 Monday afternoons in the month and its great fun. But, its my charity now, and all of a sudden, for unknown reason, I wear my heart on my sleeve, and I was asked to attend a meeting within the village from the police, Thames Valley Police and the local council. When I went there, one evening, the policeman started spouting on, when it came to question time I put my hand up and was promptly put a microphone in my mouth, I asked him if he wanted all

the community to attend this meeting on crime disorder ASBO, he said yes he said I asked him why he had not got a Palantypist or a person that did BSL, or somebody that did language or even put text up on a screen so that people with disabilities and deafness could actually know the whole meeting was about. And he put his hands up and admitted that he and his force had made a big mistake. Three weeks later I got a letter asking me to attend the strategic independent advisory group up at Kidlington in Oxford, to the Thames Valley Police. And be part of the strategic diversity group and advise them on disability and in particular, hearing and I have carried that job through now for 18 months. With great passion. I believe I am now making breakthroughs into the police work that we're doing, and they starting now very slowly to recognise, understanding and working with deaf and hard-of-hearing groups.

*I mean it sounds as if there's a lot still to be done with institutions, and the medical profession. Looking back, do you feel, what are your feelings about how the medical profession has dealt with you?*

I think that the NHS has a lot to learn. However, it is guided by the Department of Health and Governments. Likewise social services have a lot to learn, and if these two can't bang their heads together, and get it right, then people attending hospitals and audiologists have really no chance. The social services can only do what they are instructed to under the 1948 Act, Section 24 where they can only recognise three groups of people; loss of hearing and sight, sight blind, and another one which I can't remember at the moment. They don't recognise the eight groups of various people adults that have deaf, sorry, that have hearing disorders, like blind, deaf children up to 16 who are deaf, people with APHL etc. etc. they don't recognise them. Likewise the NHS has no statistics in this country for how many people have hearing disorders and they seem to be working on children through the University of Manchester section for looking at problems with children coming through with deafness. And leaving the adults to find their own way in life. If it wasn't for the special audiologist helping and the very good work that LINK as a charity gives, then there is no hope for people. That's why it's so important that there are volunteers that go out into communities and keep pressing for them to change.

*Were you pleased at the merger of Hearing Concern and LINK, and do you feel that will have an impact?*

There is a feeling that in this world everything has to change, and this something I learnt a 3 M. Its a bit like tumbling grass on a prairie when it keeps on changing, you have to take the good bits out of it. So when I learnt about Hearing Concern in actual fact I was really quite pleased because their experience of 90 years has to be something that we can learn from. And yes, we are both aiming at the same groups so I think there is a great opportunity in the future, and I can only say that this year has to be the way forward.

[10:30]

*Can I ask you, to tell us a little bit more about the Cochlear Implant operation. You mentioned that St. Thomas given the go ahead but what happened after that, how long did it take, and was it a life changing thing?*

It took two years of tests before the consultant, Mr Fitzgerald, sat down with his team, looked at all my statistics and all my tests to say yes I was actually the right person to have a cochlear implant. The cost being £38,000 to the NHS is something that has to be borne in mind and with postcode lottery I was very fortunate that Berkshire NHS actually funded it for me. The date you are given you go up; you listen to the nursing staff they give you a run down of it. But one of the good things was I that been on a course to be an outreach volunteer, and I had to go to Scotland; I met for a young lady who just had her implant. She gave me a lot of valuable advice, about going into hospital and what I should do. Which I took and was very grateful for. Because what you have to remember is that when you are talking to the consultants, they are very good they understood they look at you in the face, they talk slowly you can understand them. But in actual fact when you go back into an ENT ward, you're actually going back into a communication that is natural and so; the first thing they come and ask you is what's your name? And of course you can't hear.

*Are you saying that the ENT departments of the hospitals are not well trained?*

No I am not saying they are not well trained but ENT looks at all the problem with ears, nose and throat's and so losing your hearing is just a small proportion. So, they are more used to talking to patients and I can only praise Guy's hospital as the best hospital I have ever, ever been in. It was so clean, and during a time when there was some scaremongering about germs

and things like that, but never at Guy's, because they measured everything, even to falls I saw this myself first hand

*This where you had your cochlear implant?*

I did indeed, it was. Three hour operation and it was very good. And I was able to come out the next day and travel home. I was asked to attend a week later, however unfortunately I had an infection in it, I was only the second person in 60 of that year to have this infection. So the consultant took great notice of it. And before I knew it I was back in Guy's for another 10 days, until it healed properly by which time I had to go back to St. Thomas' to have the actual transmitters fitted and we get my first tuning. This was my first hearing of any sounds and the first thing they asked me was whether I could hear my wife I said yes she sounds like Minnie Mouse. And they tuned it, and we walked away back home for the first time for another 10 days, and all I could hear was clip clop, clip clop I looked round and it was my wife walking alongside me. Then we walked out into the street where there was this great big roar, that was traffic. Gradually, over the course of months, I gained it, listening to birds, listening to woodpeckers, listening to running water, looking at television, being able to lip-read at the same time. Although sometimes when you are in a group, it can be very difficult and I have to revert back to lip-reading. And to having a piece of paper and pen with me.

*Can you explain is it like learning again how to hear? Because I know it takes time, doesn't it, is that I am just interested is that a very tiring at first?*

Its very different for everyone, because we all suffer with something different. And for me I had only lost my hearing for five years so my communication skills and my word of English was very still very clear in my mind. So I was able to, and my first test when I went there before I had the cochlear was I only got 38 % on the screen looking at a face, and nothing without a face and hearing a voice. The first time I had my cochlear I got 60 and 30. And on my last achievement I achieved 98% hearing, looking at somebody talking to me, and 90% with no face but just hearing. That is something that St. Thomas' has never experienced. However...

[End of Track 5]

**[Track 6]**

However, for somebody that has lost their hearing for a number of years, it may have a different effect and could take longer. So yes, there is a factor in it and it depends on how long you have really lost your hearing and of course, for a child that we used to see coming up at St. Thomas's age four or five its an absolute blessing and this was what really gave me the little laughs and that, seeing this girl so happy dancing and skipping up and down with here new fundamental toy, in wavy locks.

[00:51]

*Can I ask you how do you feel, looking ahead and what do you think of the future now?*

I think we have got a lot of work to do as a charity, and we need every resource, and help so that we can actually get the true picture through. It is very common when you get out to hear that another 10 people in six months have lost their hearing, within your area. And they need help. And we need to get to institutions to change the way that they accept people with us and of course we need to change the act. But it's slowly happening, and the more we stick together the more we push. It has to be better. And I think that's true in the area that I live because we have worked very hard at it.

*Is there anything else that you would like to either return to, or talk about that you think you have not had a chance to talk about today? Maybe not to do with anything we have talked about even.*

No I would just say to anybody that has lost their hearing, don't give up hope. There is a light at the end of the tunnel, and there are many means, not actually known but there are people out there that can help to make your lives much more enlightened and to help you deal with this disability. And its really just a question of word of mouth, and going and just being honest and asking for their help.

*Do you go on holiday very much, do you travel? I just wondered if that's been something that you have done less of that you're now able to do*

Unfortunately I don't travel much these days, although I do drive my car and really its the work that I get involved with in the Thames Valley and also down to our holiday places down in Devon. Because I have travelled all over the world so really I have no need to go and that, although it would be nice to go in the sun as we get older spend a little bit of time there so one of the things that I think for me is that I tend not go out so much in the evening times now because once I lose cochlear implant then I am a liability because I cannot hear so I tend to keep at home at night time. Or within a safe area.

*Sorry is that because, are you saying you worry about being attacked? What do you mean by losing your cochlear implant?*

Well the batteries only last for so long, and while I carry batteries with me, you never know and if you trip over, and lose your cochlear then really you could be vulnerable and so, a tend to take everything on the safe side now.

*I am wondering whether we should finish here, would, is there anything else you would like to talk about? Shall we stop? Okay we'll stop at this point.*

[End of Track 6]

[End of recording]