



Unheard Voices: interviews with deafened people

Vivienne Keightley
Interviewed by Stephanie Pennell

British Library ref. C1345/55

IMPORTANT

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Interview Summary Sheet

Ref no: C1345/55

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Keightley

Title:

Interviewee's forename: Vivienne

Sex: Female

Occupation:

Date and place of birth: 1959, Derbyshire

Date(s) of recording: 31st May 2009

Location of interview: The Westminster Hotel, Nottingham

Name of interviewer: Stephanie Pennell

Speech to Text reporter: Lynn Allen

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[Track 1]

This is Stephanie Pennell interviews Vivienne Keightley on Sunday 31st May 2009 for the unheard voices project at the Best western Westminster hotel in Nottingham. The speech to text reporter is Lynn Allen.

Vivienne could I please ask first if you would say your full name including your maiden name and spell it if appropriate.

Right, my full name is Vivienne Vienna Keightley which is V-I-V-I-E-N-N-E and Keightley is K-E-I-G-H-T-L-E-Y. My maiden name was Vivienne Plummer which is double M.

Could you give me your occupation or former occupation?

My former occupation before I lost my hearing was a secretary. I have not worked since then, only in voluntary work for Hearing Concern LINK and Hearing Dogs etc.

Thank you. Can you tell me where you were born and the date of your birth?

My date of birth was 30th May 1959. And I was born in Chesterfield, Derbyshire.

Could you tell me, please, your father's occupation?

My father is now retired, various occupations. As a young man he was -- he served in the army in the Armed Forces and then a couple of clerical jobs before he had to retire early due to ill health.

Thank you and your mother's occupation?

My mum didn't work until sort of middle age I suppose and then she worked as a home help until she retired at the normal age.

[02:42]

Moving on to some background now. Can you tell me, please, about your family background - about your grandparents?

My grandparents to my father's side I don't really have much of a history because unfortunately my father lost his mum as a teenager, so I never met my grandma on my father's side. I have only ever seen a few old photographs of her. But I can surprisingly, even though I lost my grandfather when I was only 5, miraculously I have stored that memory of the last time that I saw him and I can still see him now you know in my mind's eye, in the clothes they used to wear you know with the sort of mandarin collar and the waistcoat and his pocket watch and quite distinctive in the fact that we went to visit him one afternoon, and went home and then in the evening a neighbour came to tell us that he had passed away. And so although I was only 5 at the time, as I say I have stored that memory because it was the last time, you know, I have not seen him for all those years. And I see him daily now in my dad, because my dad looks the same as I can remember my grand dad did at that age. So, on my other side, on my mum's parents' side, we had obviously a lot more involvement with them, with losing the other grandparents early. And spent lots of time with them, Christmas, birthdays. They lived quite locally so they would visit quite a lot and even into my teens you know I still used to go and stay there on a weekend and stay with grandma and grand dad and be looked after and things like that. And I think when I lost my grandfather I would possibly say he was the closest relative at that time, you know. More so possibly than my Grandma. And I was quite devastated by that, you know, I really really missed him. And even now, even though I was 50 yesterday we have made no secret of it today, I was 50 yesterday and I still have a few tears on the 4th November you know the day that my granddad passed because I was very, very close to my granddad and there was little bits -- there was always little bits of friction in the family with grandma with favourites and grandfather we were all exactly the same. So I always loved him that little bit more for that because there was never any difference. And of course, when my grandfather did die, passed away, my grandma was then on my own. I was possibly still the only grandchild that used to visit on a regular basis and she passed away about 8 or 9 years later. So, I have no grandparents now. But very happy memories of childhood, you know, and days out at the seaside and things like that with that set of grandparents, yes.

And would you like to talk about your parents?

Uh huh.

Tell me something about them?

My parents. I will talk about my mum first. Both my parents are still alive. Unfortunately, I am going to say unfortunately I don't want it to sound too bad, but unfortunately as I mentioned earlier, about my grandmother with the favouritism, unfortunately it didn't miss a generation and there was always favouritism within the family from my mum. And to my brother. I have one brother. So, I don't want that to over shadow the fact that I had what I would consider to be a normal childhood, an average childhood, but I was always very much aware of the fact that no matter how hard I tried I always somehow just seemed to miss the mark. It was never quite good enough, do you know what I mean? That kind of thing. Still, it still happens to this age. My brother is 54 this year. And we have a few jokes about it, me and my brother and I call him Saint John, because you know in the family rounds he has never been known to do anything wrong in 54 years, it is quite a thing to live up to that isn't it? So, but having said that I wouldn't say it was a big issue. But it was just something that I was aware of. I think it possibly stems from the fact that grandma was the same with my mum. And you know, I suppose if you have lived with a certain situation you will either go the same way, or you will steer yourself the opposite direction. So, there was always that little bit of friction. But I am not saying there is no love there or anything like that, but it is just an awareness that various episodes through my life it wasn't quite good enough you know, you could have done better. If I got 95 right in a test out of 100, you know, it would be questioned what were the five that I got wrong you know that kind of thing, that kind of balance. So there was always that little bit of tension there growing up, even as I say into the years that I am in now. My dad is very much on the opposite end of the scale. That very easy going, very you know as long as you have done your best that is all anybody can expect of you, that kind of thing. Take no notice, don't bother about things you know. So they were very much opposites. Which is as a child sometimes it is hard to juggle, there was no middle ground do you know what I mean, we got a fierily one who expected perfection and one who was very, very, very laid back and everything was okay. You know and there it was - no sort of middle ground, but having said that, as I say, normal things happened in the family. You know, I am not going to pretend that I had an unhappy childhood, but there was just that little bit of.... I felt a bit out of sorts with not being able to get the balance sometimes as I was growing up.

[10:51]

I was going to ask you about brothers about sisters apart from John. Did you get on very well with John apart from this sort of slight rivalry you had in a way?

Surprisingly even from a young age, I never projected that on to my brother, because I knew, even as a youngster, that it wasn't anything to do with him. And he never took advantage of it, in fairness to him. I dare say he could have had some families, especially with just the two siblings as well, where they could have exploited that situation. And we have never had that. Mainly, possibly, because his personality as well is very much leaning towards how my dad is, that he is very laid back. So if things were happening he was oh things are happening that sort of thing so there wasn't any problems any issues between myself and my brother as a result of that. We just knew, we just accepted that that was the situation and as we have spoken as we have got older, there are certain situations that I have related to him where I don't think he was actually aware sometimes of what was happening. So, there is no issues at all really between myself and my brother in regards that.

So are you actually close?

I think we are close in some ways, even though we don't see an awful lot of each other. I know that if I had a problem I could go to him. But, again, he is very very quiet and very laid back, and I am also used to dealing with things from that young age, of things happening, I am used to dealing with things on my own so I perhaps don't go to people as often as I should or I could. But I do know in the back of my mind that if I needed to, so there is a closeness there even though there isn't seeing each other on an every week basis or whatever. Yes.

[13:32]

Yes. Do you have a partner?

Yes, yes. I have been married for 22 years in August. Melvin, Melvin is my husband and we have two daughters Nicole and Nathalie T H.

Will you tell me a little about them and your family life?

My family life, yes. Nicole will be 21 in October. I will start now and go backwards if that is okay? She is at the university of Birmingham and she is in -- she is just coming to the end of her second year in her joint honours for English literature and modern history. She is enjoying it far too much. And spending all our money. But yes, seriously, she has worked very hard through school and he is enjoying herself very much. The little bit of independence now living away from mum, although she does forget that when she comes home and drops her bags in the kitchen and expects everything to just pick up as if it was yesterday when she was there. When I am going to go right back to the beginning now if I may. When she was born she was planned, she was really wanted, and everything and everything was fine. I had a lovely pregnancy with her and she was a very very happy baby. I really could not understand all the other mums, you know, who were moaning about all the problems that they had because she just used to smile all the time. She didn't sleep a lot, but at least when she was awake she was always very happy and she was a very, very easy baby. And obviously apart from the trauma of the problems that I was going through with my hearing loss, set this aside for one moment and everything was just, you know, fantastic really. She was the second grandchild to my mum and dad. And everything was just brilliant really, that is the best way I can describe it you know, I can just see it now you know she was just so beautiful. And really wanted and although obviously again with a hearing loss problems there was nervousness and fear, but she was a healthy, happy baby and she was 3 and a half when I had my second daughter, Nathalie. Horrible pregnancy, a child that never stopped crying until she was about 5. I only needed to lip read one word with my second daughter and that was why, it didn't matter what you said to her as soon as she could talk it was all why. Why. And then we developed to but why. Until she started school. They both went to the same primary school, local village school church of England, and stayed there had until they were 11. It was a very small community school. When Nicole first started there were 85 children in the school between the ages of 4 and a half to 11. So it was very much a R nice, it was like an extended family. You know, 3 teachers up there and a head teacher. And it was marvellous they had a really happy school life up there. There was never any tears or anything from either of them about wanting to go to school. They just didn't like having 7 weeks off in the summer, you know. They loved it. And both of them were known to put their hand up a few times and say, mum, instead of Mrs Whatever. We were very much involved in the school, because we went to church as well and my daughters went through Sunday school at church and it was the church school, so there was a good relationship there all round you know, that the teaching

staff went to school, went to church and everything and we got involved in anything that was going off in the community really. And Nathalie is now 17 and she is halfway through her A levels and hoping to go to university at the end of next year. Have I left too big a gap there. Starting off with you know going to school and then on to A levels?

Tell me about your husband?

My husband, my husband is an only child so we have a very small family. He did or should I say he would have had a brother that was 3 years older, but sadly his parents lost that baby at just a few days old through his mum's ill health and different things. He lived in a very very quiet location, Ashover which is in Derbyshire. Very small community. I always jokingly call him a typical single child, only child. You know, very very narrow in his thinking you know he sees everything from one angle. I think when you have brothers and sisters you have to balance things a little bit more. But maybe that is just my opinion. But he sadly lost his mum as a teenager again, late teens. His mum lost a long struggle with cancer from late 30s and passed away sort of early 40s. It is very difficult to get him to talk about anything around that time. So I don't really know too much about his childhood really, because I think he just because he had always seen his mum ill, and in an out of hospital and then when she passed away he just does not like to talk about things so I don't really know an awful lot about his growing up. And he was in his 20s when I first met him, early 20s, and we knew each other for a while and then didn't come into contact with one another and then when we met up a few years later that is when, it sounds an old fashioned saying now, but that is when we started going out or courting or whatever. And we married in Staveley church the church that I go to and the church that, you know my daughters were baptized into and confirmed. And we still go there now. So it is all even though we have both come really from quite small communities and blended together in that respect.

[22:43]

So where do you actually live?

I live in a village called Woodthorpe.

And have you always lived in Woodthorpe?

No, when I lived with my parents I lived in a village called Inkersall. All the villages that I am mentioning now Inkersall, Woodthorpe where we live now, and Ashover where my husband used to live, were all in the Chesterfield we have not moved out of the immediate town should I say. Yes.

Tell me a little about your employment?

My employment? Yes. Well, when I left school I was already having problems with my hearing loss. Not too severe at that point but lots of infections and things like that. And I worked in an office for the first 3 or 4 years for the sweet company Trebor do you remember Trebor sweets? It later became known as, I think it was Trebor Collarny CO Sharps. which were three sweet companies altogether. And I initially worked there for 3 or 4 years. It was quite a large office. And then I left just after there to take up this job as a secretary to a gentleman who was starting his own business, it was a steel company and then I moved on to there. It wasn't too long after working there that things really got bad with my hearing and then I left just before I had my first daughter.

[25:01]

Can you tell me about your leisure time and leisure activities?

Leisure. Leisure time, past and now?

Yes.

Yes. I was -- it is very difficult sometimes and I am guilty of doing this, but I do split my life in half sometimes and think before and after deafness and I look at things and think my leisure time before I lost my hearing I used to like to just go to the cinema, go out with my friends, socialising, go to the pubs. I used to love going to the disco as they were called then now my daughters tell me we don't use that word any more mum it is clubs. But we used to I used to really enjoy that, you know, the music and dancing and socialising. Holidays obviously, and I was working at that time. Then I went through a period of not really doing anything leisurely, you know, lots of things were lost to me. And I think now I have probably

dropped down on to lots of different things that I would say, you know, my hearing loss does not affect them or whatever and I do really like to garden a little bit now and read and obviously with Bunty, we go for lots of nice walks and things like that. And I have recently started going back to the theatre with joining and helping run a club that we take people to captioned theatre and I am very much enjoying that after, you know, sort of almost 30 years of not having that kind of experience. So that is very good now. I went to see Phantom of the Opera last week one of the shows and it was absolutely fantastic to just cry at the same time as everyone else or laugh at the same time as everyone else, you know, rather than just sitting there looking all puzzled and wondering what is happening. And obviously, now my daughters are a little bit older and driving we can go out for the day and, you know, bash the credit card or something like that. Lots of things really, you know, you sometimes sit there and think you don't do anything don't you, until someone asks you a question and then you start coming up with this long list.

Do you have any political views?

No not really. I am sorry to say no I haven't. I find it all very -- my experience of politicians is thinking about things like the general election although I must add I do always go and vote but I do have to be honest, I don't really know what I am voting for, do you know what I mean? I sometimes veer towards a party and I am quite consistent in the party that I have veered towards, but I couldn't really sit down and have a conversation with somebody. But I have got views on things, but as a whole I just tend to think politics at the minute is just all wrong and all so corrupt and it does not really matter which party is there and we don't seem to be winning. That is my opinion and I do if I see anything like that come on the news, I don't look at the subtitles or I will just switch off. It is probably very wrong of me, but that is my opinion on politics.

[29:38]

Let's move on now to a totally different subject, that of the hearing loss?

Uh huh.

Can you talk through the various things that happened to you during the loss of your hearing

and when and where and whether it was sudden or gradual?

Yes. I would say mid to late teens I started having lots of ear and nasal and throat infections. I was constantly backwards and forwards to the GP. Looking at my throat, looking in my ears, all this that and the other. Tried these tablets, try those tablets, lots of different antibiotics. Which seemed to make things sometimes feel a little bit better for a short while, then it wasn't long before we were starting the cycle again. I am quite ashamed to say it for the person that I am now, but you do tend to let these things go on and this carried on for it must have been 2/3 years constantly going backwards and forwards. I mentioned the fact that my hearing a lot was very, very muffled, that was the best way I could describe it to someone I didn't really know any technical jargon or any medical terms for it I just kept saying it is as if people are talking to me very quietly and it is not very clear. No one that I saw at the GP's surgery seemed to think there was anything major wrong. It was all caught up in these infections within my tubes et cetera. I was not a forceful person and I did just keep accepting this. And, you know, I was putting up with the sore throats and the headaches and one thing and another, but the thing that I was struggling with the most was not being able to hear clearly. But no one as I say seemed to take that on board, how big an issue that was for me. They sent me to the hospital to ENT, and I saw someone there. He did exactly the same tests as my GP, looking in the ears, looking at my throat, no can't see anything there. There is nothing major. So, I mentioned about the muffled hearing and it was very much the opinion, exactly the same as my GP, we have a blockage somewhere et cetera. So, it was decided that I needed an operation. I can't tell you the name of the operation, because I never heard it clearly and nothing was ever really explained to me properly. But in layman's terms it was to clear these blockages and then everything would be free again and a little bit like the sensation when you have a cold or flu, you know, and your hearing feels a little bit down it was very much treated from that angle. And no tests were done, nothing was done to determine if there was actually anything wrong with my hearing in its own right. I had a letter from the hospital to say that this operation would be available to me in two years time. This was the glorious days of the NHS in the 1980s, when people were waiting two and three years for especially what were considered routine operations and all this time the sore throats, the headaches, the muffled ears and everything carried on. So much so that I even paid to go and see another doctor privately, because I was not convinced that it was nothing.

[34:48]

His diagnosis was very much exactly the same, that we would just have to wait. But I can see how uncomfortable it is for you so I will see if I can do anything to get the operation brought forward. Incidentally this doctor that I had paid to see was on the same team as the NHS, so that is where his sway would have come shall we say to bring the operation a little bit further forward. In the meantime, while I was waiting for this to happen, I had a really bad throat, a horrible headache one night, went to bed, taking tablet after tablet and pain relief because the headache was so bad and I got up the next morning and I couldn't hear anything. It wasn't muffled; it wasn't distorted, there was nothing. It was a really strange sensation in terms of you know when you have sort of you feel as if you are watching someone else go through something, like watching the TV or watching a play or something like that. And I can remember just sort of sitting up in bed and thinking "what time is it"? What and I looked at the clock and I thought why hasn't my alarm clock woken me? And then I thought I must be in the house on my own, I can't hear anything. You know because normally my alarm clock would wake me, I would hear my brother in the other room with my parents downstairs or the dog barking or something like that, and it was like, you know, sort of getting up and going downstairs to see that everything was normal. You know my parents were sat there talking, my brother was walking about, the radio was on I could tell the radio was on from the lights and am thinking "I can't hear". And it was a really strange sensation but it hadn't hit me, nothing had hit me other than the fact that I can't hear. And I was looking at them like that, you know, because I could see that their lips were going so they were obviously talking to each other and things were happening as normal in the house. And then all of a sudden I think it, something made me think "you can't hear" and it went into a completely different league then, I realised I can't hear and I think I just squealed. I was aware of the fact that I was either squealing or shouting and then at the same time thinking but I can't hear myself squealing, you know, and I can remember sort of like hitting and kicking the fridge door in the kitchen, because and banging a tray you know, because I wanted to make me hear I wanted to be able to hear something. And I think if I am honest I don't know what happened over the next 2 or 3 hours, other than sort of being taken into the lounge and calmed you know sort of lots of people I was aware of lots of hands going like this you know, sort of sit down, calm down. But I couldn't hear them. And I just kept saying "I can't hear you I can't hear you I can't hear you" and it was really frightening, because I was watching people do things that I would have normally heard them doing and I think I started to sort of run round the lounge as I say trying to hit things and kick things and pat things and I want to the

television to turn it up and my brother was trying to really turn it, because it must have been frightening for them because the television was just so loud and I could not hear it.

[39:18]

And then I don't know, I don't really know then again what happened for a while other than, you know, they were obviously discussing we have got to get a doctor or we have got to do something. And at that time our GP was quite local and it wasn't an appointment system, so I was virtually sort of carried off down the street and you know you will see her that kind of thing. And looking back now, that appointment was my first experience of just not being in the room because I couldn't hear. And you know, my mum and dad were sort of talking to the doctor like this, and they were having a conversation that I was clearly, sorry clearly no part of. And I just am just sat there thinking they are just talking about me and then I think I just cried then for months. But looking back now, the annoying part about that was there was still, even from the GP, no concern that I couldn't hear. It was all we must get this operation brought forward, that kind of thing. And nobody even at this point did anything to test my hearing. I was just sent home with more tablets and a few extra ones to keep me calm because I was being neurotic. And we just waited for while and the operation, fortunately, was brought forward. But I still had to wait almost a year before I had the operation, but it was brought forward because it wasn't considered an emergency. It was still very much pretty routine and all this that and the other. And I got to be very honest, I got through those 12 months just purely on the fact that in 12 months time they are going to put it right. I couldn't lipread, as you know, the hearing goes lipreading does not automatically switch on. I just existed. I sat there, I got up, I washed my face I did my hair, I put my clothes on and I sat in the room. And I did this for whilst I was waiting for the operation. And it was brought forward to nearly a year by the time I had this operation. I was still going with sore throats I was still taking antibiotics for the sore throats and the ear infections. My balance wasn't very good, they told me it was probably because of the ear infection. They didn't connect it to the hearing loss, it was to do with the ear infection they said. And then I went into hospital to have this operation two or three days afterwards the consultant came round to see me and I still wasn't hearing. I was not happy because I had set my store on this 12 months when I had this operation I will be able to hear again, I wouldn't have sore throats any more, I wouldn't have these horrible headaches and of course when I came round from the operation, the consultant they come round to see you, stood at the end of the bed and he is looking at the

chart and he looked at me and started talking. And of course his lips were going and I still couldn't hear what he was saying.

[43:45]

Of course, I think that was the point, more so than when it first happened that it became real. Because you know I had been told almost for five or six years that oh it is just ear infections you have just got a blockage when we clear this blockage that is what has kept me going especially through the last 12 months. And even then, the consultant was trying to tell me that there is a lot of swelling and we will give it a couple of days and see what happens. And again I think I just started squealing or something, because I knew, I knew then there was no more being fobbed off. And he eventually then did say I think we ought to do an audiogram. I mean I didn't know what one of those was. This had never been mentioned to me in the five or six years previous when I had been talking about muffled hearing. And I was booked in to have an audiogram as soon as I was sent home from recovering from the operation. Of course, I was just sat there not knowing what to expect. And the old fashioned ones were very much just pressing the beeper, press the beeper when you hear a sound. I just sat there I thought they can't have switched it on yet. All these kind of things are still going through your mind, you are still trying to think there is may be a little bit of hope you know or something. And he said kept saying to me you can press the button when you hear something. I said I haven't heard anything yet. And then scuttled off and brought another gentleman in and they just said I am sorry and they used this expression profound whatever. I couldn't understand what they were saying, he wrote it down for me and put profound hearing loss. Question mark. What does that mean, I thought I got a blockage you were going to clear it. And then I had -- I was sent to another room, and they said we will do another test for you where they play a tape of words that you have to listen to with earphones on. If you can identify it was written down for me I should add at this point, if you can identify any or part of these words just say back what you think you have heard. And I sat in there for about an hour and I was just crying all the way through it, because I was picking up a sensation as the earphones were on, sort of a buzz, that is the best way I can describe it, nobody had mentioned anything to me at this point about vibration or anything like that, but I couldn't actually really identify the speech. I got a couple of Ch, T and they told me at the end that they had played something like about 350 words to me and, you know, I couldn't identify what was being said. And they said the only thing we can suggest is may be if we get you

some high powered hearing aids you may be able to get some residual sound and environmental sound, whatever. But they probably won't be very effective with speech but it may just give you a little bit of awareness.

[48:20]

So, I don't know, I can see myself now in my mind's eye sort of being this. Sorry I am getting upset now, sorry, like watching a film and seeing like a very sort of dejected person, you know. Sort of I don't know what is going to come next. Now I have never been a person looking for sympathy and I didn't want people to see me in that light, but I just wanted someone to acknowledge that I now had a problem. You know after telling me for about 6 years that it is nothing. And they said, I thought 'oh ugly things hearing aids', I hope I am not going to offend anyone listening to this by saying at that point in my life that was something that elderly people wore. You know, not someone in their early 20s. But if I was going to be able to hear again, you know, it is worth a try. And I was sent off for this test to try and decide which aid would be best for me. And I was given a very looking back now, a very, very basic aid. Sort of one size fits all of the 1980s, you know. And it was given to me in this little cardboard box. And I looked at it and I thought I can remember thinking that has got to be one of the ugliest things I have ever seen you know and I don't want you know I don't want to be seen out wearing something like that. Thank the Lord I have got long hair all these kinds of things were coming into my mind. But thinking at the same time well it might be worth a try. You know, it might be able to help. And it did exactly what they said. Despite the fact that I had lost my hearing profoundly in both ears, they gave me one aid, that was how things were done then, you know. It is quite a relatively new thing isn't it these days that people are being given two aids. And so I put it in, and I did find when I went outside that yes, I could pick up some sort of noise and I must have been stood there thinking what's that and looking around. And obviously now I have learned to hear through my eyes, so I now know that if I hear a hum or something like that, it is the build up of traffic or something like that. To be perfectly honest it didn't give me anything that I wanted back, because it wasn't giving me speech. So it wasn't giving me communication. And I found it very very frustrating because I wanted and I could remember what a car sounded like, and I could remember that I could tell if it was a car or a lorry or a bus. Whereas now it was just one long sort of hum or buzz. Or just a noise really. It was an awareness of sound it wasn't hearing. That was the difference. And I was very guilty of this aid spending 95 per cent of its life in a

drawer. Because it wasn't really doing anything for me. And if I got a little bit nervous and had to go somewhere, I sometimes used to put it in, you know, because I was very afraid when I was out on the street of not having any awareness of what was happening around me. So, I did occasionally wear it but the situation was that I was sent off with this hearing aid. It was in as I say this tatty little cardboard box which I still have, I have still got that little box at home and it is in a sorry state now, but I won't throw it away because sometimes even now when I am feeling really fed up, I get that box out and I look at this box and I say I am never going there again. And that box is a constant reminder that that was the day that I hit rock bottom. My hearing wasn't coming back, this is my life now. Whereas before I had been trying to bluff through it, thinking it will be okay.

[53:50]

And I never had a follow up appointment to see if anything or everything was going okay, whether the aid was working okay. None of this happened. And I was sent off with a little pack of batteries. And I can remember looking back now, and I thought the aid had broken I didn't realise that this battery would only last for, you know, a week or so maximum. I thought well that is no good and it went back in the drawer. And I went through all little episodes like that. And then I used to go to chemists and buy them, because I didn't know that I could go back to anyone and ask for these batteries and get them on the NHS. So, I used to go to chemists. And I am quite ashamed to say this now but I used to go to various chemists I never used to go to the same one, I used to go to different chemists I used to pretend I was buying them for my grandma because I was so embarrassed to -- they must have realised when they were talking to me, but I went through the charade for many, many years of going to different chemists and going and buying these aids for my grandma and things like that. As I say, through lots and lots of things I think I just existed. I didn't get any support or any help from the NHS whatsoever. I had my two daughters with wearing this same aid occasionally. How it survived I don't know. Because it had been thrown at the wall, and slammed in a drawer and just pushed to the back of a drawer for many, many years. In fact, you know, I often have a laugh with it now, with my daughters and say it must have been a bionic aid you know because I did everything I could to kill it. And it survived through everything.

[56:08]

Until eventually as I say I had had my daughters and if I may I will talk about that you know the problems that that caused, but for the moment I am just going to say I was almost 17 years into this, into this hearing loss and struggling with my family and one thing and another, when I finally went back to the GP, it was a different GP by then, and said have things changed, is there anything you can do for me to help me in any way I am not getting any help from the aid, what support is out there, anything? And I was shall I say got in very quickly through the back door to audiology again and I saw a fantastic audiologist, completely different to the experience I had had all those years ago. And we actually even had a little bit of a laugh when he was doing the test you know. And he just looked at me and he said well actually, your hearing is really crap isn't it? You know. And he said this is just an outreach clinic, you need more extensive tests, so they referred me to the hospital. And the verdict was still the same, they couldn't give me my hearing back. There was nothing to be done. But there were other ways that we with could possibly get some support in terms of equipment and things to help. And he said to me would you like to see a hearing therapist? And I just looked at him and I said I probably would, but I don't know what one of those is. And he said well we have one in Chesterfield, I am going to refer you to this hearing therapist. And I went to see her and she told me all about things like going to lip reading classes, being referred to social services and to have some equipment on loan to help you in the home. So from that I got a room loop which didn't actually work that well for me, but it was somebody trying to help me. I got a pager system for the doorbell, the phone, which I always found really amusing that people wanted me to know the phone was ringing even though I couldn't hear the person on the phone. But they were insistent that I had one of these on the phone and that kind of thing. That was later exchanged for a text telephone. Just a chance conversation again talking about a gentleman that I knew who had a guide dog, and the hearing therapist said to me well they do dogs to help people, you know, with hearing loss. I didn't know anything about that. So, I applied for a hearing dog. There on the carpet is the result of the application bless her. Bunty. And I was told about The LINK Centre for Deafened People. And going on a course there, a rehabilitation week. My consultant didn't think there would be any justification in spending that kind of money on someone who was so far into hearing loss. Because there is nothing that they can really do for you that you don't already know. But I found some strength from somewhere, and I said the NHS have saved lots of money on me for the last 17 years by doing nothing for me. So if you put that altogether I will still be in credit even when you have sent me on this course. So, anyway I did go on that course and I always describe

that as the turning point for me. All those years on, but it was a turning point for me, meeting other people for one thing. And for a change, you know, having a conversation with someone who was actually nodding when I was saying something instead of making me feel as if I was making something out of nothing. I found help then about tinnitus and all these things, you know when I had been saying I could hear things I couldn't hear externally, no one had told me I had got tinnitus. You know all these noises goes off in my head and I am walking round the house trying to find out where they are coming from. All these kind of things. And from then on going off on a completely different angle that is when they were also thinking of setting up the volunteer network.

Let's just leave it at that point and take a little pause and then we will come back to that.

[01:02:04]

Just going back a little, can I just recap on your operation? Tell me when it was?

The operation was in February of 1984.

And then when did you get your hearing aid?

If I remember correctly, I am sure it was towards the end, about November time, of 1984.

As far as other hearing aids were concerned, did you get a chance to consider a cochlear implant?

I was told about the cochlear implants when I went on the LINK programme week. And very much mixed feelings. It was good to have the information, but if I am really honest the thought of that kind of operation did frighten me. But when I went back to discuss this with the consultant, after I had been on the programme week, I was asking him if he could give me any more information than what I had already got he said if I was interested in that he would refer me to one of the hospitals and could discuss it further there. So, I was referred to the hospital at Nottingham and I actually went on the assessment programme for the cochlear implant and went through all the tests and everything. I was a little bit dismayed at the time, because I really just wanted some information and I felt as if I was being sort of pulled along

when I was worried that it was going to be a situation where you will have this operation at the end, you know. But they were very, very good. And it did take just over a year from start to finish of going for all the different tests that they do. Looking at things on a TV and trying to lip read with sound, without sound, that kind of thing. And the MRI scan to check the health of everything internally. And chat with their hearing therapist about my expectations and what have you. I was always very honest from the beginning that I didn't know whether I was seriously considering the operation until I had all the facts, because from finding out things from LINK and then getting little bits of information myself, it was perfectly clear that it was a little bit of a lottery the result. Especially with me by this point already being deafened, what, 18/19 years. But at the end of the assessment I was offered the chance to have the implant but I was a little bit -- it was sort of February time, the money was in place, so it would have to happen now and I was not happy after getting all the information to then make a decision within a couple of weeks. And the gentleman that I saw was a Mr O' Donahue, who was very, very nice and his advice to me was if you are not 150 per cent certain that you want this operation, say no. Because you can come back. You can come back in 2 years, you can come back in 5 years and we can look at everything again. If you are not sure, say no because you have to be 100% up for it to get the best from it on the other side and I wasn't. There was something holding me back. I was very much afraid of the operation. And I was also afraid of -- I was not afraid of the hard work afterwards because I had been struggling all these years. But I was afraid of putting myself through all that for none or very little benefit. And it took me a long time afterwards and lots of people said to me well why didn't you go for it, why you know you had the chance to hear. And I said no, I had the chance to possibly receive some sound and I think I want back what I have lost, which is normal "normal" hearing and I know that the operation is not going to give me that. It may give me something, so at this point in time I said no. And I have stuck with that. Nothing has made me change since. Even though I can say hand on heart that there are not many days go by when I wake up and wish I could hear again but I want full hearing. I am greedy, I want back what I have lost not just a bit of sound. So, I have left it but I was offered one.

[01:08:52]

Can I ask you about communication? You seem to be able to use a full array of communications. Can you tell me the sort of things you use to communicate?

Going back to the beginning, can I? Obviously it was just a nightmare. Communication was completely gone. No speech perception, so you know having a conversation just didn't happen for a long time. I got used to very angry faces, shouting at me a lot and constantly repeating the same thing. And I still couldn't get it. And getting upset. Until I went back and saw another -- when I saw the lady, the hearing therapist Claire Roberts, I didn't actually know there was an expression of lipreading. I just thought that I us taught myself this skill, to me, it was just sink or swim. It was survival. And I can't really pinpoint a time when it suddenly dawned on me that I had been watching everything, just an instinct I suppose that kicked in. When I couldn't hear. And lots of people will say to me you are a very good lipreader, you are a fantastic lipreader. May be I am, I don't know. I do know, though, that there are still millions and millions of people out this that I cannot lip read. But when I am in company like this, when someone knows how to speak to me, I do seem to manage pretty well. But obviously, we are talking on one-to-one here. If I go to any meetings for the volunteer work that I do, then I use speech to text. Electronic note taker. Out and about on the street that is the not available, so I do bluff a lot. I know I am very very naughty and we shouldn't do that any more but there are some days where I just can't be bothered to go through everything. And I do nod occasionally and smile when everyone else is smiling. But by and large I have realised over the last few years that from having bad experiences in the beginning I went through a period where I stopped telling people I couldn't hear. Because I didn't want them to laugh at me or mock or whatever. Or worse still shout at me. So that everyone else in the room knows what is being said and I still don't know what is being said. But I have gained more confidence now to tell people that I can't hear and I am a lipreader. And I find that the best method for me is when I can see that someone is trying to help me, I calm down a little bit inside. And that makes my communication better. I have finally realised that well how do they know? You know, people can't guess these things. And whilst you don't want to give someone a lecture on the street about what they have got to do, but I do find that if I can pluck up the courage now to say I am sorry I can't hear what you are saying I have to lip read, if I can see that they have taken this on board I feel a bit happier that they are trying to help and that seems to get things going a lot better.

[01:13:30]

When the children were small it was very very very very hard. Obviously, toddlers don't

know about walking up to someone, standing in the right position with the light in the right position and all this that and the other. But, when my first daughter got to a certain age, we had a bit of an upset with nursery school with leaving her and me walking off and not realising that she had been calling to me. And to condense it, it finished up with having a chat with her about why she was upset at nursery today and she said to me that, you know, in her words were she knew that mummy loved her but that she got upset when I ignored her. And that just, oh that just broke me you know to think that my daughter could think I was ignoring her. Because it wasn't an expression that we used at home and I think it came from a conversation within the group 'your mummy is ignoring you' that kind of thing because I was walking off you see. So, then I spent months walking up the drive backwards and waving to her you know. But from that point on we had a little chat then because up until that point it had always been that mummy had got poorly ears, but she couldn't really understand what it was. So we had a chat then about mummy not being able to hear and she had to come to me and look at me and she basically taught my other daughter that as soon as she could talk, you know, she would very much go for the chin you know and move my younger daughter's mouth to do you have got to look at mum. Whilst it was difficult, yes, we somehow muddled through. But obviously it had its upsetting moments and as they get a little bit older I had problems with them helping me communicate outside. I didn't like the role reversal. It was supposed to be mum looking after the kids when we went to the shops not the kids looking after mum. And not pulling mum back in from the road I should be the one you know helping them in traffic. So, we had a few hairy moments there. You know I took it all on myself that you know I was a horrible mum; I was a terrible mum I should never have had them, you know, I am putting them in danger. They are only 5 and 9 and I am a burden already. All these kind of things you know were going through my mind. But, we did at some point by the time my youngest was 6 or 7, we had really reached a good understanding on the communication. You know, and when we went on the the programme week they learned the finger spelling and things like that, and so we use a bit of anything that helps really.

Do you use sign language?

We do use a little bit of sign language.

Is this something you have learned?

Yes. Again I never thought about using sign language. Because I thought, I know it sounds stupid and I am going to be embarrassed myself by saying this now, but I thought this is something that I shouldn't use because I am not deaf because I used to think, I still think of myself as a hearing person who cannot hear. Does that make sense? And I don't know, it felt almost disrespectful that that is their language, it wasn't something that I thought could help me. Again, until hearing therapy and coming with LINK, and realising that you could do sign-supported English. So basically, you know, either do a sign-supported English course, which there wasn't anything in this area at that time, but I was given some other advice to go and do the BSL course, learn the signs but use that in your natural flow of speech. So that is basically we have got a little bit of we call it our sign supported English and it works for us. But myself and my husband both went to college and did the exam for just stage 1, to learn the signs and they help us in day-to-day life. Taught them to the girls at home, and the finger spelling alphabet which they still use a lot for me now. First letter of the word, it helps in the evening when I have been lipreading all day and I have had enough. You know. And I am missing the bit or whatever, so if I have got a bit of a visual clue as well, a bit more. So, we use a bit of everything really. Dependent on the situation. But it works for us as a family. And we have got a few signs of our own.

[01:19:52]

Moving on now again to the impact of the hearing loss on yourself, you have described it very clearly. Do you think you see yourself as a disabled person, with that kind of label or do you feel it is just a handicap, or none of those?

Disabled, my daughter my eldest daughter had an argument the with a girl at school whose mum uses callipers to help her walk. And she always used to say anything that was happening out of school well I can't do that because my mum is disabled. And Nicole had this argument that well my mum is disabled as well, but we work round things. And the argument was that the other girl couldn't see that there could be a sensory problem rather than a physical problem. And to most people's views I think a physical problem is seen as a disability. My daughter argued the point that I was disabled from hearing, I was not able to hear. Myself, I wouldn't label myself as disabled. I wouldn't use that word. I just tend to use the word hearing loss rather than I don't know, it is a funny word. I don't like the word disabled. I just say I have a sensory impairment. That is the way I would describe myself.

But I suppose in one sense yes I am disabled, but I don't -- I try not to see myself as a disabled person.

[01:22:22]

Yes. Moving on now can I ask you about your personal relationship with your husband. Since you have been without your hearing, did you know each other before you lost your hearing?

When I first met my husband, when we were just friends, I was having all my problems with the muffled hearing. I consider that I was actually losing my hearing then, I don't know. But it has never been fully described to me and I have never had a full diagnosis. But, I think it would be fair to say he has never known me with full hearing. And then when we did actually get together if you like as a couple, I had already gone through the experience of losing my hearing, so he hasn't really known me as a hearing person.

So it won't have had any particular effect on your relationship?

He has not had the effect of the loss of when I actually lost it. But obviously he is living day-to-day with the effect of what it is like to live with someone with hearing loss. And I do acknowledge that not so much now, but in early days and especially when the children were small and everything was very much heightened I was difficult to live with. You know, because I was and this is not me at all, especially now, but at that point when the girls were small I was very needy because there were so many - I hadn't got any equipment, I hadn't got any support or any help then so of course when he was coming home from work, you know, he had lists you know. Got to ring the doctors about this, got to ring that, got to do that. All these things that, you know, had been taken away from me. I couldn't -- I had a telephone down the hall and yes I didn't know when it was ringing. And even if I had have walked past it, and just picked it up I couldn't speak to whoever it was. So, he had the impact of living with someone, but he didn't go through the stage of me losing the hearing. Does that make sense?

Do you think that he copes with it? Given that you are still together he must have done, but how do you think he coped with it over the years?

I think, and I would say this to anyone, I think he copes with it because -- no. Sorry, I might be saying this wrong, I have got to be sure what I mean. Yes, obviously he has coped with it because I used to say to him in the beginning, if I used to get upset about anything, thank you for understanding for being understanding. But I still feel sometimes there is parts of it that he does not really understand. Is that a bit deep? Yes he is understanding, but and I think by and large yes, he has coped with it remarkably well and I mean so have my daughters, you know, because they have never known me as a hearing person and that is possibly for them a good thing. That they have not gone through the loss just the effects of it. But, my husband, yes, I mean I have to say I am a little bit naughty some days and you have to get a bit of fun somewhere don't you? And you know sometimes, you know, you can feel a situation can't you where someone really wants an argument and I just don't look at him or I just go in the other room. You know I have to get my sport somewhere don't I? So yes I think on the whole he has coped with it remarkably well, yes.

[01:27:21]

Do you think the hearing loss after all this time has brought about any change in you?

Definitely. I am a completely different person. And I think there are possibly some things where it does make you appreciate other things much more. If you have gone through some sort of, I consider it to be a trauma that I went through and I think if you have been through something like that, I think you can empathise much more easier with other people. Not just with hearing loss, anything that anyone is going through, I think you can have that little bit of empathy and respect for someone who is dealing with some other form of impairment.

I was not an overly confident person as a child. I don't think I am now in a lot of situations. But in some ways I think I am actually more confident now than I was before. Because I have spent so many years trying to sort of claw my way up to some sort of "normal" existence again that it has in some ways made me a little bit stronger. And in some days I just feel so weak it is unbelievable that something can just bring you down sometimes, you know, a memory or you know. For instance, I went to the seaside with my daughter a couple of months ago, and we sat on the sand and we were just talking and having an ice cream and it was a lovely day it wasn't particularly sunny but it was nice. And it was just nice to catch up and have a bit of time. And I just started crying and she said why are you tear every why are

you crying and I just said "I can't remember what the waves sound like on the pebbles". And there are some things that I have stored in my head and I can remember them and others have gone because it is just too long now because it is not something that I see on a regular basis and I just said I just feel sad that, you know, in my head I can sort of remember some things and I said but I am just watching that water now and thinking I can't remember what it sounds like and yet I know I have heard it. You know, the sound of the sort of water coming up and going back and what have you. And I said it has gone. I just realised we have been sat here for half an hour, and I have just realised I am not getting anything from it you know because normally I like to watch water things. It is quite soothing, people tell me it is very soothing when the water is trickling down, but that has just gone now. And I don't know when it happened but I was just sat there watching it and I just realised I can't get that at all. Sometimes you can force yourself can't you to remember something, but that has gone and it just really upset me that one thing. Maybe it is nothing major it is nothing important to another person, but things like that. That sort of strength and the weakness.

[01:31:22]

Tell me about LINK?

LINK. I think I said earlier that I have always considered that that was a real turning point for me. It was just so good to be in a room with someone else, one person would have done, let alone six, you know but one person would have done just someone who did understand because this was 17/18 years into being deafened and no one had asked me how I felt. And I was in an environment where it was okay to say how I felt, how it made me feel. You know. Because, you know up until that point you do -- I really did consider myself to be a nuisance to everyone that I was wanting, you know, not wanting sorry, wanting is probably the wrong word but needing this help with so many day-to-day things not knowing what is happening, you know, what is happening around you. So it was nice for -- to see a nodding head for a change instead of, you know, feeling as if I am being a little bit neurotic or making too much of it or whatever. And it was nice to be able to actually open up and say how I felt and it was fantastic for me as well, to see tutors, you know, like Cathy, who were also deafened and they are getting on with their lives and things are happening because at this point nothing much was really happening in my life. Apart from the day-to-day getting up, looking after the kids, taking them to school and doing that kind of thing. But outside of that front door there wasn't

really that much happening in my life you know, I was really backed off from getting involved in too much. Uh huh.

And your involvement with other things with LINK?

I couldn't actually believe it when I came away at the end of the week, I didn't want to come home because I just felt that this week has been so fantastic to meet these other people as well who were, you know, living through the same things. To share a problem and also share a laugh, you know, we have to laugh sometimes as well at the things that we do don't we but at that point I could not. Before I went, there wasn't too much that I could laugh about. And we had had a few laughs during the week and that was something that had made me realise that maybe I can still laugh a little bit more again, you know. But I really didn't want to come home. Because I was thinking I am just going to come back to what was there a week ago, you know. How can I get people in, you know, my circle of friends and family and things to take on board how they can help me? And the very last session before we all went home they were talking about setting up a volunteer network where you would be helping people in your local area. And I thought oh, that sounds like a good idea, because I had always been a sort of person that I would rather help somebody else than help myself. You know. That kind of thing. I couldn't believe it when we were coming home and I thought why have I volunteered for that I won't be able to do it, I will be frightened to death of meeting these people who I won't be able to lip read, who I can't understand and all this that and the other. And typical how my mind used to think at that point, I thought they won't want me anyway, they probably won't even get back to me I will never hear from them again. And then a few weeks later I got the letter asking me to go on the training programme. And really, that is the history of it. 11 years ago, I started off went on a training course to the Friars in Kent, and I got accepted on to the training programme and I have been -- we have had various titles along the way but I have been involved, we are now called outreach volunteers. I do talks for them I do talks for hearing dogs, I do programme support anything really. And somehow, something has come from inside me after being allowed to talk about how I felt, that I find I can talk to oh groups now and tell them what it was like and spread awareness or whatever. And I have really, really enjoyed it. Because if I just see if one person comes up to me at the end of a talk and just says, you know, oh that was really interesting or I have to remember that you know, you get someone who will come up and say I have a friend who wears a hearing aid and you have just made me realise I have not been very nice to him sometimes, you know, when I have

been saying things like turn your aid up or whatever. I will have to remember now not to do that - you have made me think about that. And you know, to me that is it. If you can achieve that, by giving an hour of yourself to talk to these people, and they are going to go home and help someone else who is hearing impaired that is fantastic. That is why I do it, because I went through so much when I could have had a little bit of support. And if giving that support to someone can help, that is the reason I do it. And I really, really enjoyed it just to see a smile occasionally.

[01:38:30]

Good. As we approach the end of our interview, I would like to ask you about your feelings on this Unheard Voices project today and the work you have been involved with in doing it?

I think it is long overdue, very long overdue. For people to have the chance to tell their story, not only is it therapeutic for them to actually have someone listen to you, I think it is it is a privilege for me to be sat here and that you are prepared to listen to me talk about what happened to me. That you are prepared to take that time out and listen. And I am looking forward to when I am in Newcastle and I will be sat in the other seat. As regards the medical world or anybody that might go into the archives and look at these stories, this it is very much an unseen I am going to use that word disability, very much an unseen disability and I think there is a lot that people don't realise how far-reaching hearing loss, especially a profound hearing loss is. And I think it will open up hopefully a lot of people's eyes as to how brave these people are. And they should be proud of themselves that they are overcoming these things, you know, and I think it is just fantastic the story needs to be told. I wish it had come sooner and I had known something about it you know before.

Finally, can I ask if you have any plans or hopes for yourself for the future?

Just to keep going. Just to get through each day. I mean I can smile and I can laugh and I am a fairly sociable friendly person but I still do keep a lot to myself and I just hope that I can just carry on going as I am now. I don't ever want to go back to how it used to be and I just hope that things will continue to improve really. I mean obviously my hopes, family wise you know I am looking forward to my daughters having healthy life and I really, really grateful that there's, I am going to touch the table now without moving the wire I hope, that there is no

problems for them hearing loss wise and that it probably was just very unfortunate for me. But I just consider myself that I can actually get up and smile now and I just want that to continue.

Brilliant. Thank you very much indeed Vivienne for this, and for coming along today to talk to us so frankly. And thank you to Lynn for all your work on the speech to text reporting. I shall finish now.

[End of recording]