



Unheard Voices: interviews with deafened people

Stephen Beal
Interviewed by Colin Ellis

British Library ref. C1345/30

IMPORTANT

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Interview Summary Sheet

Ref no: C1345/30

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname:	Beal	Title:	
Interviewee's forename:	Stephen	Sex:	Male
Occupation:	Carpenter	Date and place of birth:	1957, Southampton

Date(s) of recording: 15th March 2009

Location of interview: The City Inn Hotel, Bristol

Name of interviewer: Colin Ellis

Speech to Text reporter: Georgina Ford

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Interviewer's comments:

[Track 1]

This is Colin Ellis interviewing Steve Beal on Sunday, 15th March for the Unheard Voices Project in Bristol. We are accompanied this afternoon by Georgina Ford, our Palantypist from Wolverhampton. Steve, would you like to tell us your full name, when and where you were born and about your mother and father and if you had any brothers or sisters and where they came from, where you all came from.

My name is Steven Beal, I was born on 2nd May 1957. My mother and father -- my mother was born in Southampton and my father was born in Kent.. I have one brother, no sisters.

Would you like to tell us if you know what your mother and father did for an occupation.

My father -- my mother met my father while he was serving in the RAF. My mother was working in a navy canteen in the centre of Southampton outside the civic centre and my father happened to be on leave and was in the navy when they met. He worked on mosquito aeroplanes during the war as a mechanic. He was very young and my mother was very young and she just worked, as I say, in the navy canteen. Eventually they went out and got married and my father worked for a company called Calor Gas and my mother worked in the retail trade.

Would you like to tell us about your brother and your relationship with him.

My brother is older than me. We never got on when we were younger. He always used to bully me and for some reason my parents always seemed to take his side. He left home eventually when he was approximately 16 or 17 to join the army and he deserted from that and I've never had any contact with him.

Do you ever recollect your grandparents or visit them and do you have any family background about them?

Going on to the story later on, my mother unfortunately was seriously ill so we had to live with one of my grandmothers eventually but I remember her husband and he used to be a bus driver for Southampton City Corporation in those days and I remember when we used to go to visit him he would give me rolls of bus tickets and I would sit on the stairs playing bus conductors.

My grandmother she had six children and so she was always kept busy baking and doing things for the other children. And then on my father's side I never knew my grandfather but I knew my grandmother. She used to live in a lovely old cottage in Sidley in Bexhill and I always remember we used to go and visit her about once every two months or so and she would never let us in the garden because she had an apple orchard and plum orchard and we used to go and sneak the apples and eat them and she'd tell us off. She was a lovely old lady but very Victorian type.

[04:20]

Would you like to describe any part of your childhood experiences and when you went to school or your school friends and the hobbies you had at that time and what you liked and disliked.

I remember after I was born we lived in a town called Shirley in Southampton. I don't remember that at all; I was too young. Then my parents were given a council house on an estate called Thorn Hill which is in Southampton and I remember the house. It was a three bedroom, a two bedroom house sorry and it was an open plan garden with small back garden which I was able to play in. I was football mad so I do remember breaking several windows in the garden with a football, which I quite often got told off about. My parents were very loving, we got on very well as a family unit.

Obviously my brother was still fairly young then so we just had usual brotherly rows. I started infant school. I got on quite well. The school was brand new. I remember going into it as it was brand new. I think I did quite well at infant school. My brother began to be a bit of a rogue and then we – I remember going up to junior school and once again I was doing very well. Then my mother was taken seriously ill, very serious, and it came to the point where we were unable to stay in the council house on our own because my mother needed help and support because my father had to carry on working because in those days there wasn't the benefits what people could get

now. So as he was the main wage earner he had to go to work. So we had to rely on my Nan to look after us.

Can you remember what you used to like and dislike?

I disliked my brother. I liked school because I think I could escape from my brother and I liked the idea I could play football at school. I was absolutely mad on football. I used to collect stamps and I liked family life with my parents. My Dad used to have the old motorbike and side car in those days and I remember he used to put us in it and just take us for drives around Southampton because in those days the roads were so much clearer.

Can you remember what type of motorbike it was and some of those trips would you like to recall one or two trips?

He had an old BSM motorbike and he also had an old Bantem. Is it something like that? The trips we used to take were to Southampton Common because they used to have a zoo on the common, it's a great big open space land and they had a zoo which was eventually closed down because the pens were so small. We weren't too far from the dockland and I used to love ships so I can remember some days he would take me down to the docks and we would see the very old Cunard liners, Mary and Elizabeth and also the old cape ships what used to go to Africa.

[08:21]

What were your first experiences of -- no, sorry, I'm going to go back a little bit if I can. Can you recall what your illnesses were?

Yes, I can. Obviously because of my mother's illness I had an insight into illness and how it can affect people and when I was about 11 years old we were then living with my Nan in a place called Freemantle Southampton. Her husband had passed away and she had a three bedroom place, which she rented privately and that was -- because Mum was so bad we had to move in with her and she was able to care for my mother and I started senior school. I was 11 years old and I remember one night I woke up

with dreadful earache and I ended up banging my head against a wall trying to stop it. Because my Dad was on nights, didn't like to disturb Mum and so I waited until Dad come home and I do remember vividly that I was crying and I said I've got bad earache Dad. Up until that point I hadn't been too bad health-wise. So as far as I knew Dad, took me to the doctors which I had a very good GP and he was the old fashioned sort and he gave me some ear drops and said it was probably just an infection. I carried on going to school but this earache wouldn't go and I was sitting in bed banging my head against the wall trying to stop it and hold a pillow against it and rub it and of course it started getting worse. Then one day I woke up and I noticed my pillow had loads of muck, discharge over the pillow and I wondered what it was and it smelt dreadful. So of course I panicked and burst out crying and went into Mum and Dad, who's bedroom was next to mine, and they come into the bedroom. The next minute Dad rushed me up to the hospital in which those days wasn't too far away. It was the old Royal Southampton hospital, which has now closed down as a casualty department. It all started from there really. I was rushed in. I had two small operations which they said I had what was called polyps in my ears and I always remember I laughed because the doctor said it looks like you've got cauliflowers in your ears and that's how he described them. I had to stay in hospital and had them removed and then I remember going home but I still had this horrible discharge. Eventually, we asked the consultant when I was obviously still fairly young and was very unwise to what was happening, and he said because I did so much swimming, I love swimming, I was also the school swimming captain, that I probably got an infection through dirty water because obviously swimming pools in those days were like lidos, they were open and different chemicals were used and they probably weren't so clean. They said eventually I would need another operation if it didn't clear up and I do remember going to the hospital and the nurses didn't -- they were more stricter in those days. They didn't have the understanding or the patient awareness they have now and I remember this nurse coming towards me with they call them kidney tins and in it there was a long wad of purple tape and I thought what's she going to do with that. She got another nurse to hold my head and she forced all this purple tape into my ear and it felt like my head was going to explode. I had to leave that in for a week. I remember going home and after two days I pulled it all out and I got a smack from off Dad.

[12:40]

Would you like to describe your first experiences of leaving school and going into either employment or did you have to have Further Education?

My school -- I absolutely loved school. I got on very well at school. Unfortunately, because of my ill-health and my ears, in my senior school I'd had approximately 15 operations on my ears where I was in hospital for a week at a time, sometimes two weeks, and unfortunately while I was in hospital I started to get severe pain in both my knees and they found out that I had a disease of both knees and I had to have two very major operations on my knees. I had to have both my knee caps removed which I was told as a young 14-year old I was told that I wouldn't walk again. Unfortunately, I was in hospital for six weeks in plaster while I had my first knee operation. They wouldn't do this operation now. They have realised it makes you worse, which is what's happened to me. So combined with that and my ears, I had a very poor teenage years. But because I liked school so much I did stay on and do extra lessons when school finished because I loved woodwork and when I went to senior school I begged to be let to do woodwork because I found a liking to it. I used to be able to relate to wood. I loved the smells, I could tell by the grains where the wood comes from and what sort of trees they came from. So I excelled at woodwork and loved technical drawing so I took my exams. I was also a church-goer. I also went to church and I think that helped me a lot. I eventually left school with -- I passed my exams, my CSE exams in those days and I wanted to be an apprentice carpenter but because of my knees, I wasn't allowed to go up ladders at that time, even though I managed to walk which I was told I probably wouldn't do, I still carried on running and they wouldn't let me be a carpenter but they did say I could train as a wood machinist, a four year apprenticeship paid for by the Government and I discussed it with my parents and they said well, it's to do with wood, you love wood, go for it. So my Dad gave me all the backing. I had to go to college in the evenings once a week and Dad used to take me down there for the first year. While I was doing the apprenticeship, I had bad flare up in my ears. Unfortunately the whole condition returned. I had to have another major operation which unfortunately started to cause my deafness and I was in hospital for two weeks and once a week the company I was working for, which actually made television scenery, and also fitted out the old Queen Mary and Queen

Elizabeth's were very good. They allowed me time off for hospital visits but unfortunately my apprenticeship and the study suffered because of my ears and I managed to carry on but I was in and out of hospital for several operations and also with my knees, the pain was so bad I used to cry quite a lot with it and found walking painful and after a while, it become too difficult for me.

[16:48]

Would you like to tell us how or where you met your wife, Sue, Chris?

You'll like this, Colin. I met my wife while I was in hospital. I was having my second knee operated on which was once again a major operation. In 1968, I just go back a step, my Mum had a tumour on the brain and she was the first person in Hampshire to have the sort of operation she had and unfortunately it caused so many problems that she had to -- she was virtually disabled. Dad looked after her but unfortunately, because of my health as well, it had quite an impact on the family. It left my mother with an illness called *aga Meglia*. I can spell that ...AGME -- unfortunately it left her on lots of medication and anyway she was still very supportive of me and very loving still even though she went through a lot. I had to have my second knee operation. By this time my father had learnt to drive and I had to have it done at Alton. It was the only hospital at that time which could do my operation and I was in hospital for six weeks. But because my mother needed a break, my father decided to take my mother abroad because she'd never been abroad and she wanted to go to Italy. But they had a big dilemma because I was 16 at the time, 17, and they were worried about leaving me in hospital. So because I was a church goer some friends of the church said they would come and visit me and have a rota and come and look after me give my Mum a break. So Mum and Dad went off to Italy. And one of the ladies who came to visit me from the church worked at telephone exchange in Southampton. This lady who eventually became my wife was a telephonist and she said would you like to write to a couple of the ladies as a pen friend. So I wrote to Chris and I wrote -- Chris wrote back straight away and said she would like to come and visit me. So I arranged with the lady who put us together and they said they would bring Chris out. I remember I was laying in bed in the hospital and it was the old fashioned hospitals with the very long wards with strict matron and you weren't allowed out of bed until the matron said you could get out of bed. So between 1 and 3, I think it was we had to lie in bed and

have afternoon rest and then they would open the doors for the visitors to come in. I knew Chris was coming because she told me by letter. I saw her walk down the corridor and I can hand on my heart honestly say it was love at first sight. She was my first girlfriend and I was amazed. It was like a vision walking down the corridor, Colin. She'll kill me for this!

[20:340]

You mentioned, Steve, that you went to church and it was very much part of your early life. Is it something that has helped you on lately or is it something that has disappeared from your life? Would you like to elaborate on that at all?

That's an interesting question, Colin. Eventually Chris and I got married and had a family. I stopped going to church because things got in the way, which is a very poor excuse I know. But with children you tend to do other things. But I've always been a Christian and just recently I've had a bad time with my ears and Chris decided to go on what's called an Alpha Course which is for church people to go to, to find what church is about. I didn't go on the course because obviously I know about religion and I read the Bible and I've read the Bible and I've done studies of the Bible. When Chris finished the course we started to look at different churches in Southampton and we felt something was missing in our lives and I would say we tried three or four churches but found them uncomfortable, not welcoming. Then we decided to go to a church about a mile from where we live, just one Sunday and we went in the door and we were made so welcome we've been there ever since. We've been going for about three years now and they accept my hearing dog Yogi. He comes up to the altar with me and we have tea and coffee afterwards with the congregation and we're made so welcome that we feel part of the family now. I feel that the faith helps me through the problems I have with my health.

[End of Track 1]

[Track 2]

Steve, you described in quite good detail the problems that you had with your hearing as a child and that. Could you elaborate any more about related problems? I mean, did you have tinnitus with it and your balance or vertigo and how did that affect you as a healthy young man and your relationships with your family and more intensely with your girlfriend at that time?

Okay, as I said before, I had a lot of earache and ear problems and discharge. I can remember having what they call a mastoid operation where they remove the bone from behind the ear to open the ear canal because Mum and I went to an appointment, Dad couldn't make it, and I remember we were sat in the room and I spoke to Mr Morgan, who was the ear, nose and throat consultant in the hospital, and he said if we don't stop this infection, it can go up to your brain and make you die and I remember I was about 13 years old at the time and being 13 years old, you don't realise the importance of it. I can remember my Mum coming out and she looked a bit white and I had to go and see the nurse to have this put back in because I had to stop taking them out and it used to make me cry so much when they put it in because it was a good 2-foot long this piece of cotton they put in my ear and I always used to cry because it hurt. It made me more determined to try and stop the ear discharging but never did. So I had to have this major operation eventually. My family were very good, but there was always my Mum in the background with her ill health. So we kind of grew up with ill-health. I managed to carry on through school and then I eventually met Chris because I had both things going wrong. So I had the knees and the ears with problems and poor Chris had never been to hospital before she met me and started visiting. Then we became a couple and I used to have a lot of hospital appointments and Chris would come with me. She understood my ill-health. She was very supportive, even in those early days, when we were 17. We decided to get married when I was 18, very early. I knew what I was doing and Chris was still very supportive and I tried to work, Chris was still a telephonist. Eventually we had our first son Richard and then Chris obviously gave up work because pregnancy and then looking after Richard as a housewife and Chris had to give up work. She loved her work as a telephonist. Then we had Sue come along, our daughter Susan and I was in and out of jobs unfortunately. I started to lose work because I was still getting bad earache and I was

still having this discharge even though I had a major operation it didn't cure the problem. I noticed I suppose I started to realise that I wasn't hearing things properly and I could say that it had been like it for years but I'd -- I think your brain adjusts to what goes in. I think your brain adjusts so you don't really miss it until people start saying did you hear me, did you understand what I'm saying? Of course with the two children, you then start to think I never heard what they said. So when I was down the hospital, no-one ever mentioned to me about having a hearing loss. I was never referred to an audiologist. I've never seen a hearing therapist and then as a young family, my father passed away and Chris and I lived a few miles from my Mum and we were always worried about her. I actually stopped going to the hospital with my ears because I was frustrated because I lost jobs because they wouldn't give me time off in those days in the very early seventies being a wood machinist/carpenter because I did take some training as a carpenter as well I went back into the job, I kept losing jobs because I just used to blame having earache or a bad ear but as the children were getting older, I would say my temper was getting worse and I started to get frustrated. The earache was there, the horrible discharge was there, I used to clean my ear out with Q tips. I could use a whole packet of Q tips a week cleaning my ear out every night. My ear would make a mess, Chris would have to sometimes help me wash my hair, she would have to do the washing on the pillows every night, every morning she would have to wash them because of the horrible discharge and it became part of my life. I lived with it. I remember one day I learnt to drive because I thought if I can learn to drive perhaps I can get a driving job because once again, I kept losing jobs and Chris and I had to rely on benefits a lot to keep us living. Chris's father was very good. He would come over and visit us and bring a little food parcel for us which was lovely. Then I met a friend, a close friend, through work who's been a loyal friend ever since. This would be about 1976. We worked together. He'd just come out of the navy. He had been in the navy for 25 years and he retrained as a carpenter and we worked for the same firm and he's been a very good friend to this day. I learnt to drive and then I was still getting bad earache. Before this stage, I can remember on the way to work I used to get the train from where Chris and I lived in Woolston Southampton. I used to work in Totton which was about ten miles away but I used to get the train in the morning. I remember vaguely I was in the train station waiting for the train and then I woke up in a first aid room. I'd collapsed on the way to work. An ambulance was called and my children were very, very young. They were still at

home with the Mum. They hadn't even started school or pre-school. In later life a few years later I realised now that this was the start of my problems, my balance problems, Meniere's disease but it wasn't diagnosed. The hospital just cleaned my ear out and said it's because I haven't had it cleaned out for so long. Then it all started again, the whole procedure of going back to the hospital, ears cleaned, wicks put in, ears cleaned, wicks put in just on and on and the children got used to it. But even at that stage I was never offered help with hearing therapists, audiologists. The consultant would say yes I've got it under control, we'll keep it clean. Then as the children were getting older, they realised Dad had a problem with his health. I used to walk with a walking stick even in those days and it got to the stage where I went to my GP and I was sent to the hospital again as an outpatient and we saw a lovely consultant and he wasn't the actual consultant who did the operations he was like an understudy consultant, like a registrar.

[08:46]

He was called Mr Flowers. I went in to him and he actually explained the seriousness of the condition. He took time to talk to Chris and me and he went through the past and said all the operations I've had which must have amounted to 20 operations on my left ear and he described why they did them, which I'd never asked before, and he said the mastoid operation that they did at that time they never took enough bone away and they left infection in the ear on the first operation and that's why it was infected again. He said your condition is so bad at the moment that if we don't do another mastoid operation, it could be very, very serious consequences. So Chris and I discussed it. I wasn't happy of having an operation again. I was actually quite frightened of what I'd been through as a child and didn't want to go back down that road. So Chris and I discussed it and the consultant was a Mr Randall and we actually saw him a little while later after I'd agreed to have the operation and at this time, I'd began collapsing and falling all over the place and having balance problems. Chris and I had gone to a shop and I was in the shop with Chris and I said to Chris we had the children with us, I'd actually driven to the shop and I said to Chris I need to go outside and I just managed to get outside the shop and I was violently sick and I'd suddenly gone very grey and I thought I was having a heart attack. Chris came running out. She took one look at me, I was laid down on the pavement, Chris took one look at me, went back

into the shop, got our children to stay with me. By this time my son was a little bit older and asked the shop man if he would call an ambulance because she was really worried that because she thought I was seriously ill and had a heart attack. I was rushed up to the hospital and I still wasn't told I had Meniere's disease. I was still told it was because of the ear infection. Eventually, I had the major operation again, the mastoid operation. I stayed in hospital while I had it done. Chris was so supportive. She tried to stay with me as long as she could even though we had two young children and she was just as worried and concerned as I was. I eventually went home and she nursed me fantastically and it just goes to show when you take your wedding vows for better or for worse. I will never forget what Chris has done for me in my life. She stood by me forever. I wouldn't be here now if it wasn't for Chris. I know that and I won't elaborate on that but I know I wouldn't be here now. Eventually all the bandages were taken off at outpatients and I had the dreaded discharge still. It just couldn't go. They started putting wicks and dressings back in. Even though they promised it would dry the ear up, it hadn't. My own GP was very disappointed. When we spoke to the surgeon who done it, Mr Randall, he actually said well, he's done his best. I haven't got -- he said I haven't got Meniere's disease. He said no you're just falling about because of your ear infection. Chris knew I had Meniere's disease. She had been to the library, she'd read up on it and she told me before the specialist eventually admitted because of what she'd read. We actually saw the consultant one particular day after he cleaned my ear out which makes me go dizzy and when they clean my ear out, I have to write the whole day off and I still have this done once a month to this day. Chris actually got annoyed with the consultant and said can we please have a second opinion. The consultant then sent me for a second opinion much to his annoyance. We eventually had a second opinion with a consultant called Mr Wogan. As soon as we walked into the room it was a much happier atmosphere. He made us welcome, he went all through the notes which by this time were a volume -- 2-volume book notepads because they'd built up. He went all through them and the first words he said to Chris and I, you have Meniere's disease. And we had confirmation. I still understand when he said there's no cure for it, but he wanted to concentrate on getting the ear dry. He did say there was another major operation they can do bearing in mind I only had one six months earlier. He said they can destroy the whole ear by taking everything out. He was the first person to say to me you are totally deaf in that left ear. He was the first person. That was before he even did an

audiology test. He said because of the two mastoid operations I had, I wouldn't have any hearing in that ear.

[14:32]

Do you think that any of your illnesses have been contributed in your life to specific sports or that or do you think it may be hereditary back to your grandparents and before them

We've actually asked the consultants because of the Meniere's disease whether it's inherited. They actually said no. But in recent time I do a lot of reading now and I've actually read that it's possible you can inherit it but they haven't got any full studies on it but they are looking into it. I did wonder because of my mother's illnesses that she had -- she's now passed away because of her illnesses -- she suffered dreadfully, she had a bad heart, bad brain, bad lungs, kidneys, everything and because of the illness she had I actually spoke to the consultant and said could I have inherited anything off my mother and because of my height and because my mother was very large because the illness she had made all her joints, her hands swell up to three times the size, her ankles were massive and her head was enlarged, her jaws were enlarged but fortunately for me they have said no. They've actually done tests on me to see if I have the same illness. She never had Meniere's and she wasn't deaf which I would just like to say I was so pleased that she never had that. With Meniere's you don't know when an attack is going to come. Did you want me to talk about that now or later?

No, later.

[End of Track 2]

[Track 3]

You described earlier on how your family and your friends in your earlier younger life treated you. Would you like to recall now how later on after this finding out about Meniere's disease your family and your friends felt about communicating to you and about your condition?

When I met Chris, we moved away and when we got married we moved away and a lot of my mother's family, we've fell away from. We don't have contact with them. So I call Chris's family my family because they welcomed me into the family their family unit and I'll be honest they treated me like a son. I got on so well with her parents that they understood my health problems, they understood why I lost so many jobs, they never looked down at me, they never made me feel inferior, they treated me like one of their own and I'll always be thankful for that. With my deafness which has deteriorated so much more in the last five years, they do understand and they are very supportive.

[End of Track 3]

[Track 4]

Steve, you've described in great detail your treatment back in the 1960s which is a very interesting time as far as hospitals and the NHS, as we know it now, which was then still only in it's infancy of under 20 years. Would you like to describe how you now feel about the treatment that you got by the people that you got?

I remember the first time I was admitted to the hospital, as I said earlier, it was more like a Victorian hospital design. There were approximately 30 beds in one ward, 15 on each side, with two tables down the middle. I remember it vividly. There was one chair by the side of each table and when I was taken into the ward to have the first operation, I looked and there was a lot of elderly men in there. I thought do they not have a children's ward I could go on, because there was no toys to play with and I got in this bed and all I could hear was all these horrible noises being made by different men because they had had a lot of nose operations and different operations and I vividly remember there was one man in the bed next to me, he only had one ear and he had loads of stitches down the side of his face and it was like a big cross on his head and they'd taken his ear off and sewn it up completely. The whole thing had been sewn and I was very frightened. Didn't look that way, I laid the other way. I thought what are they going to do to me? In those days, the nurses didn't come round with loads of forms for you to fill in or for your parents to answer or anything, you were just taken the, your notes were at the end of the bed and then I remember I cried when my parents went, my mother went home, because I was frightened. Even though I was, you know, at that age of 13. The nurses never come and comforted me. They never said "oh look, don't worry it will all be all right" and we used to have I now realise it was the matron and the sisters and they walk up the ward and they would brush the bottom of your bed off. They were forever tidying the bed even though you were laying in it they pulled the covers up. They wouldn't let you go out of bed to go to the toilet even though I could walk and even then I had a stick because of my bad knees, they wouldn't let me get up to the toilet. I always remember that and they made me go in the glass bottles. I don't know if you remember they had a glass bottle and for a boy to be told to do that ... they didn't pull the screens round because it was an all male ward it wasn't a mixed ward, but if still a bit intimidated by all these men around and there was nobody else my age there. We were given breakfast in bed and

still weren't allowed out of bed. I remember the trolley and at the end of the ward was a side room which I now realise was where the anaesthetist puts you to sleep and they had their own separate operating theatre for ear, nose and throat which was next door to them. I remember being laid down and obviously I'd been asked to sign a form with my parents as well and suddenly this man come towards me with a black mask and I can remember trying to fight it, I was frightened. Then he just held my head and put it on and that was an experience I had. After that I knew it was going to happen every time I went in. As I said earlier I probably had about 15 operations and things gradually improved. They then started giving you pre-meds because I was always very sick after every anaesthetic and I still am to this day. My body doesn't like anaesthetic even though I have to have a load.

[04:47]

How did you think of as a profession then or compared to today's national health services? You told us that you never was referred to an audiologist. If and when were you ever asked to see an audiologist? Was it after Mr Wogan and have you ever been asked to go to hearing therapists or even lipreading?

It's changed drastically. In those days I remember the consultants would come round, stand at the end of the bed, and talk about you and not to you. I remember I used to say to them "what have you done to me"? Well, I lose my hearing, because they used to see we've had to go behind the eardrum and I thought the eardrum was the way you heard things. Obviously I have much more understanding to it now. They would just say no, no you're okay we've just got to get these polyps out of your ear, get rid of this infection you will be okay, you can carry on life as normal, you can go swimming, you can play your football do all your sports, nothing can go wrong you're in our hands, you're in safe hands. No comforting no words of comfort and no explanations not even to my parents. My parents used to say to me you're in good hands they know what they are doing. But now I ask questions -- older and wiser, I ask questions. Chris won't let them do anything to me until we know what's going to happen. We find out what they are going to do and about I would say approximately eight years ago I saw the consultant who eventually he got my ear dry and then he said to me

we're going to concentrate on your Meniere's disease now because I was having so many what they call drop attacks. It was about 22nd December.

[07:09]

I can't remember the year but I'd say eight years ago, nine years ago, Chris and I drove into town, into Southampton, to do a bit of Christmas shopping and it was either Chris or I were going to the car parking meter to put the money in and next minute I was on the floor being very, very sick. The whole world to me was spinning. I couldn't focus on anything at all and the tinnitus was so loud in my left ear that I thought my head was going to explode.. We were both frightened. Chris went up to a traffic warden or car park attendant -- I can't remember what it was -- asked him for help, could he ring an ambulance or could he stay with me while Chris went to ring an ambulance. This was before the time of mobile phones. He looked at me and said fancy being drunk this time of the morning. I'm not going to help drunks and he walked off. So I was left there while Chris had to go off to ring for help. I was eventually taken to hospital, eventually discharged, taken home. A little while later the following year, probably March time, Chris and I went up to London with our good friend I mentioned earlier and I went to a woodworking exhibition at Wembley Arena, had a lovely day, plenty to eat, no drink because we were driving, my friend was driving I was a passenger, I was approaching my, I think it was my 40th birthday so it would have been 12 years ago actually, and on the way home at Fleet services I had another bad Meniere's attack which at this time didn't know it was Meniere's. I was violently sick in the car so poor Chris and our friend had to drive home with me being sick in the car. I was dizzy, I didn't even know where I was. Eventually talking to the consultant he said well, we can give you medication which I now take beta histamine stemetil tablets and I would have to learn to live with it. He said what I will do is I will send you to see a hearing therapist which he did and she was lovely. She arranged for me to have balance therapy which unfortunately I can't -- I've tried twice since then and I can't do because as soon as I start to do the balance therapy I go dizzy and I fall over. I've tried to get my brain to adjust to the Meniere's but there is no telling when I'm going to get an attack. Unfortunately, because of the Meniere's I've gone completely deaf in my left ear and I only have 20% hearing in my right ear. I have since seen the hearing therapist again and she's there if I need her. That's as far as she can take me.

In the meantime, about ten years ago, I was sent to see an audiologist who confirmed that I have no hearing in my left ear. They call it a dead ear and also that I only have 20% in my right ear.. They gave me hearing aids but they said I might pick up a little bit of sound in my left ear but unfortunately I couldn't hear anything at all so they took that away. The hearing aid in my right ear was okay to start off with and I always remember the very first sounds I heard was a crisp packet or paper bag being screwed up and I thought it was wonderful. I've since had new hearing aids but because of the Meniere's which has now gone bilateral, I now struggle wearing hearing aids. They tried me with new ones but the power of them causes me to have balance problems. I was assessed for a cochlear implant last year at the start of the year but unfortunately because of the Meniere's disease they were very unhappy about doing it.

[12:12]

Can you remember how you found out or who may have recommended you to the organisation called LINK, a charity for people, for adults with acquired profound hearing loss?

Yes. Because I attend the ear, nose and throat department regularly, Chris is a great leaflet collector. Wherever we go if there's a leaflet she'll pick it up and one day we were down the department and before I get to LINK we saw a hearing dog leaflet and we took that home and we read about it, made no commitment and after a while, we decided to just send off for an information pack. Amongst the leaflets was a LINK leaflet and I thought what's this? Now I was going through a very low stage. Because my hearing had deteriorated and like a lot of deafened people you think why me, where's life taking me, my children have grown up and left home making a life for themselves, I felt I was holding Chris back, things got on top of me. So I thought well, this leaflet says they can help me. So I asked Chris to fill it in, send it off and see what happens. This was probably 2005, near the end of 2005. We eventually got a letter from LINK explaining what was available for me and would I like to see an outreach worker and also they wanted a copy of my audiology report and just a brief description of my health problems. I made an appointment to see Penny, my hearing therapist, who supplied the information for me. We sent it off, LINK arranged for an

outreach worker to come and see me, she came the once, just described what the intensive programme is about, and we had our name put on to a list and we eventually went in June 2006.

How do you think going on that programme helped both you and Chris and also has it rubbed off on to your children?

I didn't want to go on the programme when the time come, Colin. I became nervous, I'd never stayed in a hotel before believe it or not. I didn't know what to expect and I thought I was the only one, to be honest, with my condition. I was worried that I would have an attack and I would be stuck in the middle of nowhere. I've never been to Eastbourne. I would be stuck in the middle of no where with no-one to help Chris get me home. But we went in the hotel, had a beautiful room overlooking the sea front and it was a lovely sunny day and it was also Father's day and Chris had brought a couple of cards down for me from our children and a couple of presents because they never come with us because they had their own commitments. It was the unknown for Chris and I. All this time Chris was my ears. She was my right hand, she looked after me and she cared about me and I relied on her very, very heavily. That evening we went for a meal, all sitting round the table looking at each other, everyone's too scared to say hello, who are you, what are you here for. But then we all had small talk and we all went to bed. Next morning we had to go to the Osborne room. We went in, there was a row of seats and I saw someone typing on the wall and it was great. I could actually instead of struggling to hear what people were saying to me I could look and read what was being said and that was my first time I'd seen a Palantypist and I was so happy to know that that was available for deaf people. That's what struck me most, that I wasn't alone because I was worried how I was going to communicate. Usually Chris and I use a pad especially in a situation when background noise is there and I thought how can I sit in a room with a lot of people talking knowing how I was going to hear. We were then introduced to Jenny who put us at ease. Obviously she realised we would all be nervous and as the time went on, the week went on, we all became good friends. Chris became to even though she'd been so good to me, she read up on my illnesses, she understood what was happening, I think it made her realise what a deaf person actually goes through.. We've always been very close together. That week, I think, brought us closer.

You mentioned that Chris is very observant and wherever you go to get help she picks up this leaflet and you've mentioned hearing dogs. Would you like to tell us or elaborate a little bit more on what happened from the information that you gathered.

Yes. When you attend the intensive programme at LINK, they set you goals and I hate that phrase. I go to a lot of meetings and what's your goal for the meeting ... I hate it. So I sat down with Jenny actually and I discussed this with her. I said I don't like setting goals. After our discussion and having my arm twisted, I set three goals. One of them was to contact hearing dogs and say yes, I would like a dog. The second one was communication, improve my communication and lipreading. The third one was to go in a supermarket on my own and actually go up to a till on my own. If you are a hearing person you don't realise how difficult that is for a deaf person and how embarrassing it can be. So between us Chris and I have achieved all three of those goals. I now have a hearing dog called Yogi I pestered hearing dogs and said look it's one of my goals, how soon can I have a dog. They sent someone down to interview me which took three hours, I was totally exhausted because I had to rely on the lipreading when the person was there he took a photograph of me and said would I like large, medium or small. I said I'd look funny with a Yorkshire terrier so could I have a medium dog, please, and eventually I was sent a photo of Yogi which is a very sad story I won't go into now because of everything, and I went to see Yogi, spent one night with him. We had to stay in a one bedroomed accommodation, no kitchen or canteen in there. We had to go to a restaurant to have our meals. We were taken to the bed sitting room where we were staying which is like a little bungalow and straight away the trainer we hadn't even unpacked our suitcase said I'm just going off to get Yogi so you could see him and I was so nervous. My confidence was beginning to go down a bit but Chris was there bucking me up and along came this dog and the first thing he did as soon as she opened --they were like stable doors the top half was open I could see her coming she opened the bottom half and walked in. The first thing Yogi did was come up to me even though he'd only seen a picture of me, he'd never met me, he rolled on his back and wanted me to tickle his tummy. So like all those years ago when it was love at first sight with Chris, it was also love at first sight with Yogi and I'll be honest with you I actually -- it actually brought a lump to my throat the next day when I had to leave Yogi behind because he had to have all his sound training and I wanted him then because I knew he was going to make so

much difference to me. A few months went by while they trained Yogi to the sounds that I need. Eventually we were asked to go up for 5 days and we went up for five days, spent the time with Yogi and we then passed our week together. I then took Yogi home, my trainer came down from the centre for the first three days to spend time with me and Yogi to teach me how to work him, and also I had to read two great big manuals to learn about hearing dogs and how he's got to work for me. Then on January 11th last year he became a fully qualified hearing dog and he's amazing. Considering the life he started of with where he was found in a dustbin in Ireland at 5 weeks old with four other puppies. A gypsy family were walking by and heard the dogs whimpering. They told the farmer whose land it was. They kept one of the dogs, the farmer rung hearing dogs who had a trainer out there who just goes round rescuing dogs and sends them over to England. He accepted all four dogs, sent them to England where they were trained to become hearing dogs. I've heard recently that they all nearly died because they were only five weeks old and they hadn't had much of their mother's milk. They needed boosting urgently so the vet put them on a special milk programme which, touch- wood and thank God that they survived and three of them have changed people's lives, including mine.

[24:08]

You mentioned earlier on and I want to go on this the impact of deafness to you but you mentioned that you learnt to drive. That must have been most difficult for you, Steve, because having hearing difficulties would you like to tell us can you recall how you got over these difficulties to learn to drive.

Determination. I'm a very determined person. When I'm going through a bad stage with my ears I'm determined, Chris will tell you I'm stubborn. If I set my heart at doing something, I'll do it. Unfortunately, if I set out to do a job now which takes me when I was younger and fitter without the Meniere's if a job took me two hours then it will probably take me two days now. But at the time my father had passed away, my mother unfortunately drove but found it very difficult and, like I said, we kind of felt isolated because no-one else we knew who drove only my friend and we used talk walk everywhere as a family. We thought nothing of walking 13 miles at a time

especially to the navigation from Southampton to Winchester. We would go on walking holidays and just walk. We loved it. But shopping and everything was becoming difficult.. I used to ride a bicycle and what with not hearing properly and my knees being painful and losing jobs because of my health, I felt the only way I could do it was learn and I was very, very fortunate. I had a very good driving instructor, a very strict driving instructor. He knew I had health problems. He was very patient but he wouldn't let me get away with anything. He wouldn't let me use my hearing as an excuse. Eventually I passed my test second time and it's opened up a lot of things for us to do and I absolutely love driving. But I do have occasions when ambulances with sirens are going behind me and I don't hear them it's not until I see the flashing lights in the mirrors I realise there's something behind me.

Are you able to drive with Meniere's disease?

Yes, I am. I do know if I'm having a bad day or I don't feel right I won't drive. I do know that if I'm feeling -- even if I have a head ache and I will light headed it's possible it could cause Meniere's I won't drive. I know the warnings. Unfortunately with Meniere's disease it alters your life because we can have a bath or a shower, get changed, tie on, ready to go out for a meal to meet the family, have all the arrangements made and then at the very last minute I have to say to Chris I'm sorry, Meniere's is coming and she has to quickly get me upstairs: me into bed, give me an injection. She's been trained to inject me and then I could be out of it for 36 hours. We've had so many appointments and family things that we've had to cancel and that's when I feel bad for the partner of anyone who has Meniere's because they have to cancel it as well.

[28:01]

During this period of your life, have you and Chris ever encountered any prejudice or discrimination that has confronted both of you regarding your disabilities?

More so since I've had the hearing dog. Chris is a very strong person. If anyone upsets Chris, she'll tell them if they are wrong. She'll stand up for herself, she'll stand up for me, the same as I will stand up for Chris and myself. If I can't hear anybody

talking to me, Chris will say don't talk to me, talk to Steve.. He's deaf not dumb. A lot of people when you're deaf look at you as if you're dumb. They don't involve you in conversations. If you are blind you have a white stick. Deafness is a hidden illness. It's a hidden disability. I don't see why I should go round saying to everybody "hey I'm deaf". They should talk to me as a person. We've encountered problems where people don't talk to me, we've encountered problems where I've had to call Chris over because people have spoke to me, I've not understood them, I've explained to them that I can't hear them, could they speak clearer and they still put their hand in front of their mouths so I can't lipread them and they turn their backs. There's a course which was run in Southampton last year which I wanted to attend. It was a pain management course because I'm in severe pain with my knees every day, especially at night-time. I went to go on this course. They wouldn't let Chris come with me because it's meant to be what goes on in the room stays in the room because there would be ten other people there and because they wouldn't have partners there they wouldn't let me take Chris with me to be my lipspeaker. I felt that was a Disability Discrimination Act. They arranged for a young girl to sit in with me who knew nothing about deafness. They said she would be a note taker and a lipspeaker for me. Every time they wrote things on the board, she was trying to talk to me at the same time, I couldn't follow her, the board they had their backs to me when they were talking even though they were writing on the board. They had a loop-system which for partially hearing-impaired people not profoundly deafened people. They couldn't really handle the fact that I was deaf. I brought it to their attention. I never went again.

[31:27]

You may have had to travel with Chris to various appointments or functions and do you find travelling on buses or even railways perhaps you've flown, any difficulties with communicating with the operators?

I don't like going on the bus. One of the things Chris makes me do is very occasionally take a bus trip into Southampton just really to make me confident. The bus drivers now have screens on. If it's sunny the light reflects on the screens, you can't see them very clearly. The train journey getting on the train is okay, getting the

tickets is very awkward. In Southampton last year they closed down the ticket office even though it's a large train station. There was a lady in there when I used to go in to book tickets ask information she was fantastic. She knew my deafness, she saw Yogi with me, she spoke very clearly. I said to her what's going to happen when you close this down for disabled people? She actually said to me any disabled people will have to go to the self-dispensing ticket machines or go to the counter. Just recently I went to the counter to book some tickets to go to London. I couldn't understand the man, he was talking to the machine not to me. I then explained I was deaf, he looked at me, asked me for the money and I said pardon how much? In the end I had to call Chris over because I thought he said a price, I wasn't clear how much it was.

How did you find travelling on an aeroplane with Yogi?

We've had one experience of that. LINK asked us --Chris and I trained as outreach workers. They asked us if we would go to Edinburgh for the next training weekend. I agreed to go with Chris, explained about the Meniere's disease it's a long way for us to go by train. It was suggested we could fly up from Southampton to Edinburgh. Very, very nervous when I fly I get bad earache because of the Meniere's. Woke up in the morning shall I go, shall I not go, a friend dropped us off at the airport went in Chris was speaking to me calming me, went to the plane, I did not hear the plane being called. There are screens there but there's a lot of people gets in the way of these screens. I would have struggled without Chris. Went up to the plane steps with Yogi, walked up the steps, a funny story first as we were going through Customs they made me take his lead and collar off to make sure there was nothing hiding underneath them contraband or whatever they call it they felt all under his coat they wouldn't let me take his coat off they said if I take his coat off I could possibly take the drugs away as well so they had to feel -- so Yogi was frisked and didn't realise even though I was I only going from Southampton to Edinburgh I had to take my belt off, my shoes off ... as we arrived to the entrance to the plane, the lady was very, very nice the stewardess. She said it's the first time she's had assistance dog on one of her planes and she welcomed us, took us to the seat and then she actually come up to us and said that she would be doing the safety talk, she would face me when she was doing it and when she's finished if I had any problems when the plane is in the air she would come up and talk to me personally which I thought was very nice.

This explanation of taking things off of the dog do you think that's discriminatory?

Yes, I do.

[36:19]

Obviously being disabled you would encounter people like Social Services and getting the benefits from the agencies. That must have been very difficult some time ago. Would you like to enlighten us on some of the problems you might have had. Are you able to get them quite easy?

Yes. In Southampton they have what's called a Disability Social Services Department. They also have a Sensory Social Services Department. They don't work together. So because of my knees I have a social worker who deals with my disability with my knees and a few years back I started having trouble getting out of baths etc. So we rung her up and she came along and I explained the problems I was having and she actually said to me have you been in contact with the sensory department and I said no. But Chris had known of them because she used to work with a blind group as a volunteer and we were put in contact with them and they actually came out to assess me and the lady was very good. She said I could have a loop-system put round the house and a pager system because I didn't have Yogi at this time and I found it beneficial.. The thing I did find most annoying was they couldn't give me anything for my music. I absolutely loved music but unfortunately, like a lot of deafened people, I can't listen to music now. I was very silly because at that time she offered me a telephone, even though it was a minicom-type phone I refused it. I said no, I can still manage with my hearing aid on a normal telephone. When I attended the LINK course we had a chap come over who worked for BT, left on the Isle of Wight and came over with all this equipment from BT. We were talking and he demonstrated a new Typetalk phone with a screen which Chris can use as a normal phone and I can use as a Typetalk phone. I felt I wasn't really ready for it. It's a very, very expensive phone but I was told I could get them on Social Services. So I left it and then a year ago because of the state of my hearing now, I wrote to Social Services and said can I please be assessed again with the possibility of having a Typetalk phone. The

answer's come back and said in October last year they stopped providing telephone equipment because of expenses. So I now can't use the phone very well and I haven't got a Tynetalk phone. I can't afford the £280 plus for one.

[End of Track 4]

[Track 5]

Steve, do you believe you've achieved everything to give you a better way, a better life with all your disabilities?

I wish I could have done more with my children. I wish I could do more with my grandchildren, i.e. take a ball out with my grandson, play football with him, header a ball. I occasionally take them swimming. I have to wear special ear plugs. I don't feel safe in the water now even though I love it. I wish I could do more for work. Unfortunately, now I can't work. I've had to give up work completely. I rely heavily on my voluntary work which I do. I do voluntary work for LINK as an outreach worker. I think that keeps me sane because I meet people like me, been through the same problems as me, I meet people who need help and I feel if I can help one person I've achieved something. I've met some lovely friends from LINK, some which I cherish forever. I've met some nice friends through hearing dogs. I now enjoy giving talks about hearing dogs which helps my confidence and gets me out of the house and explain about deafness to people who aren't deaf. I explain to children about deafness, about hearing dogs and about the way deafness can affect you, especially with their way of life with music they play. I explain to them that they have to value their ears, they have to look after their ears. The future: who knows?

[02:33]

Now this is a real posing question that I'm going to ask you. Say somebody like your ex-work colleagues, your friends or a friend, somebody in the family even, came to you one day very emotional, pointing to their ears and saying, "Steve, I can't hear any more. What shall I do?" What would your advice be to them?

I would sit them down comfortably, calm them down, explain that they need to see a GP straight away. I would then straight away give them LINK's telephone number and say there's someone at the end of the phone who's not a member of the family, not someone you know, who would give you information about where to go, what to do. If they are good friends, they know my story. I would tell them that there's light at the end of the tunnel. I would tell them that I am there for them.

Well, Steve, I just want to thank you very much. It is a most interesting story, full of content and I'm sure will be helpful to many in the future.

Can I just say I am very grateful to LINK for this opportunity. I'm grateful for Colin for listening to this. Most of all I'm proud and grateful to my wife for standing by me.

Wonderful. Thanks very much Steve.

And can we thank Georgina for the marvellous work you've done.

[End of Track 5]

[End of recording]