



# Unheard Voices: interviews with deafened people

Sharron Pridham  
Interviewed by Christine Beal

British Library ref. C1345/28

## IMPORTANT

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## Interview Summary Sheet

**Ref no:** C1345/28

**Collection title:** Unheard Voices: interviews with deafened people

<b>Interviewee's surname:</b>	Pridham	<b>Title:</b>	
<b>Interviewee's forename:</b>	Sharron	<b>Sex:</b>	Female
<b>Occupation:</b>	Sales Manager	<b>Date and place of birth:</b>	1977, Exeter

**Date(s) of recording:** 15<sup>th</sup> March 2009

**Location of interview:** The City Inn Hotel, Bristol

**Name of interviewer:** Christine Beal

**Speech to Text reporter:** Hilary McLean

**Type of recorder:** Marantz PMD660 on compact flash

**Recording format :** WAV 16 bit 44.1 kHz

**Total no. of tracks:** 2                      **Mono or stereo:** stereo

**Total Duration:** 1 hr. 36 min.

**Additional material:**

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**Interviewer's comments:**

[Track 1]

*This is Christine Beal interviewing Sharron Pridham on 15 March for the Unheard Voices project in Bristol. The speech-to-text reporter is Hilary Maclean. So, first of all I just ask you a bit about your background if that's OK. Could you tell me your full name?*

My name is Sharron Rachel Pridham.

*Have you got a maiden name?*

Maiden name is Hole - HOLE.

*Can you remember your mother's occupation and your father's?*

My mother's occupation she still works, my mother is actually a medical receptionist for a GP's surgery. Unfortunately my father has passed away but he was a panel beater with car repairs.

*Where were you born?*

In Exeter in Devon. I've stayed in the same place I was born.

*Have you got any brothers or sisters?*

Yes I've got one brother. He's 4 years older than me.

*And what about your grandparents?*

I haven't got any grandparents left. Unfortunately they've all passed. I've actually got, she's my step grandmother but to me she's my grandmother. She's the only one still alive.

*Do you remember the area in Exeter where you grew up? Was it a house or a flat?*

Yes pretty well, yes.

It was a house.

*Did you have any pets?*

Yes, I had quite a few over the years. I think most people had a gerbil, we had a dog, a dog for many years. We had two or three dogs whilst I lived at home. I've now got cats. I'm a cat person

[02:44]

*Do you mind if I ask - were you born deaf? were you born with a hearing problem?*

No I was born with full hearing. I'm 31 now, had to think there, and I started to lose my hearing when I was about 21 and I have no hearing at all now and that's been since about 2005.

*What year were you actually born?*

1977.

*So you had no problems with your hearing at all as you were growing up?*

No, not at all. No, no.

*Did you have a good childhood and schooling?*

Yes I think no different to anyone else really. Everything was fine.

*Would you tell me what happened with your hearing, how it actually, how you lost your hearing?*

It's always difficult to make this a short story –

No *that's OK*.

I have a genetic condition called neurofibromatosis type 2. My late father was the spontaneous, was the first person in our family and when my brother and I were created my parents weren't aware that my father had the condition. My father had had brain tumours removed in the early eighties but the surgeons just thought it was just sort of one off brain tumour still hadn't linked in that we had this genetic condition. My brother was in the navy and had an accident. He was on the ships, had an accident on board ship and we believe there was something in the medical notes possibly linked to my father that led to my brother having an MRI scan, subsequently these tumours were found. I had actually had an epileptic fit and I was waiting for an MRI scan when it happened. My brother's my MRI scan was brought up quickly and within the space of a week both my brother and I found out that we had tumours and whole family was diagnosed with NF2, that was in '93, a very, very tough year for us. We learned a lot about neurofibromatosis. One of the main things is losing your hearing in a very short space of time. One of the routine checks for neurofibromatosis is the hearing test and back in '93 I had above normal hearing. Everything was great. I knew that I was very likely to lose my hearing but at that time everything was fine. My tumours were actually quite large for somebody of my age. I was 17 when I was diagnosed and they wanted to operate, they wanted to take both of them out very quickly, and I would have become totally deaf within the space of months which was something I just could not comprehend at all. I looked into other forms of treatment and I actually had radiotherapy. Unfortunately that was unsuccessful and the tumours carried on growing and gradually over the years I started losing hearing in one side. I still didn't have a hearing-aid at that point because the hearing ear was so good I was very much found myself turning in situations I could cope pretty well with only one side of hearing loss. The tumours became quite large and I knew I needed surgery otherwise I was going to die. It was really that bad. And I had the tumour removed and lost all the hearing on that side. I think because the pressure had been released within my brain the hearing went up a little bit in that ear so again yes I could cope quite well. One ear, this is easy. But I can do this. That was '99. Between '99 and 2001 my hearing started to drop in the other ear, things became more and more difficult. It was actually my boss. I was still working full time. I returned to work after the operation, 6 months off work, and it was

actually my boss who said I really think you ought to get a hearing-aid, you're really struggling. I knew consciously I needed that but I didn't want to have a hearing-aid I was 21 and still wanted to hide it and everything but eventually after a lot of persuasion yes I got a hearing-aid and it was good. It made me realise I should have got one sooner. As the hearing went down the hearing-aids got bigger. I eventually got a digital hearing-aid but I think that my hearing had deteriorated so much by then I didn't really get the quality of sound from it I was really really struggling. And in 2005 my hearing seemed to really drop off. I really wasn't getting any use from the hearing-aid at all. I was quite surprised within a matter of days everything really changed and I wasn't getting anything in 2005. Took the hearing-aid out and since then totally deaf. I had a hearing test to make sure definitely there is nothing there, which was quite weird, because I could feel how loud the beeps were that were being bashed in to my ears but I definitely couldn't hear anything. I've been deaf coming up 4 years now.

[09:22]

*What about your brother? You said he had the tumours as well. Did he have the tumours?*

Yes. Sean has had the same as me, the radiotherapy treatment. He had a slightly more positive result from me but wouldn't say it exactly words his tumours are still going unfortunately although he's 4 years older than me his tumours are quite a bit smaller so he's not in the stage where he needs surgery. We unfortunately don't have a close relationship and I believe that a lot of it is to do with genetic condition we've got. He still blames my father but my parents didn't know. I would never blame my father. He didn't know. I do know that Sean is losing his hearing but he doesn't want to do anything about it any hearing-aids or anything, he's in a very bad place at the moment.

*It is a genetic condition then?*

Yes. Every child he's got 4 children, every child once you have the spontaneous mutation every child has a 50, 50 percent chance of getting, unfortunately both my brother and I have it.

*Have his children been tested at all or are they too young?*

You can have children tested from birth if you wish, from a simple blood test. My brother and his wife didn't want to know, didn't want to think about it, my oldest niece is coming up to 16 now and it's recommended that tests should start maybe after about 10 years old, Gemma has been tested. She was tested about 2 years ago and yes unfortunately she has got it and 2 middle children have been tested but we're waiting for the results. We don't know. We don't know yet.

*Must be very difficult I would think though because obviously you didn't know about it til obviously sort of late teens, so must have been a bit of a shock for you after having normal hearing.*

Definitely it's been the biggest change in my life. I can remember I was quite young when his father had his brain tumours removed and started to lose his hearing, out of work, all the changes of that, and when I was told that I had the tumours I didn't think about immediately didn't think about an operation. All I could think about am I going deaf and look how horrible life is for my father, really worrying time. I didn't want to be like that. I'd seen how much it affected him, how low he'd got, how hard it was to get support. Bearing in mind that was in the eighties. Things were still very difficult for me but I can see support is a little better than it was when my father went deaf. I suffered from the late teens early twenties my father started losing his hearing probably late twenties early thirties so slightly different between us but still very difficult.

[13:04]

*Was it difficult for your mother?*

Yes. When you are in it you can't see that. Now that he's gone we can talk about it. My poor Mum felt so hopeless because four of us and she was the only person without it she felt so helpless. Feels awful to say it but at the time you think you haven't got it you should be fine. I'm older now I can understand where she's coming from. Mum just wanted to do something to help. It was awful. She worked in the medical profession. She felt she should have diagnosed it sooner even though she's a secretary not a brain surgeon. She started running marathons. She'd never been fit at all. He was quite a large lady and she started running

marathons to raise money and so proud of her for doing that. She's run three marathons.

Really proud and she still felt helpless but it was her way of feeling I'm doing something I'm raising money anything to help, it definitely affected my parents marriage definitely. It was very hard for my Mum.

*They stayed together?*

Just about. I can remember hearing arguments that they were staying together for the children. It was hard. Really hard.

*You said your fathers passed a way now. Was that anything to do with the tumours or just naturally?*

It's really unfortunate really sad story. My father had surgery in 2000 to remove a tumour that had re-grown acoustic neuroma, and he had an auditory brain stem implant inserted, have you heard of those?

*No I haven't.*

They're similar to cochlear implants but they're about 30 years behind in technology, I actually had one fitted in my operation. I don't use it now. When I first - because I had such good hearing in the other it wasn't very useful hearing this noise but I could see the benefit of it when I lost all my hearing you'd be aware of environmental sounds and from things I spoke about my father who by then had lost all his hearing thought yes actually may be I could have one and was really surprised when he asked the surgeon can I have one and we got letters and campaigns. Surgeon, yes of course you can. So my Dad was really pleased he'd had the implant. The surgery went well. It was long, difficult tumour operation. About a week after the operation he wasn't right. They thought he had an infection. They couldn't find anything. Started to run tests and he actually died of DVT.

*Deep Vein Thrombosis?*

It was awful. Probably wasn't the operation. They don't know what caused it. Blood clot to the heart. Gone!

*How old was he?*

My Dad, 51 I think he was.

*Not very old. Sorry, yes.*

Literally saw him for 10 minutes. Our healthcare is based at Cambridge a centre of excellence for the condition and very difficult seeing him, went in that day and he didn't look right and we were literally with him 20 minutes and he just went straight in front of us. Hard.

[17:13]

*Goodness, yes. It's a condition I'd heard of the condition but I didn't know what it was. It's interesting for me to hear. So now do you feel that you've been sort of treated very well by the National Health Service?*

I don't think I was initially. Neurofibromatosis is extremely rare and I appreciate I do appreciate that. My nearest neurological hospital at the time was actually Plymouth which was about 30 minutes away from me. I understand surgeons do have difficult jobs and they have to give out bad news. But the way I was treated, I had a brain scan on the Tuesday, the GP gave my Mum the results on the Friday, my poor Mum had to come out and say yes you had got tumours. I was down the following Tuesday to see the neuro surgeon and I took with me my Mum, my Dad, still lived at home 17, my boyfriend at the time who's now my husband Simon came down, as soon as we went into the room "who are all these people?" He objected to having extra chairs brought into which the nurse was rolling her eyes, for goodness sake she's a young girl, she's brought her support network here with her. Basically he was very brash. There were no scans on the wall. He just said right as you know you've got brain tumours, no mention of neurofibromatosis, nobody had told us you've got brain tumours what's going on just thought it was a horrible coincidence. Basically you've got brain tumours what we need to do is operate and take them out and you will lose all your hearing and we were completely dumb struck what do you mean. Straight away, what else. And he was very cold almost he wasn't going to answer any questions. It was the complete worse day of my life, complete shell shock. My brother was adamant they were not going to have

surgery. Fortunately for him his tumours were smaller. Somebody had mentioned to him about this radiotherapy so I asked my brother blah blah blah the radiotherapy, you can't have that the tumours are too big you can't have that is it worth can we meet blah blah blah, can we try and meet, oh yes I'll write the letter you can find out and it was based radiotherapy based up at royal Hampshire hospital in Sheffield, we met the chap there, very helpful very honest and said the tumours are on the larger side this possibly what could happen and these are some of the results I've had. He spoke about a lady that had similar to me similar size tumours he said I gave her 12 years of hearing which at the time still sounded really short to me but I actually got a similar time scan to her and I think yes I still had another 12 years so he was very good very helpful. I had the treatment. Think it was fine. We just weren't happy. We didn't have confidence in surgeons at Plymouth. Plymouth is where my father had his operations and when we found out we had this genetic condition the surgeon in Plymouth said that he knew but he thought it was better that we didn't know which was ridiculous because my brother if he'd known may not have had the children, of course we love them and wouldn't be without them but taking a great risk with their lives. We did go down the road of possibly looking at a negligence case because they should have told us. We had a right to know that we had a genetic condition we might have made different decisions with our life. We didn't know what to do really. Very limited information about Neurofibromatosis. We have an annual weekend specifically for people with NF2 at a hotel have speakers come in have surgeons, geneticists, hearing dogs, you name it people come in and talk to us and that year there was the surgeon from Cambridge that came in who was trying very much to build up a reputation as a centre of excellence and he just seemed so human, and we asked to be referred and I went to meet him and he's lovely and I don't know what I'm going to do when he retires. He looked at my notes. We had the appointment, looked at the scans, decided to have an operation, everything is OK my scans used to have hearing tests everything at Cambridge I don't have anything to do with my local health authority.

*So you travel up to Cambridge every time.*

Yes for everything. I think it's hard for the scans it's a little bit annoying to travel four, five hours for a 20 minute scan but Mr. Moffat my surgeon, I believe MRI scanners are different in hospitals and he's got his own scanner his own radiographer and I have to have it there. On average it's one scan a year and one appointment so it's not too bad and they are kind. If they

can we will combine the two into the same days. For the confidence I have in them and the peace of mind it's worth it.

[23:28]

*As you get older do the tumours get less as you get older or do they more likely to grow faster, is there any set pattern?*

NF2 - that's it for short - is extremely erratic and no person is the same. Normally will follow similar patterns in the family. I'm a little bit different. I started losing my hearing a little bit sooner than my father but my brother looks like he's going similar to my father. It's the same - I was quite surprised how much smaller my brother's tumours are compared to mine but he's older, everybody is very different. I'm very fortunate at the moment and I'm really quite a rare case my tumours stopped growing in the last three years. Nobody knows if that's it for the rest of my life or it my change tomorrow or next year or five years. Nobody knows. That's a very strange feeling to get your head around. I'm aware of it but I put it on the shelf and I try my hardest to get on with my life. I would never wish to cause offence to anyone with cancer but all I can explain is I feel like I'm in remission for the rest of my life I don't have a 5 year goal. I might get to 5 years and it can still change in 6 years or 20 years time. The fact that they're not growing is amazing so I'm very rare. And I know I'm really lucky. Lucky that they're not. In my early 20s they were really, really growing which apparently is quite normal. In your twenties you go through quite a growth spurt. It's very hard question. Really different for everybody. I think that's why it's such a difficult condition to treat. Nobody can give you any clear answers.

[25:32]

*Because obviously you were very young, so did you get - obviously you said you had your boyfriend then, later married, but did he find it difficult? Did he know you when you had full hearing?*

Simon - yes it was difficult because we'd been together a year, we were 16, 17, we were in love, everything hunky-dory, suddenly bang got the diagnosis in my head I'm thinking I know I'm likely to go deaf not quite sure when but it will happen it was inevitable and we had a very

difficult conversation and I said I love you and you love me and we want to get married one day but this is going to be a really difficult road for us and you can see what's happened between my Mum and Dad. I don't want that for us. I said to him I knew that I put him in a really hard situation but I said "stay with me and help me through this or leave me now if you don't think you can cope with it". I can just about cope with you leaving me now I will get over you and life will go on. He was horrified that I had asked him that, said "I love you, we'll go through this". He seemed so full of admiration for me, how I coped with it and we were saying no it's affected you as well, it affects every aspect of our relationship. I'll try and have that conversation with him quite often specially as I'd gone through a lot of change before I went through an intensive week in LINK 2 years ago I was in a horrible place I wasn't me I had lost my confidence I wouldn't go out with friends I felt I was a burden on Simon he was almost my interpreter all the time and he's always been really good. I know he finds it hard sometimes when I've said no I don't want to go out but it's never caused an argument. He's always been OK about. I feel really bad. I feel like I've let him down when I don't have the confidence to go out. It's hard because I expect him to say more but he doesn't. He always says it's fine it's not me, it's you. He's my rock. I don't know what I'd do without him. He's great.

*Right from the early stages of your relationship he was like that then.*

Yes. I don't think this has changed him I think that's the sort of person he is. With everything we had to go through, together a year, then radiotherapy - surgery was hard for him, I know that. He went quite quiet in the build up to the days before the surgery and when I had the surgery he wanted to be on his own which was fine my Mum and Dad went off somewhere for the day and Simon went to the pub at the hospital, played some pool, he needed time out to get his head round it and in the evening I was in intensive care for the first 12 hours and like everyone who goes into intensive care machines and tubes and what not and Simon, like a lot of men doesn't like hospitals he was OK and he came in, they all came in together to see me. My Mum was really shocked. Apparently my facial nerve it had been saved but of course I had 9 hour surgery, not to my face, had changed significantly my Mum was really shocked at how I looked and thought "oh my goodness what have I let my daughter do". Simon has never admitted it but I think it was obviously a shock to him too. He actually passed out in intensive care bless him. I'm not sure if it was just my face or the tubes. Suddenly the nurse was all "are you all right" and he went white and he ended up on the floor

with everyone looking after him. It's hard because I'm a woman I like to talk a lot express feelings tried to get him to open up about it but he says he's fine. Again that was a lot that we learned about each other at the intensive week in Eastbourne I was really worried about Simon thinking he was trying to protect my feelings not opening up about how it affects us and the week was brilliant. When it came to summing-up in the end ... Simon realising how good it was. I wouldn't want to say I took him for granted I just didn't realise how he really felt about it. He just sees me being deaf part of who we are. I think because, I mean we've been together for 16 years. I had hearing for the first three or four years then when my hearing has gone gradually we've learned to cope. When we used to go for meals which side of the table is she going to sit on that sort of thing and as I've gone completely deaf yes it was really difficult for us when I went through the low period and I know he's definitely happy now that I've come back to being who I was before, pretty much, I'm OK, I'm really lucky, I can lipread really well. I'm OK we've been through a lot but he doesn't really doesn't really talk about it – but that's how he deals with it, not to worry about him he says he's fine.

[31:40]

*Going back to when you were first diagnosed obviously did you have apart from Simon have a good circle of friends and that? Did that change after your hearing - after you lost your hearing. Did that alter at all?. Did you find people treated you differently?*

I think, I was quite a typical teenager when I got a boyfriend and my friends didn't have boyfriends we dropped off a bit any way but definitely as my hearing went down I became withdrawn, people didn't know how to communicate with me I definitely became very isolated. It's a horrible thing to say but you certainly learn who your friends are when people won't persevere and again I saw that in my father I can remember, I would ask my Dad to communicate when my Mum wasn't around I would go out with Dad and help and can remember one evening I think there was one of the Grand Prix cars coming down do local car dealer ship and Simon and I and my Dad went out and there was a man that they'd been friends with for years I think to caravanning and what not and he was one of those people who you call Uncle Ted and he saw us he didn't realise Dad had lost his hearing oh you all right John. He didn't realise he had to get Dad's attention. So I was “oh Dad, look, it's Ted”. He started talking and I interrupted. “Really sorry Dad is deaf now. Do you remember we had an operation”? You could see instantly he looked different in the face and he pulled away

from the conversation very quickly. He spoke to Simon and I Simon who he'd never met and me who he only remembers as a little girl and I felt awful that my Dad had been knocked out of that conversation. I definitely hit a real low before I asked to go to the intensive course at LINK and that was yes nobody - I didn't really have any friends. Nobody at work really talks to me. I felt guilty in that that I lean on Simon. He's not just my husband he's my best friend it's not fair to lean on him for all of that.

[34:21]

*What was your job at the time?*

I still work, I can't believe it, I work in retail. I wanted to be a primary school teacher. I was in college when I was diagnosed doing foundation courses and I couldn't help it, I didn't want to be a deaf teacher. I know that's very narrow minded but I had an idealistic school view growing up, to grow up, 2 children boy girl, be a primary school teacher. I didn't have big plans. I didn't want to travel the world, be Prime Minister. I wanted to be a primary school teacher. I finished college, I didn't know what I wanted to do and temporarily went into retail 13 years ago, I worked my way up to management. Used to work for New Look. I now work for its called Tony Price Sports its a local sports firm down in the south-west. I worked my way up to assistant manager. My hearing just became too difficult so you've got background noise, mainly the customers. I'd managed to build up enough with staff to sort of tell them, I had hearing and a hearing-aid it was quite difficult but as long as you were on the right side I could do it. So with my staff they cue tap her if he's not looking. With the public it became so difficult. Even though I would explain to customers. I'm lucky I can lipread quite well, it just became so hard, I decided to come off the shop floor but I didn't know what on earth I was going to do I thought I was out of a job. Simon and I just bought our first property together, what am I going to do? and the company at that time were really good, really supportive. They created a hybrid role for me and I'm now stock room manager in the same company. They were really kind they created that role for me but then they sort of left me. Nobody knew anything or who to contact regarding fire alarms or phones. I had to do all that work and finding out and I was sorting out about Access to Work money and everything.

*Do you meet the public now at all in the job or you're in the background?*

Not really I can go out on the shop floor sometimes if I'm doing something and it's quite strange to have the confidence now. People don't know I'm a stock room person so they'll still come and ask me where is the...- and the first thing I say is I'm stock room staff and I'm deaf and I can do my best to lipread you and go and have a look and I quite enjoy helping customers but I don't know if I could do that on a full-time basis. I've been lucky with the few people I've helped that they've actually been quite good. Not oh she's deaf go and ask somebody else then. OK it's very mixed bag. I don't think I could do it full-time. Makes you feel really lazy but I can remember how hard it was when people haven't got the patience to take two seconds out to talk to you a little bit more.

[37:53]

*Going back again when you were diagnosed and your circle of friends obviously people did treat you differently then.*

Yes. Because we're a couple, people would speak to Simon, wouldn't speak to me, we like going to pubs, we were youngsters, boys playing pool and the girls chatting round the table, I didn't have the confidence to say "can you look at me" or anything. Nobody thought to include me in the conversation so I very much dropped back. I've made more friends now since I've become deaf because, and that's hearing people not all my friends are deaf. We've got great friendship with our neighbours actually. Once people know that I'm deaf and they realise I haven't been ignoring them saying good morning to me in the morning it's fine and it think its easier to make friends with people who only know me as deaf. People I've lost are people who knew me as hearing and as I become deaf I've worked for my company for coming up 10 years and in that time I've gone from having really good hearing in one ear to nothing and over that period of time our relationship has changed so much with the people, very isolating, even being as confident as I am now people are still quite reluctant to talk to me. Very boring lunch hours. Reading.

*In the early days did anybody sort of help you with equipment then? Did anybody tell you about the different things that were on offer for deaf deafened people or different groups –*

I think erm. We didn't really know what to do. When my father was losing his hearing Social

Services sensory department were quite involved. I still lived at the time. Mum was I'll ring the social worker see what they can do to help. They were great really nice really helpful yes she came out and we have a place in Exeter where you can borrow the equipment. She advised me to go there. She spoke to me about DLA. The form took me about three years to fill in because every time I tried to fill it in I didn't want to answer the questions. But you're entitled to it. But the form is so hard. And so many people were saying how difficult it is for deafened people to get the DLA form that I just couldn't find it within myself to get really low filling in that horrible the I've done it I finally got DLA, had it for the last couple of years but it was really difficult. I think there isn't anything for deafened people. I contacted the RNID to try and help me with work. They sent out an employment officer. She was very nice but she didn't understand deafened. She was treating me as a deaf client a born deaf client. She was trying to encourage me to learn sign language. It's like but I tried to learn sign language but it's just not the way that I speak. I didn't do very well with languages at school and to me sign language is the same as learning French, German anything. It's a whole different language a whole different grammar, very difficult. We had deaf awareness training. That was brought in from the RNID. Again the training was really good but it was a born deaf lady who had an interpreter doing sign language and some of my colleagues came out saying "oh yes that was interesting" this bit that bit it came across very much people couldn't link that to how I was, that was the deaf lady with the dog and the interpreter but they couldn't interpret where it was me. Although some of the basics are similar, it is very, very different being deafened compared to being born deaf. I still do. I have great empathy for people that are born deaf and through the RNID I went on some courses to try and help my job some management training courses and they were good and I met some great people, they weren't really what I thought they were. They were managers courses but with sort of communication support for the deaf, it wasn't actually about being a deaf manager and how you - it wasn't like that. Everybody else on the course was born deaf. I got there on the first day and they're all doing sign language and I was trying to pick up little bits I could and we were outside and I was too nervous to introduce myself, I didn't know how to sign to say hello. We went up to the room and they were "oh are you with us"? And I was like yes. We came to the coffee break and I explained that I'm deafened and I was really shocked by their reaction. "Oh my God, I am so sorry, oh it must be really hard for you" and I was like "what? But you haven't heard anything". Yes but we don't know what we're missing, this is our life, we're trying to get everyone else to understand our culture our way of life but oh it must be really hard for you and I did not expect that reaction at all. Really strange. It was really good to talk to deaf

born deaf people but I felt as if at that time I was trying to fit in some where and I thought oh I go on this course I'll fit in with them and I tried to socialise with them for a little while and I tried to go to their deaf club but I still felt left out which was - I didn't expect to be like that, because they were all signing. I don't fit in here either and it's taken me a really long time to feel that I fit in and there are still certain situations where I still feel left out because I can't hear.

[44:51]

*I was going to ask you what age, you've obviously been with Simon sometime so what age did you get married?*

Got to think now - I was 25. I had the hearing-aid then and my hearing was definitely deteriorating. I think and we've both agreed that I think we're honest we probably got married perhaps a year or two earlier than we would have because it was really important to me that I could hear on my wedding, on my wedding day.

*You don't have any children?*

No. When I was first diagnosed, no, not having them, don't want to pass it on, then as friends had babies I think I got broody, but that was OK. Now I'm of an age where it's very difficult and my confidence I would quite like to be a mum but the NF2 is still there and I don't want to do that but Simon definitely doesn't want children, he admits he's a big kid himself and he says it hasn't got anything to do with me being deaf or anything but when we first got together he did want children so I'm not quite sure why or when that has changed for him but I don't think I will have children but I'm only 31; I don't see myself as being too old quite yet but I don't think I will.

*Is that then more because do you think perhaps he is a bit worried about - as it is hereditary do you think it's more to do that with really? I know it's a bit big challenge.*

I think it's possibly something he wouldn't admit to himself. He says "I'm seen how hard it for my mates and I don't want that hassle. Then did you see so and so's little one. Oh I wish we had that ourselves. I think there is a lot and perhaps some things he's not even possibly

admitting to himself. I'm definitely going through that stage at the moment where could friends of ours are our neighbours and Sarah is 6 months pregnant and it's hard because I know I would like the they got married last year and I'm thinking yes I would like children now. It's not an easy decision for me and it's not something Simon wants. It's something I'm dealing with.

[47:52]

*Is there any sort of counselling out there or anything somebody - I mean are there any organisations for your illness that you've, well, deafness that you can contact or been able to contact. You said it's a very rare condition.*

There is. It's very few and far between. The Neurofibromatosis association have what we call support workers. They're usually linked to genetics departments and due to funds they're very few and far between. There used to be one in Exeter called Di and she was nice as some one to talk to, she was there for the family not just for me. But funding like a lot of charities money is very tight. Her hours were cut she wasn't allowed to come out, made it really very difficult. I believe there is one link to Plymouth but now Plymouth are trying to become a bit of a centre of excellence in Neurofibromatosis but I haven't made any contact and she hasn't made any contact with me. I get so much from Hearing Concern LINK although it's not Neurofibromatosis it's about the main thing that affects me. I think I'm very fortunate I'm very mildly affected by Neurofibromatosis compared to some of my friends and the main problem for me is my deafness, biggest thing for me is my lack of job satisfaction, my problem and LINK, Hearing Concern LINK is helping me through that. Very positive.

*It's not a national society or anything for the N F –*

We've got the Neurofibromatosis Association. There is 2 types of N F. They really are the they're called the same thing, one is type 1, I have type 2. They're called the same thing because they were discovered by the same chap but they're very different. Nf1 is tumours on the skin and learning disabilities. It's a totally different condition. Neurofibromatosis affects approximately one in every 40,000. Nf1 affects every one in every two and a half thousand so there are a lot more Nf1 people out there. I'm probably wrong in saying this but it fills there is a little bit more towards Nf1 than there is NF2 and in some ways rightly so there are

more people Nf1 than two but it feels very unbalanced where there isn't an association for us it feels very unbalanced.

*Have you met other people with the illness with the disease apart from your brother? Have you been in contact with other people with it?*

Yes. I think I've met most people through the annual weekends that we go to, yes. And it's very strange. One of my closest confidants - they're called confidants, we've not met in person yet, is a girl, a lady, I regularly use for speech-to-text put me in contact and we've communicated via text and email the last three years feels like I'm having an internet relationship with her and I can't wait to meet face to face and she lives in Swindon so she's not far away from me she's two and a half hours away from me she's probably the one I contact the most but there is probably a network of about six altogether similar age men and women we're all different degrees of the condition, we're all completely deaf, but Cheryl her name is, she's probably the most similar to me and I think that's probably why we find it easier to talk to each other so much. For years, my Mum loves me I know but she's a pushy Mum bless her, trying to push me to be in contact with people but I didn't want to it was the way I dealt with I would go to the NF2 weekend and put it on the shelf and it think about it and it took me a really long time to want to have contact with others and now I know it's nice we don't just sit there talking about NF2 and deafness but we talk about – especially Cheryl similar age both got partners really nice to have somebody to talk to you understand where you come from shows very difficult period at the moment and I know she thinks she knows Simon is wonderful in comparison to her partner he really is, her partner doesn't seem to be quite so understanding I don't mean to criticise him like that but he doesn't seem quite as understanding as Simon so I'm there for her. I know what she's talking about when she feels low and she wants a whinge and that. I'm there for her and likewise. It's really good but strange to have a friend on the end of a phone and not a girlfriend to go out for coffee with. I don't have a close friend like that.

[53:44]

*What is Simon's work? Does it take him away from home?*

He's a white van man. He works full-time but he comes back in the evening. He's always

back in the evening, works Monday to Friday same as me so we have our weekends together, he plays bowls he's a World Champion at short mat bowls. That can take him away at times. He semi-retired from that about 18 months ago. We thought I was going to need another operation and decided to give that up to be there for me. Unfortunately it didn't go that way but he says he enjoys his weekends at home a bit more time with me, time to do decorating that sort of thing. We do go out with friends now.

*Do you travel at all, have you been abroad?*

Yes quite a bit. Simon's parents live in Cyprus so that's an annual holiday for us, cheap flights. We normally try and have one holiday a year if we can. We will go away.

*Does travelling affect the hearing at all in any way? Are you treated differently abroad or –*

Definitely. I think possibly it's a confidence thing. On my own it's quite - when I go to places, doesn't have to be broad, it could be a different place in this country, if I go somewhere where I don't know, it's going to sound really silly but that's when I feel deaf, that's when I revert back to out in the back a bit more let Simon do the talking. We went to Cape Town in South Africa last year. My Mum is hoping to emigrate and wanted us to come out in the hope I would emigrate as well but it's not for me. Obviously they're English speaking and it was very strange to - I was very aware there that people with disabilities might complain about this country but we're far ahead of them. It seemed at the minute we tell somebody at a restaurant I was deaf they would pull away from me they wouldn't talk to me at all if they were coming up to the table ask for me in the evening come to the table would you like any more drinks they wouldn't look at me at all it was really strange. Anywhere in shops or anything. It's not that easy in this country but to go there and face that for me it was quite a factor that I could not start a new life somewhere like that where it really felt that people really didn't want to talk to you at all. It felt to me like I was being set back again. Really isolated again.

[57:04]

*Do you feel over the years from when you were first diagnosed that you have been*

*discriminated against? Has it affected like you said about your work. Would you like to change your job but discrimination as welcomes into that.*

I think discrimination is a very strong word that I would use in certain circumstances for myself. When you look at black and white it's not that. I do believe that I've been discriminated at work but when it was happening I didn't have the strength and I feel bad that I say that, didn't have the strength to try and take it further. I just wanted to know that I had a job to pay the bills and I was concerned if I took discrimination, very, very difficult work as far as they're concerned they've done everything they can for me but I really don't feel like they have I do feel that they think I'm awkward because I need a fire alarm, I need my own adjustments it's really quite bad and it's quite hard when I've worked there 10 years. I used to be seen as really good worker. That's why I stepped up the promotion ladder and like I say I was grateful that they were prepared to create this role. They didn't do that because they were nice they thought I was a valued employee yes we want to keep her yes we can make this vacancy for her then I was just left. The employment advisor from RNID said what about Sharron's career progression and she was on the shop floor it would have been manager of her own store area manager up and up and up. Not even thought about that. When it was broached well she can't that's the job she doesn't like it she needs to leave. I can understand where they're coming from but that's quite harsh. I am an ambitious person and I know, and I know they know, I can do so much more than what I do there. And every day when I'm doing something really boring it's fighting against come on girl get off your back side you must try and get out and get a job. When things were really difficult 18 months ago there were days when I felt I would walk out if I didn't have a mortgage I would walk out and I really did apply for lots of jobs even jobs I didn't want. I don't mean any disrespect but I even applied for cleaning jobs and I haven't been offered a single interview and I don't know if that's because deaf or not. Not being horrible cleaning jobs you don't need qualifications for them and I'm not even interviewed and that really knocked my confidence. I was so adamant I wanted to get out and I would have done anything. I easily applied for over 100 jobs. Not a single interview came through and that knocked my confidence again. OK, plough on. Stay in the same job. I don't really know what I want to do. I'm so afraid of not being able to get there. It's really difficult. My job is probably the main thing that it affects.

[01:01:00]

*You said you went on the LINK course about 2 years ago. Hearing Concern LINK. How did you hear about them? Have you been involved, found out about them some years ago?*

Back in what did we say '94 back all those years ago when all my family were diagnosed it was actually the social worker that mentioned about LINK and we went quite quick I think we went March or April of that same year and that was my Mum, my Dad, Simon and I went, and it was a really good week.

*Was that for you or because of your Dad.*

I think was for me as well. Everybody was trying to do anything they could to help me come to terms with what was going to happen and I went up with that frame of mind that week and I learned to fingerspell that week, something I always remember but through the week it was learning how to live with Dad, how to help Dad. That's what I really learned. It's not just you and it's not just you it affects and it's not up to you, it's the deaf person to do all the work for communication and the things at I learned from that week definitely did help as I began to lose hearing myself but a couple of - that was it we didn't have any more contact with LINK then. We knew they were sort of there but didn't really know anything. A couple of years ago Access to Work somebody at the job centre somebody at RNID I was trying to grasp anybody to help me stop feeling like I felt and I found LINK on the internet and I emailed LINK blah blah, I need help I'm at a lowest ebb ever, how can you help me? and somebody came back to me, really sorry to hear you it was really nice and may be you'd like to come to an intensive week and I sort of went back yes all right but actually I feel I've already been to one. No that's fine. Come back to another one. It sounds really dramatic but it was the biggest turn around. That week changed so much for me. That was a massive, took real-time about 18 months to take in everything that happened in that week but I left such a different person and I feel so strongly about Hearing Concern LINK, much, much, much more so than I do for NF Association, that's why I decided Simon and I are now outreach volunteers that why I'm doing the Oral History Project. I'll do anything to support Hearing Concern LINK, they've changed so much for me.

*Did you have an outreach worker come to your house at all before you went on the course?  
Did anybody come to see you at home?*

No, a lot of it was done by email and we are the only people in Devon doing outreach support. I believe there is possibly somebody in Cornwall but there is nobody covering Somerset. There is a poor lady in Dorset who is trying to cover a lot of areas and it is going to try and work with her between us cover Somerset, vast area. There wasn't any offer and I don't think - it might have been the lady from Dorset poor thing come all the way down to see us but no the information was done via email because I'd been before I knew sort of what to expect.

*Do you think, was it for a week you went to Eastbourne?*

Yes. It was specifically NF2 week.

*Everybody on the course had the same condition.*

Yes.

*So do you think it helped Simon as well or was he pretty good. You said he was very understanding any way but do you think it helped him?*

I think it affected us in a similar way. 5 sufferers and 2 of us were a couple, somebody else was a lad that come with his Mum and another man was with his family wife and 2 children and I'd been diagnosed the longest and initially I felt quite guilty that I was there especially with a chap with his family, only known for 12 months you could see he was shell shocked "God what had happened to him" and because Simon and I had been diagnosed the longest we quite soon found ourselves people were asking us a lot of questions and our experiences and it was like we were the people with the knowledge. Quite strange but at the same time very nice to be put in that position. That's what got us thinking about being outreach support workers. We became like a support for the others. But at the same time I got so much out of the week and I think part of giving that support to others was making you realise hay actually I have been through it but I've started to come out the other side. It was very, very good. We were both like that very much but in our own way I'm the deafened one and Simon is the partner of deafened one and help people in our own ways. (Break)

[End of Track 1]

[Track 2]

*Check its working again. I was going to say to you, I noticed on your questionnaire you mentioned something about a plus and a negative when you were at work, you said that somebody, when you worked on the shop floor, a customer told you once that you shouldn't be - I was a bit shocked to read that.*

I tell a lot of people, a lot of people that. When I was talking earlier how difficult it could be working on the shop floor. Used to different people's reactions. Some people were really good. Some people place would try and help by just shouting at you or the normal reactions you get the various reactions you get. It's quite funny because the lady, I think in her own way she was actually trying to be quite nice sort of. She just looked really shocked and said "well actually I don't think you should be down here with the public then". I just didn't know what to say. Hurry up finish the sale and let her go

*I'd have found that quite upsetting.*

Really hard.

*Then you mentioned the positive bit of not being able to hear babies cry on a flight. To South Africa.*

That was when I went to South Africa and the rest of my family were moaning about being awake and I'm fine, I can sleep.

*So there are positives as well as negatives because you'd listed it as a plus and a negative that was very interesting. So you actually do lipreading. Mainly the main way you communicate now is lip-reading so did you have classes for that? Did you go to any classes to learn that or did it come naturally?*

I think a mixture of both. It's difficult. My father couldn't lipread at all. We were always pen and paper and I was very concerned I would be the same. When I knew how difficult it was to learn to lipread. I was really nervous. After the surgery I had one to one sessions with a lip-reading - no she was a hearing therapist, I had one to one sessions for may be three months

I think it was and it was really good. May be I was being hard on myself. She was saying you're doing really well I don't think I am. You are. I can't really give you any more exercises because you are actually doing it. I think because I had hearing it was quite hard. She would switch her voice off when we do it and yes I could do it. Of course then I'd leave and I'd go into town or something and I'd still be trying to do it but I didn't think I could but it's because I was listening that you can't switch your mind off if you've got some hearing even when it was really bad your brain will still make you try and hear. Sort of three years ago when the hearing-aid came out I didn't actually tell my Mum for a couple of days. She lives near me we live in the same village and we'd not seen each other for a few days and I popped into visit her and we were chatting and I was actually really surprised myself how well I was doing. I was lip-reading to some degree by then because of the amount of hearing lost but somewhere in the conversation I think my Mum looked away or something and I said no a need to look at me I'm lip-reading you I'm not wearing a hearing-aid any more and she was really upset she didn't realise then she went "I'm so proud of you, you can lipread really well". I am really lucky. I think it comes quite natural, combination of one to one learning, how to spot those words and sounds that are similar. For a lot of people it's always difficult when I meet somebody new. Or like trying to read you this afternoon the lighting is not that good. And at the beginning you offered to swap my ways. I thought no I'm going to use this any way. I know in this sort of circumstance I would get tired I wouldn't be able to lipread you so I would use the speech-to-text, it's probably a combination but again I know I'm really lucky, I've seen it from my father, I've seen other friends, can't lipread, difficult, I know they're trying to be supportive, oh you're really lucky can lipread really well. They don't mean it nasty I know that I feel so guilty that they can't lipread as well as me and I can't help people always ask me how can you lipread that well. I don't know.

[05:34]

I can't put it into words. I can see accents which is some people haven't heard very often and people like how can you see the accents. I can't explain it but I can. We've got a girl from work who's from South Africa and I got introduced to her and she was talking and I was thinking because it's quite similar to Australian a little bit and I was thinking something different, where is she from and I was trying to work it out. Somebody then jump in trying to be helpful and told me she is from South Africa but I think give me a few more minutes and I

would have got there. I can normally sort of tell. It's really strange. I didn't expect that but I can usually spot an accent even Scottish or Welsh I can see an accent or up country.

*You don't need to hear it. You can see it from the mouth the way the mouth moves.*

Yes, you can see it. I think it's the way the mouth moves. I think possibly it's different dialects isn't it the way that people speak around the country. Really strange. Quite like that. Oh she's from so and so. People look surprised they haven't had to tell me. You'd think you need to hear it and I know hearing people when they've asked me that cannot understand how I can see that. Really difficult one to explain.

*So a cochlear implant wouldn't be any use to you then would it if you've got the tumours which are possibly going to, might come back so a cochlear, because it's not to do with that, that wouldn't help you at all?*

Where I've had the tumour removed everything has been taken out. There is definitely one person with NF that I know with a cochlear but it's truly rare to be given a cochlear implant. It's all to do with the tumours. The place of the tumour. If it's not already been removed it will get damaged by the tumour.

*Can I just ask you, when they removed the tumours do they go in through the ear or do you have to have an operation is it on the back of the ear behind the ear?*

I've the scar it's in the back of the head. The tumour. That's the risk. With NF2 you always have 2. Anybody can have one tumour. When you have 2 it's - that's NF2 and because of the position of them they put pressure on to the brain stem. It's through the back through the skull. I don't think any surgery is through the head. I think they have to go through the back for any acoustic neuroma.

*Sounds quite frightening to me. Must be a worry when you've had them out obviously for your husband it must be the sounds of it he's very good and puts on brave face but it must be quite worrying.*

Definitely. Just to go back I feel really bad I'm really open about talking about

Neurofibromatosis and your not the first person to react because I just spit the words out it takes people back so I'm really sorry I'm quite.

*No that's fine.*

[09:34]

I'd say it's really difficult. I respect - Simon's father is exactly the same he's his father's son respects that he doesn't talk about things. I spent many years worrying about him like that but I now understand that is how he works and if I talk him and if I push he will get angry so I have to leave him. He doesn't want to talk about things. He feels he's fine. He's like that with everything he deals with things in his own way. He puts on brave face. He feels he has to be strong. I wish he didn't. And still, because we learned so much, both of the weeks we went to LINK specially the recent one it was about us as a couple going it wasn't Mum and Dad, us as a couple and my hearing loss and I feel really strongly about how much it affects Simon but he always says it's not me, it's you, and he does understand it, been going along to the LINK week with blinkers its not that he doesn't he understands it he thinks it's me,. There are times when I apologise and he else me shut up and don't be silly. He's never made me feel bad about even when I was going really low apologising for letting him down social occasions not wanting to come out it's been hard for him to understand sometimes but he would never get angry, I don't think it affects us as a couple like that. And I'm so pleased, because I saw that happen to my Mum and Dad.

[11:28]

*I was going to ask you on a social level when you go out with people and that there must be times because obviously a lot of places we tend to go to nowadays are noisy aren't they just society in general, but even pubs have loud music don't they going so it must be quite awkward in those situations.*

It's quite strange when I would class myself as hard of hearing it was and trying to find somewhere that had a loop-system on and all the rest of it. I think like I say when I initially, when I took that hearing-aid out when I class myself as deaf yes of course it's a bit of a shock also it's a bit of a leap I felt years dreading this was going to happen the last few years really

struggling going out to an environment like I can't hear anything it's horrible and being completely deaf now there is no two ways about it. If you want to talk to me you have to get my attention and I have to lipread and I actually going out to noisy places is quite strange now. The problem I come up against I don't talk loud enough people can't hear me so I don't know what I'm trying to struggle over but I can communicate across a noisy bar if Simons forgotten what I want to drink or something and I can lipread. It's different, it's strange. Of course I'd love to have hearing but I would rather be totally deaf, I find this easier now, wasn't always like this, but I find it easier to have no hearing than I did when I had really poor hearing with hearing-aid, it was more of a struggle then in like those noisy situations. It's easier now. It takes work if I'm out with a group that's always quite difficult. I can lipread up to 2 people. I can keep in a conversation like that but anybody else and I get taken out of it. If we go for a family meal or something I will always get Simon to sit opposite me and by watching what he says I will try my hardest to keep into a conversation. That's easier, it works best. He doesn't have to keep stopping if he sits beside me he'd have to stop and let me in but by facing him I can kind of pick out what's going on and I can stay in the conversation quite well. I know it's nothing like when I had hearing but it's nowhere near as isolating as it used to be when you are sat there trying to struggle. It's difficult. It's not something that Simon and have even really spoken about it's just the way we've worked it out now and he always knows sit opposite me. He can carry on all but as normal if I get lost I'll stop and say what are you talking about and try and get back in. It's really tiring doing all that lip-reading but we've found our own crude way of trying to mix in a group situation. It will never be the same as when I had my hearing but it's not as isolating as it was when I was hard of hearing

[14:54]

*What about the music side of things?*

*Obviously you were young when you lost your hearing and most teenagers love to listen to music and groups and may be go to see bands and things like that. Did that make any difference to you? Did you sort of feel angry?*

Yeah, I did feel angry. Yes, music is, I think like a lot of people I really enjoyed music, music was very emotive for me. I loved the film Out of Africa. I had that music at my wedding and that's a film I can't watch any more. I think music is one of the hardest things to have lost. I can watch a really good movie now and I know that the music must be really good. I can't

remember what film it was Simon and I saw last year, some movie that we saw, and I said bet the music's good in this and he says it's John Barry of course John Barry Out of Africa and I know that it affected my enjoyment of the film because I couldn't hear the music and it was only late last year which is really silly it's only late last year that I got rid of all my CDs. I hadn't heard music for 12 months before I took the hearing out it was so distorted I couldn't enjoy it any more. But I couldn't touch the CDs. I didn't want to look at them. They sat in the cupboard collecting dust for the last 4 years but finally last year I did it, it was really hard. But I'm glad I did it because it was a very strange reminder having them in my lounge these things I can't do any more. It was positive. It wasn't a negative thing. It wasn't about packing them away getting rid of them it was a positive thing that I was finally ready to deal with it and I've given them away to friends and charity shops, Simon has kept the ones he likes. Music's the hardest thing, one of the hardest things.

*Do you say now, like obviously when you watch a film television now is very good with subtitles and that, you can't go to see bands or anything like that. Some people say they can pick up from the vibration but –*

That's strange, a lot of people have said that to me and I thought I would get that, it's something I don't. I seem to have do so much, I'm really fortunate but I can't do that. I stopped dancing if we went out to a club or an evening reception and last year when my neighbours got married when they sent the invitation out they wanted to know three songs that were guaranteed to get you up on the dance floor. It was really hard. Oh my God, what can I put in? So I thought, well, one that always gets people up and something that's good for me is YMCA, I can follow the actions. I knew from that that it didn't matter that I couldn't feel it. Simon is quite good ventriloquist and would sing for me so I knew get ready, YMCA! And I did dance. On songs like that it was OK. Other songs where I was trying to do the same wiggle as everybody else I felt a bit daft but songs with actions quite retro quite seventies I could do but nothing up to date and it's quite strange now seeing new bands come up, I don't know anything about them, like red nose weekend this weekend I was asking Simon about the girl band that sang, that's very strange, apparently I'm not missing very much but I am missing it. It's very weird seeing new things come up and about. It's hard. Makes me feel like it's a negative. I couldn't go do concert. I don't pick up the vibrations up like that. I know people who can do that. Yes it's all right vibrations but it will just - I feel vibrations

but it feels like a ... it doesn't remind me of the song or anything.

[19:48]

*Going back over the years then, I mean I can't, saying is there any positive things, there is obviously some things which have come out of your illness but the big thinking of the big negatives, obviously the music is a big one, it's difficult to sum up but is there anything particularly you feel you've missed or you've gained in your life. Hard question.*

64,000 dollar question it's really difficult. I say music because it's an easy thing to pinpoint. I know, I think my life in general is, the path I'm taking with my life is completely different because I'm deaf. It sounds like an excuse but I know that my career path, I would have never have gone into retail and stayed in retail if I was deaf and I know I make excuses about staying there but I would not have been in retail and stayed in retail if I wasn't deaf. I think the lack of understanding of the general public of customer services even now even though I'm quite confident I still come up against difficult situations, situations knock my confidence. Doesn't come naturally. It's funny, shy as a child but now I'm an adult doesn't come naturally to be shy and withdrawn when I get put in situations I feel like that it is really difficult. I don't think I can specifically pinpoint anything. It's affected my life in so many ways. I'm glad that Simon and I have evolved around it. From a positive thing, if anything, you hear people say, it's so true, it's the people I've met through it, that's what has been positive. I've got some really good friends through NF, through Hearing Concern LINK and I wouldn't have met those people if I didn't have hearing loss and they're important, they are important to me they're good friends and as I've said it's not just talking about deafness. I think it's just about being in a group of people who completely understand what you feel like and you are not the odd one out. It's quite funny in a lot of situations more so Hearing Concern LINK than neurofibromatosis where Simon will be the only hearing person and he'll say that's really weird for him to be the only hearing person in a group of say 6 us 6 deaf girlies whatever and he's fine with that but I say to him now you have some idea of what I feel like in a group of hearing people. It's a very difficult question to answer but it's affected a lot of my life say my career but I think my general path in life has been affected by my hearing loss. I think that because the services aren't there, the understanding isn't out there, I think because being deafened is so incredibly rare there is even less the everybody seems to think oh you're deaf it's not the same as being born deaf, I've had to learn along the way as well and it's trying to

educate you remember when I had hearing now I'm deaf but it doesn't mean I'm the same as deaf people not the same as people on see hear programmes being deafened is very isolating condition because there are so few of us so few of us around. Very different being deafened as opposed to being born deaf.

[24:12]

*Where do you see yourself in the future? Obviously you mentioned that you probably would like a career change. Do you think much ahead about the future?*

Not really I think that's a combination of being deafened and the neurofibromatosis like I talked about the remission feeling. I don't feel like I can plan that far ahead because I don't know what's round the corner. Yes I know I'm now deafened and my hearing won't come back. I think even if modern medicine creates another miracle it could be years before something effective comes out to give me my hearing back. I lived with that feeling all the time. It's very strange not to think forward in the future. Like the career change I don't know when it's going to happen and I'm quite a goal driven person, very set, when am I the I can't live my life like that it's quite strange. Quite strange. The only thing know for certain in the future that I didn't know five years ago is that I am finally deaf and this is it I don't want to think anything about the future I just live day by day.

*Has religion played any part in your life? Has that helped in any way?*

No. I've never really followed a religion. I had some friends that was when I was hearing my first year in college I had some friends who were Christians and I may sound pessimistic I went along to one of these clubs and they were also high on life if I can put it that way and I just couldn't understand why they were all being like that and they were all very happy, very it was nice environment to be in but it wasn't something that I felt comfortable with and the say I dabbled with it for a small the but decided it wasn't for me. I don't know why I believe in but I don't follow a certain religion.

*Or politics or - you could go into politics. Sorry, go on!*

Politics I think is difficult. I am a little bit narrow-minded in politics with regards to deaf

issues, very frustrating again the government have declined our recent petitions and what not and I think as a general rule not very positive about politics in general what happens in the country from a deafened point of view. Feels like a constant ongoing battle to get them to listen to us and very much that they feel they're catering for the deaf community. But it's like we're here as well. Very annoying. I appreciate there are a heck of a lot of other things going on in the country and we're not the only condition but I really feel like we are being missed out.

*Is there anything else you would like to add to the interview that you feel has not been covered?*

No, I don't think so, no I think I've said everything.

*Can I thank you for coming along and you certainly made me much more aware of the condition. I wasn't before. Thank you very much. Thank you.*

[End of Track 2]

[End of recording]