



Unheard Voices: interviews with deafened people

Bill Jones
Interviewed by Roger Keeling

British Library ref. C1345/60

IMPORTANT

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Interview Summary Sheet

Ref no: C1345/60

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Jones

Title:

Interviewee's forename: Bill

Sex: Male

Occupation:

Date and place of birth: 1958, Fife

Date(s) of recording: 20th June 2009

Location of interview: Holiday Inn, Washington, Tyne and Wear

Name of interviewer: Ann Thallon

Speech to Text reporter: Carina Raglione

Type of recorder: Marantz PMD660 on compact flash

Recording format : WAV 16 bit 44.1 kHz

Total no. of tracks: 1

Mono or stereo: stereo

Total Duration: 1 hr. 7 min.

Additional material:

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Interviewer's comments:

[Track 1]

Your name is Bill Jones. I am interviewing you. My name is Roger Keeling. Our speech-to-text reporter is Carina Raglione. Can you give us - for the benefit of the tape - can you give us your date of birth?

I was born on 20 January 1958.

Your mother's occupation; did your mother work?

She was a catering assistant.

And your father?

He was an engineer.

Family? Have you brothers, sisters?

I have four brothers and three sisters. Going into it completely, I have a wife and two children of my own, and something like 12 nephews and nieces. It is a big family.

What area of the country do you live?

I live in Cowdenbeath.

That is now. That is where you are now?

Yes.

You have been in other areas?

Going back I was born in a place called Rosyth. That is in Fife. Then we moved to Milton Keynes when I was still a young lad. I lived there for approximately 30 years, and then, 15 years ago, decided to move back up to Scotland.

What about education-wise, where did you?

I went to school in Bletchley. My first school was Trent Road Primary School, then went to Rickley Lane Junior School, and then Denbigh Comprehensive.

Any qualifications?

None.

Just the normal run-of-the-mill things.

Yes.

No higher certificates and things like that?

Get out of school quick as possible, please.

What about hobbies, et cetera?

I would like to take part in Formula 1, but obviously can't, because it is too expensive, so I watch a lot of it; photography and before I had my balance problems, motorcycling. Needless to say, motorcycling and balance problems don't go together.

What about holidays? Do you take holidays abroad?

No. I have been across to Germany twice with the British Army, but that's about it. We don't really do a lot of holidays, me and Joyce. We prefer to stay at home. We have got a house at East Fife, and renovating it, that takes a lot of time. My daughter's wedding is coming up in a fortnight's time. We are trying to get everything sorted for that as well.

What about religion, have you any particular...

I have no religion whatsoever.

And the other one, politics? Any particular...

No. I used to vote Labour, because that is what the rest of the family did. Now, I find each politician is as bad as each other, so I don't bother at all.

[05:37]

To go on to your hearing loss, when did you first realise you had a loss? Did anybody tell you or did you realise for yourself?

That is actually quite a long story. When I was approximately eight years old, I had a bout of the measles. I picked up a mastoid of the left ear. This gives me problems with the hearing in my left ear. I was told at that time - I am talking back in the 60s - that there was nothing they could do for that ear and just basically live on my right one. I didn't get a hearing aid or anything like that for it and I just carried on working through that. It was quite difficult at times, because, obviously, only working with one ear in a classroom, you know, you are sitting in the middle of the classroom, you are not picking up what the teacher is saying, so it was very, very difficult to go through education like that. Then I had a few operations on that left ear to see if they could do anything with it, never anything worked. Then when I moved up to Scotland, basically 2003, May 2003, my hearing in my right ear just went overnight. That was it, gone.

Prior to that, had you any references to ENT or...

They were always looking at my left ear, and they done a few hearing tests on my right, but that was okay. My right ear was always my good ear. There was never any indication that it was going to go or anything like that. As I say, the left ear, we had problems with from day one. The right ear, there was never anything.

Then when the other ear went down, what happened then? Did you go straight along to your doctor?

It was actually quite ironic. I was a lorry driver for a local distribution company - local

supermarket. I had just been promoted to transport shift manager five weeks previous to losing my hearing. It was the fact that I was - I had been on the night shift, gone to my bed, hearing was perfectly okay, woke up halfway through the day to go to the toilet, my hearing was muffled, but I thought it was probably just a cold, get on with it. I went back to work that night, struggled that night, went back to work the following night and was getting nowhere. I said to the top boss at the time, "I am going to A & E". I went up there, they basically told me 'there are some steroids, take that, see how you get on. With no difference in a week, come back and see us'. I went back a week later, still no different. They referred me to another hospital. I was told it could be sudden acute deafness, which, in any other country bar Britain is classed as a medical emergency. In Britain, it is just, tough. So then they said 'give it three months without steroids, see how you get on with it. It may come back, it may not'. I went the three months and was given an appointment to see a consultant, an ENT consultant, and we went in to his room that morning and his whole attitude was, "Yes, Mr Jones, you're deaf. It is permanent. There is nothing I can do with you. Goodbye". Rather, it wasn't said to me, it was said to my wife Joyce, because he knew I couldn't hear a word he was saying.

He didn't give you any indication other than the fact that you were deaf?

That was it.

Which you could have told him!

Correct. There was no kind of, "Sorry, we can't help you, but take that leaflet, they may be able to point you in the right direction". So when my wife turned around and said to him, "What about hearing aids?" Fifty-two week the waiting list, I have just been promoted; I need to get back to work. I was not saying I was anything special. I was still a young man, still got a life to live and to be told you have to wait for a year before you can go back to living a life is no fun. We walked out of that hospital that day with absolutely nothing.

This went on for how long?

Well, because Joyce is so strong - and I am glad she is, if it wasn't for Joyce, I wouldn't be here - because we kicked up so much of a stink in the hospital, so much we were led out the back door of the hospital, within three months I had been given hearing aids, analogue

hearing aids. I struggled through with the hearing aids. They weren't the best, but they were better than nothing. In the meantime, before I got my hearing aids, we - when we were sitting at home that day, Joyce phoned around - she actually phoned RNID in London, remembering I am in Scotland, to see whether we could get help, and they directed us to Fife Sensory Centre. They came out and helped us. While this was going on, I got a phone call - sorry, I got a letter from my employers, asking me to attend a meeting. Because I had lost so much of my confidence as well as my hearing, I wasn't driving, bearing in mind I was a class 1 lorry driver. Because of this loss of hearing, I just didn't want to drive. Joyce drove me into work that day. We sat and waited outside the personnel manager's office. She came out and it was a meeting between her, my manager and myself. She asked me to go in to that meeting on my own, knowing full well I didn't have hearing aids, I would not be able to understand a word they said. Because Joyce was there, she said, "No. I don't go in. He doesn't go in". This was the sort of thing I have been up against since 2003. We went into that meeting, and the personnel manager turned around and said to Joyce, "Our drivers know sign language, but I am too much of a lady to show you". It kind of sticks in the throat a bit, doesn't it? This was the person who was supposed to be helping me get back to work. It is a joke. So I went back to work and, for two years, I struggled through. Within that two years, I had been given a grant by Access to Work, which supplied digital hearing aids, which made it a little bit better, but over those two years, my hearing went down even further, so obviously those hearing aids were of little use. By August of 2005, drivers were putting in grievances against me for getting aggressive, yet it still hurts to tell this story, even now. I didn't agree with them. As far as I was concerned, I was fine. They investigated it all. They went on the side of the drivers. Then in October 2005, we moved to a new house. At that time, it should have been a really exciting time for everybody, but for me, it was an absolute nightmare. Joyce could see what was happening to me, but I couldn't. She told me that, basically, if I didn't go and see a doctor, our marriage was over.

Do you want to take a break there?

[17:19]

We were talking about your problems with work and what happened with going in for the interview for the fact that your hearing wasn't what it was. When you mentioned about aggression with other drivers, was this just general or was this your workmates that were

complaining about your aggression, or was it just other road users?

No, this was the drivers I was actually in charge of. I was their manager. They said that the way I was talking to them was totally aggressive. Which is to say, to me, I was just being myself, or so I thought.

You considered that they were using your deafness as an excuse to complain to higher management?

No, I wouldn't say that. It was the way they looked at it, the way I was talking to them was wrong. Instead of just asking them to do things, I would actually be telling them. As I say, this was then followed by grievances being put in, and basically backed up by my managers.

Then you went on to the problems that suddenly started being created at home with your deafness.

Yep. As I say, we had moved house. I mean, we would - because it was such a big house because a lot of Joyce's family still live around us, we would have family coming in, sitting there having a meal, and then as soon as I had finished my meal, because of all the problems I was having hearing people, I would literally just get up and go upstairs to my computer.

Can we just establish, has Joyce got a hearing problem?

No. She has perfectly good hearing, and the rest of my family have all got good hearing. It was just because, obviously, you are sitting around a meal table with all that noise going on, pretty much as it was last night, actually, I just couldn't understand the conversation, and rather than confront the problems, I pulled out of the situation. I hid away, not just from them, but from myself as well. It got to the stage where, as I said before, Joyce realised what was going on and basically told me that I needed to speak to a doctor and if I didn't, our marriage was over. It was as simple as that. The good thing was that because we'd moved house and moved into a new town, we ended up with a new doctor. I got the appointment, went and saw him and said I was going to go on my own and Joyce said, "No, you're not. I am going with you", because she knew if I went on my own, he would only get half the story. After I finished everything I had to say and after Joyce had said everything she had to say, the man

did the most amazing thing. He pulled out his own hearing aids, and at last I found somebody else that actually knew what I was going through. Because, until that point, I had never actually met anyone else who was deafened. It was such a relief to find somebody that knew what I was talking about. He basically referred me back to ENT. Because he was deafened himself, he spoke to his own consultant and told me he - to give you an idea, my house sits on one side of the road, the doctor's surgery is on the other. Now, he could have just called me in and spoke to me face to face, but he didn't. He actually wrote me a letter so I could read every word of it. He told me to get in touch with the RNID. By this time, he actually - on that day, he signed me off as being clinically depressed. That is where all my problems were coming from. Obviously it wasn't just that, but because of the deafness and the stresses that I was going through at work, I'd lapsed into depression, just didn't know it. As I say, he referred me to - told me to get in touch with the RNID, and I did. Because I was so desperate at that time, I waited four and a half hours to speak to the lady. The employment adviser for RNID, who I met in Edinburgh, she sat and listened to me for something like three hours, and made me realise that I wasn't on my own, and made me understand that I was actually going through basically what is a grieving process for the loss of my hearing. The way she put it was that losing your hearing or any other of your senses is like a member of your family dying; you have to grieve for it. But because I had gone, basically, straight to work, I didn't allow myself that time and that is why I was getting worse and worse. Again, I signed off for another six months. In the meantime, we have had a change of my manager and the employment adviser had started meetings with my work and we went to this one meeting, and I am thinking, "Here we go again". It is going to be back with personnel, just the same as it was the last time. I was quite pleasantly surprised, because personnel were never anywhere near that meeting. It was actually the people who mattered most: my manager, my senior shift manager, the transport administration manager, and the health and safety managers were all there. They were the people who I would actually be working with. It was what my manager said to me. Because his mother was also deafened, he knew what I was going through.

[26:11]

Do you want a break?

No, no. What he said to me was, he turned around and said to me, "Bill, you are a valuable

member of my team. No matter what it costs, I want you back”, which meant a lot to me. You are only seeing the employment side. There are other things in it, there are a lot more bad things to come yet. I went back to work and that would have been March of 2006 I went back to work, and I carried on working right the way through to July 2007. In the meantime, unfortunately, my manager had to leave because his wife was very ill. We had another manager come in and he started changing things about. To give you an idea, we work in a transport office and there are two people in that office, the transport manager and the transport clerk. As you will know, Roger, living with deafness, it is very hard to understand people, so you get used to the people you work with all the time. I would be working on a four-on/four-off shift, on four days, back off for four nights. I would always have the same clerk. He decided he was going to change that, you would have that clerk for two days and that clerk for two days, bearing in mind my transport office sits in the middle of a transport yard with trucks all around. It was difficult as it is, but then he goes and changes the clerk. I carried on the best I can. Then in July 2007, I was an hour into my shift on night shift when I suddenly collapsed. I couldn't stand. They called an ambulance and took me to A & E couldn't find anything wrong with me, but lucky enough, I was already speaking to audiology about my balance. I was having problems with my balance, but on that particular day, it hit rock bottom, and I couldn't get my balance at all. I explained to A & E that I was actually going to be going to see a consultant on the Tuesday - this was the Sunday. I would be seeing him on the Tuesday, so they just said, well, go home and wait for your appointment. Again, I was signed off for five months. When I went back to work, with the approval of my consultant, albeit with restrictions, I had been back at work for maybe three or four weeks, and got called from the occupational health officer to go and see him. So I went up and saw him. That was ten o'clock in the morning. At quarter past ten, he said, “I am just going to nip out”, because he got a phone call. Okay. At 25 past ten, another one of the managers came in and said, “Bill, go and get a cup of tea in the canteen. HR will call you when they want you”. At one o'clock in the afternoon, he finally came back and got me. He turned around and said to me, “I have to send you home”. I asked “why”. He said, “Because you are a risk”. So straightaway my back was up and I turned around and said to him, “So you are going to overrule the consultant who has already told me I can return to work?” “Yes”. I said, “Well, no, you are not, because I am not going to let you”. “Right, go back to your desk and your manager will speak to you when he's ready”. Five o'clock that evening, they call me back up and they turned around and told me, “No, we're not going to send you home after all”. In other words they couldn't send me home, but, basically, we are going to take your job off you. You are not going to stay as a

transport officer. It was at that time I called in a full-time union official. I have been fighting that man ever since. When I went to the meeting with the union official, his words to my manager was, "I am not trying to tell you how you do your job, but I really do believe you should take expert advice in the field against the Disability Discrimination Act. The answer he got back from my boss was, "I suppose we should do. We haven't done that yet". Yet this guy was trying to get me out of my job. Needless to say, he didn't win. I am still working there. The more he tries to push me out, the more I will dig my heels in. That is my job so far. That is what I have been through just work-wise, let alone anything else.

[32:47]

It is a long story, isn't it?

Sorry?

It is a long, involved story. So what has happened during that time from anywhere else? Anything at all, just as you have said it there, or have you had any other support from the RNID or...

Yes, LINK happened.

Can you tell us how you got involved with LINK in the first place, or do you want a break?

No. As you remember, I said back that I had been in touch with the RNID employment adviser. As luck would have it, she knew Lorna McNae, who was the LINK Scotland Manager at the time. That was say 2005. Obviously Lorna then got in touch with Eastbourne and the next thing I knew I had been contacted by LINK and I was to go on their intensive rehabilitation course in the April. I had returned to work in the March and it the course was at the end of April. So I muddled through those six weeks. Then when I went on the course, it really opened my eyes, because as bad as I thought I had it, when I sat and listened to everybody else that day and, in actual fact, Jim Hudson was one of those people who was on that course with me, I sat and listened to everyone and I thought, "My God, you're lucky". There were so many other people on that course that were worse than me. One of the women had Ménière's disease; one of the other women had mobility problems; one woman was so

deaf she couldn't hear a thing, although she had hearing aids, they were doing absolutely no good at all; and there was me, just deafened. I had some sort of hearing because I had decent hearing aids by that time. Then to learn everything you do learn on the intensive programme, all about cochlear implants, coping strategies, communication strategies, it was such an eye opener, and it was that course that literally saved my life. I know for a fact if it wasn't for that course, I wouldn't be here, simple as that. Once I finished that course, we went home, worked out everything we were doing. We actually then became outreach volunteers for LINK.

[36:40]

Away we go then. Bill, you have mentioned LINK and told us a little bit about that. Can you tell us how it has progressed from there with your work for LINK?

Like I say, back in 2006, I and Joyce went on the intensive rehabilitation course and Joyce, I have to say, up to the day we were actually going didn't want to go. She was dead set against it, what was she going to learn? Even she came away with a different point of view, so much so that we then decided that we would take this further and become outreach volunteers. We have since done a lot of referrals, contacts, and it is so good to be able to give something back, to be able to help other people that have suffered the way that I have. It is very true in that people say that the best teacher is somebody who has been through it and the number of times you go into people's houses, and explain what you have been through, and, again, it is like when I saw that doctor, it is such a relief to be able to find somebody who understands what you are talking about. For so long, you go through life thinking, "I am the only one", but you are not. We must have had, over the last three years, something like 12 or 13 contacts and we have managed to help ten of those. Sometimes you get contacts that just don't want help. Why they get in touch with LINK, I don't know, but sometimes they get referred to LINK. Out of the ones that we have helped, they have all come on leaps and bounds. Then we were asked by Lorna in 2007 if we would do the programme support volunteer. That basically is that we go to the hotel and look after all the guests while they are on the intensive rehabilitation course. Again, it is like giving a bit back to LINK after they helped us. The amount of satisfaction you get out of doing that one week's course is extremely exhausting to do it, but it is worth it. We have actually done that for the last three years now. We have been giving our support. I have also gone a step further and become a deafened awareness trainer for LINK and, unfortunately for us, the funding for that run out, and I still feel they should

still be going, because it seems to me that we have been trained up to do this job, and it is a waste. Hopefully they will resurrect it and we will go back to it. It is not just about LINK, either. Once you start finding out that there are other people that are deafened out there, there are other people who understand what you are doing and why you have to do it, it makes such a difference to know that there are people who can help you. It takes a lot of weight off your shoulders. The other thing is that my family live with me and my deafness are not easy for them. That is why the LINK is so good, because it is not just the deafened person that they look after, it is the whole family. A lot of people think that when you have lost your hearing, give you a pair of hearing aids, that is you sorted, off you go. What they don't realise is that you don't just lose your hearing; you lose your confidence, self-esteem. You lose so much through that one thing, and it takes a long time to come back, and it is not easy to come back either. Since then, through LINK, and through other organisations such as RNID, I have been fortunate enough to be asked to do a certain number of talks. As I say, one of them was in front of the Scottish Parliament. I had the dubious honour of having 16 MSPs in tears - I enjoyed that one - I have also become a member of an organisation called Civic Participation Network, and this tends to give communication support to not just deafened people, but all sorts of disabilities at public events and such like, because it is - in all the time I have worked with LINK, it has just been deafened or deafness I have worked with, thinking that is the only problem. A couple of years ago, LINK were approached by the Civic Participation Network and asked to do something similar to this for a thing called Talking for Scotland, which is a basic set of rules for people who try to set up a public event to supply communication support. When I went to the launch of that and I saw the other people that were actually involved with it, people with Alzheimer's, brain injuries, learning disabilities, all sorts. There was one guy there, he has got the opposite to us, I and he can't get on, because he hasn't got a voice box and I have no hearing. It is virtually impossible for us to talk to each other. Again, because there are such things as communication support out there, we do get through, and we do talk to each other. It is so nice to know there are other people out there like LINK and Hearing Concern LINK that are prepared to help people. As I said back at the beginning, I left the hospital with nothing. Had it been a different story with my consultant who said, "Yes, OK Mr Jones you are deaf, there is nothing we can do for you, but take that leaflet, they may be able to help you" it may have just been that little bit that kept me going, instead of suffering depression and living a nightmare for the length of time that I have done. But, no, I walked away from there with nothing and nowhere to turn to.

[44:40]

Have you found with regard to other disabilities - you mentioned the other disabilities - have you found your deafness can create a problem with dealing with other disabilities?

Yes, and no. As I have said before, I have dealt with other disabilities through the Civic Participation Network, and they have always got communication support in place. You are playing on an even field from day one. When you - the likes of here when you go to breaks and that sort of thing, it can get quite difficult. One of the things I took away from LINK in that first programme was communication strategy: carry a notebook. If I can't understand what they are trying to tell me, I get them to write it down. Even if there are some people I have met with disability that can't talk properly, but they can communicate in different ways. One guy I know who is in a wheelchair, and he has a picture board in front of him. When he is trying to talk to you, he is pointing to each picture, so there are different ways to communicate. It can be difficult, but we get through.

I mentioned that one, because I thought, as you have explained now about this business, I have thought about pushing along a wheelchair, and you can't read somebody's lips and things like that, so that is why I was curious about that, how other people saw that. That is how I see it. I would ask somebody else to help them, which makes me inferior, in a way. What is the situation with regard to work now? We have moved on, obviously, two or three years since your problems with work. Are you just carrying on now normally?

Sort of. Back in December last year, there was a problem at work. I was on my day off, and if I am on my day off, I don't answer my mobile phone. I got back to work and I was pulled in by my manager and was told I was going to face a disciplinary for not answering my own personal mobile phone on my day off. By the time we actually get to the disciplinary meeting, because he knew he was on a hiding to nothing with that one, it changed to not doing my job properly. We went through it and, again, it was just an excuse to try and get rid of me. Again, I called in the full-time official, because being a manager and a union member, I am entitled to full-time official all the time. Again, by the time we finished with him, we wiped the floor with him. He wasn't going to stand a chance of winning. Then at the last intensive rehabilitation programme, me and Linda Sharkey, who is now the Scotland manager for LINK, Lorna left and had a baby, Linda Sharkey is back and trying to talk while everything is

going on, the others were using BSL. I don't. Both me and Joyce said the same thing, it is time we learnt. I don't know what is going to happen with my hearing in the future. The way we do things with LINK, it could be - it will be easier for us to communicate with other people. We found a course that starts in September. The only problem is it is on a Monday night. As I work night shifts, it means I am going to take a couple of hours off on some of the Monday nights. I am thinking my boss will never go with this. And I think he has finally learnt he can't beat me. He has given up. I actually asked him if I could do this course, and he said, "Yes, not a problem". I am glad I was sitting down. I would have fallen down because he actually agreed with me. I couldn't believe it, because all this time I have been fighting this one man and finally I have got him to understand where I am coming from. I am sure it is not the end. I am sure there will be something else at some time. Watch this space, as they say.

Do you see this as individuals or your general work - individuals making life difficult for you because of you're - possibly starting off being your deafness, but then, in their eyes, possibly consider you to having been awkward with them and they are taking these actions because of that?

Part of me says, yes, it is individual. But then this guy - you have to understand, he is one of these people who believes he can get everything by bullying. It is not just me, it is our drivers as well. He seems to think he can just walk in and change the drivers' rota as he so wishes, because he wants it done. I have now got to the stage where I don't hate him for it. I have a better understanding of it. The way I look at him now, I must be something pretty special for him spending so much time thinking about me and thinking of ways to get rid of me. That is the only way to think about him. He is not worth bothering about any more.

[51:11]

What do you see for the future?

What do I see, or what would I like to see? They are two different things. I personally see at the moment not a lot of change, not just in my work situation, but things in general, still having to compete in hotels for having the loop switched on. Going to supermarkets and getting them to face you when they are trying to tell you something at the tills. You know, that I can't see ever changing, but that is just human nature. What I would really like to see,

and I don't suppose I ever will in my lifetime is people being able to understand the deafness of people and being able to accept deafened people for what they are, and not treat them as idiots. There is a saying I heard a long time ago - it is spelt D-E-A-F, not D-A-F-T, because that is the way people treat you. It is amplified for me even more because of my balance problem. Because they see you staggering down the street, the first thing they think is you're a drunk. They don't bothering to take the time to find out the truth, and that can really hurt sometimes.

Work wise, you will keep fighting to keep your job? Obviously, it is your income that is important. What do you see from the RNID, the Hearing Concern LINK situation with yourself, your involvement there? What do you see for the future there? Will you continue with the same?

Firstly, let me correct you, it is not just about my income for my job. It is about fighting to be a human being, knowing full well I can still do my job, knowing I have a disability and I am entitled to do my job with a disability and no-one is ever going to take that away from me. Why should they?

Why should they, indeed. That is what we all fight for, our rights as individuals. What about cochlear implants? You mentioned those earlier on, but nothing seems to have progressed there. Has anybody offered you any thoughts on that?

Yes. I have been in touch with a cochlear implant team and, luckily enough, because I have the level of hearing I have, because of the hearing aids, I don't actually need cochlear implants at the moment. That is another story, one of the good ones. Having been to the intensive rehabilitation programme, they told me about cochlear implants, and I thought I am going to find out more. I went back to my doctor to ask him to refer me and found out that he already had them. I got an appointment through to see the consultant, went through the motions. He sent me to an audiologist, it was actually a hearing scientist that I saw. Her name is Sharon Wilson, and she is at the Royal Infirmary of Edinburgh. She sat for four hours adjusting my hearing aids, because the hearing aids I had were never adjusted for the hearing loss that I have got. Now I can understand why I was struggling, but she sat and adjusted them and went through everything with me, and I come out of there - I had actually ridden my motorcycle over there, before I had my balance problems and I was wearing my motorcycle

clothing. I walked out of there, and I could hear my clothes rustling, which was the first time I had ever heard that in my life. She adjusted the hearing in my left ear, which had been told four odd years before I got nothing. She adjusted the hearing aid and gave me back the hearing four years later, which was bloody amazing. Excuse my language, but it was. I couldn't believe that I actually had hearing in that ear, because for so long I had been without it. Again, she adjusted the right ear as well, and left me to get on with it, basically, yet I was going backwards and forwards for different reviews. I was on my motorbike and whenever I put my crash helmet on, I take the hearing aids off. It is hard to wear both. I used to put them in my glasses case. However, it was in the way and I run over them, and completely crushed them! Four years, I spent, getting them right. But I cannot fault the audiologist in Royal Infirmary of Edinburgh. They have been absolutely brilliant with me. Whenever I have had a problem with my hearing aids, it is straight back and get them sorted out. They have spent time with me, even down to my balance problems. It is actually the audiologists that sort you out for balance as well as for hearing. I am actually going through more tests at the moment to find out if I can get my balance sorted yet. It is possible an operation on my left ear, if that is what is affecting my balance. If it is my right ear, he won't touch it, because that is the good ear I have got left, and he doesn't want to wreck that. You know, it always sorted me out whenever I had a problem, it has always been the Royal Infirmary that has sorted me, which is very good. All too often you hear bad things about audiologists and I have to admit, the ones where I actually live aren't that good. It took me to go to the cochlear implant programme before I got a decent hearing test. Now I have had it and I have got the hearing aid sorted properly, I don't need a cochlear implant. It is something to look to in the future.

[59:02]

Has your hearing gone down much that you have noticed over the last two or three years, three or four years?

My right ear has gone down by another ten decibels in the last two years. At the moment, it is still being compensated for by the hearing aids. We are okay at the moment.

The hearing threshold for cochlears are supposed to be - some say 40, some say 50. Where do you come in that? Are you above that? Have you got better hearing than that?

I think I am 60 at the moment. It is getting that way.

It is going down, so in the near future, you will be looking at a cochlear.

The thing at the moment, because I have a problem with my left ear, I get discharge in it, it could cut off my hearing aids, they are looking at a BAHA, a bone-anchored hearing aid, it will leave my ear open so it is not getting the infections it gets at the moment.

Anything else you want to know, or is that enough?

[01:01:02]

Bill, you were talking earlier, or I asked you about the future with regard to the different organisations. Do you want to fill a bit more in on that side of it?

What I would like to do is a lot more volunteering work. Hearing Concern LINK, as I say, I would like to see, as I said earlier, the deafness awareness project resurrected. It was such a good thing in teaching people what it is like to be deafened, although it wouldn't just be about deafened people any more, because of Hearing Concern LINK, it now covers the whole spectrum of hearing loss, and I think that can only be a good thing to get people to actually understand that. If it wasn't for the fact that I have got such a large mortgage, I would quite happily give up the job I have got now and work for LINK full-time, because I think they are an absolutely terrific organisation. Not just that, it is the fact that you can give so much to other people who have suffered the way you have. That means so much to me. Somebody once said to me, it was actually my sister-in-law, we were talking about coming down here for the weekend. Joyce has hurt her back, and I said if it comes to it, I can drive. Joyce said, "Well, not that we wouldn't go for the weekend, no matter what, you are going". My sister-in-law said perhaps that is because he feels valued.... That is very true. As a volunteer for Hearing Concern LINK, I do feel valued, and it is the one place I know I can go and be on a level par with everybody else. I am not trying to make myself understood or fight for my corner as I do in every other part of my life. Yes, I can see me doing a whole lot more for LINK.

Good. We all want to join you there. Finally, I was going to say I noticed that you have a walking stick and we have not touched on that. Obviously that is a different disability. Is it

something you want to tell us about?

That is a balance problem brought on by my deafness. It is called vestibular neuronitis. It is - I am not too sure what it is caused by, but I am told that within the cochlea in the hearing canal, there are balance receptors and mine are completely unaligned. It makes it very difficult to walk. As you said, I have to use a stick to get around. At night it is very difficult, because I need to watch straight ahead so I can keep myself focused to be able to get anywhere. Of course at night you can't see straight edges. So to do my job at work, they have supplied me with a torch that sits on top of my head. Drivers being drivers think it is very funny to sit me in a swivel chair and treat me like a lighthouse. That is the thing about the drivers. Although they know I have got a disability, they accept it more than what my managers do. They have a laugh and a joke about it, but underneath, they know it is serious and they respect me for it and respect me for the fact that I am still working with it. It is just their way of dealing with it. They are not making fun of me, they are just having a laugh. Even if I didn't have a disability, the drivers would still be having a laugh. It is just the way drivers are. At least they acknowledge it, which is more than what my managers ever try and do. As far as they are concerned, it doesn't exist, apart from when they want to get rid of me. The balance problems, hopefully will get sorted out over time. I was told it should only last for 18 months. It has gone on for longer than that. They are looking at operations for my ears to see if there is anything they can do for it. I went for tests about three weeks ago, and when I got to the hospital, the machine had broken down so I have got to go back again. That is just my luck. I have got to the stage now where I try to be as positive as I can.

[End of recording]