



# Unheard Voices: interviews with deafened people

Joyce Jones  
Interviewed by Roland Hilton

British Library ref. C1345/62

## IMPORTANT

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## Interview Summary Sheet

**Ref no:** C1345/62

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

**Interviewee's surname:** Jones

**Title:**

**Interviewee's forename:** Joyce

**Sex:** Female

**Occupation:**

**Date and place of birth:** 1966

**Date(s) of recording:** 20<sup>th</sup> June 2009

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

**Name of interviewer:** Roland Hilton

**Speech to Text reporter:** Julia Jacobie

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

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

**Total no. of tracks:** 6

**Mono or stereo:** stereo

**Total Duration:** 1 hr. 18 min.

**Additional material:**

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**Interviewer's comments:**

**[Track 1]**

*The date is 20<sup>th</sup> June 2009, and this interview is being carried out in Newcastle to record the oral history of deafened people. Deafened people are those who've spoken the language for communication but have acquired a severe to profound hearing loss. To avoid the communication problems due to hearing loss the interview is being supported by palantype that provides a verbatim, real time text display of all that is said. Our palantypist is Julia Jacobie. My name is Roland Hilton and I am deafened. And today I am interviewing Joyce. SO Joyce, can you please introduce yourself by telling us your full name and date of birth*

My name is Joyce Jones and I was born on the 1<sup>st</sup> of November 1966.

*Are you married?*

Yes I am.

*Can you tell us your maiden name then please?*

My maiden name was hardy H A R D I E

*Where do you live now?*

I live in a place called Cowdenbeath in Fife in Scotland

*Any brothers, sisters?*

C O W D E N B E A T H. Sorry?

*Any brothers or sisters?*

I have two brothers

*Any children?*

I have two children, a boy and a girl

*A boy and a girl?*

I do

*No grandchildren yet?*

Yes I have one. I have a 7 month old boy, Lucas

*Oh great! Any pets?*

I have two Great Dane dogs [laughter]

*What's been your career, your main career so far, or employment?*

I work for myself. I run my own business for the last twelve years, doing care and odd jobs for people who are stuck at home, or professional people who are at work.

[End of Track 1]

**[Track 2]**

*Starting with your, childhood what are you are very first memories?*

My first memory would be taking medicine and it was pink, from a squeezey bottle on to a spoon because seemingly I fell against a wooden couch, and I had split my eye open. I was 3 years old.

*Your Mum and Dad at this time were they both employed?*

My Dad has always ran his own business.

*Your Mum was looking after family?*

Sort of.

*How much did you see of your wider family at the time, uncles, grandparents so on?*

I lost one uncle when I was about 4, because he had a hole in his heart and it wasn't treatable like it is now. My other uncle was in the army, training gun dogs to sniff out guns and explosive in Northern Ireland, who admired greatly. We had a lot of involvement with my gran, she was like the matriarch of the family. That was all my Dad's side not my Mum's.

*Your house and neighbours at that time what do you remember about theirs?*

Not an awful lot I didn't have a very good childhood so I don't have many memories of neighbours and things.

*Were you living in a town, city or out in the country?*

We moved around a lot, I would say mostly towns.

[02:21]

*We'll move on to your school years now, your first school, what do you remember about the first thing?*

It was horrible.

*Why was that?*

I was terrified I was an unhappy child I didn't like change. There was nowhere where I felt safe. And I hated the school, even today it looks glum and horrible when I pass it

*Was that just the first reaction did it change?*

It never changed that school, no.

*You're sort of dissatisfaction with the school, hating it?*

Erm. I think because my childhood wasn't good it followed on into the school. My whole life as a child was not good. So it never improved any aspect of my childhood. So nothing was good and fantastic so it was never going to improve. That's how I perceive it now.

*How did you spend your weekends and evenings at that time? What did you do?*

As a child?

*A huh*

What we were told to do to be honest.

*Did you play in groups, did you have groups of friends or individual friends?*

Didn't have many friends, very few friends. Weren't really allowed out to play much.

We had to do as we were told.

*So did you play at home with your brothers?*

I was a girl, I wasn't allowed to play with the boys they wouldn't let me play with them. I used to take their cars to school and sell them.

[End of Track 2]

**[Track 3]**

*Tell me a little bit about how your life and education moved on before starting work, what was your later education?*

I left school as soon as I could, and I went to college for about 10 months, but again family moved and I ended up moving down south, then I had my children so I really can't do further education.

*How would you describe yourself at the time your character, your personality and so on?*

Oh God ... very insecure, erm, oh God ... lacked confidence. Didn't know where I was going to go in life,

*How did that move on you were insecure at this time, how did you sort of move through life did you get...?*

I moved away from my family and that was the best thing I could have done.

*Why was that? What was the reason you mention your family?*

Erm, it's very hard to explain, they had such a hold and when you have grown up not knowing any different you have, you live by those rules. And it's not until you become an adult that you can stand up and say actually 'this is not right', and step out. That's when I become the person I am now.

*So you feel you were kept under the thumb a little bit as a child not given your freedom?*

That's a slight understatement but yes that's one way of putting it.

[02:34]

*When you moved away from home how did you use your freedom what did that do for you?*

Gave me my laugh, made me the person I am now, gave me confidence I learned more then in what I had done up till that point.

*How long was it after you moved home before you met Bill?*

Ooh about a year I think. It wasn't that long.

*Short as that?*

I think so. It's a long time ago now!

*Had Bill got any sort of indication of hearing loss or hearing problems at that time?*

Yes he did, he was deaf in his left ear and had problems since he was 3 years old because of measles but it wasn't a major issue.

*Did it need any sort of accommodation, did you get used to making some allowances at that time or did it not matter at all?*

I think you make allowances without realising. You just accept this is the situation and deal with it and move on. It wasn't a big deal at the time.

*Were there any strong influences on your life at that time, religion, politics anything big that you are into?*

No.

*So after meeting Bill how long was it before you got married, soon a long time?*

We lived together for two years before we got married, that was 22 years ago.

22 years ago.

Yeah.

*So you were married for quite a while before Bill's hearing loss?*

Oh yes. He didn't lose his hearing until I think we just gone into our 6th year. 6 years passed, if not its 5. It's not much between them.

*So how old were the children, were the children around when Bill lost his hearing?*

Oh yeah

*How old were they then?*

They were mid-teens, 15, 16 the pair of them. It had a huge affect on them.

[05:21]

*How did Bill lose his hearing?*

We were told it was called sudden acute deafness. And in any other country it would be classed as an emergency but in this country its not. And he lost his hearing overnight when he was on night shift.

*He was actually working at the time was it?*

Yes He's still working now, he was doing night shift he hat a little bit of a cold not even a proper cold, didn't feel fantastic, came home went to bed, and got up no hearing.

*So he was asleep at the time when he went to bed?*

Yeah.

*What was your reaction when he got up and said he couldn't hear?*

Erm, we went ... I have to think, I like to get facts right. We went up the hospital. Or he was referred up to hospital I can't remember exactly what now if it was doctors then hospital. He was given a course of antibiotics, and told to come back in 10 days.

*So at that stage you thought it was probably something that was temporary perhaps?*

To be honest I don't think I thought anything, I just, one thing at a time. I didn't panic because if you panic everybody else panics round you. You have got two teenage kids, him trying to deal with a hearing loss, and to be honest I think we spent more time adjusting to the fact he couldn't hear and probably deep down hoping this was only temporary because he had a bit of a cold.

*How was Bill feeling, what was his sort of reaction to it all?*

I think he was very confused. He had just been promoted five weeks earlier to transport manager. So he had a real fear that he had just started a new job in this, his work, and he wanted to get back to that because he was still proving himself at the time so there was a lot of that going on in his head.

[End of Track 3]

**[Track 4]**

*As time went on, and you realised that things weren't getting better, did you get more concerned?*

Yes. We had gone backwards and forwards to the hospitals, and we saw really nice gentleman who then told us it was called sudden acute deafness. And that he gave him steroids I think to try to see if that would improve. And then we had to go back and see another consultant, and then that was about a total of 6 weeks after he went deaf. And we classed that as our D-Day. That was the day, it was make or break it was either permanent or it would come back or whatever. And that was a scary day. It was a beautiful day I remember it so clearly, it was fantastic day. I remember walking in there. And I saw the consultant's name. And I was so disheartened because we spent time with this guy before, we found him very arrogant. And it was a disaster from the minute we walked in.

*Did Bill have any other problems at this time or just?*

No

*Just deafness did he have balance problems?*

No balance problems that side was perfect, purely down to deafness.

*With time to reflect now, what are your sort of, thoughts now about that time in your life?*

Erm, [laughs] its a hard one to answer because I was so irate with the consultant, I lost the head. Which I generally don't do. But I was so disgusted by the way he treated him, he wouldn't speak to him, just spoke to me and basically said 'he's deaf take him home there is nothing we can do'. And I am still angry about that now because you hear other people going through the same experience, and it shouldn't be happening this day and age with the technology that we have. That comes down to people skills, and they should have them. So I would say anger for that, and the rest of it you look

as you know let's get on with it there's nothing else we can do here. Let's find away to deal with it.

*Did you get any other help, elsewhere, any sort of professional help as to services for safety and things like this?*

From the hospital we got absolutely nothing, we got sent away. Because I made such a scene, a nurse actually showed me a quicker way out of the hospital; I still say to this day we got thrown out of the hospital. I am not proud of it but you have to fight for your rights. We had nothing. When we came home, I got on the phone to RNID London, remember now in Scotland, and they gave me a couple of numbers and I phoned them and started the ball rolling to get help. But it was 5, no I am lying now, it was 2003 before I met anybody else who was deaf. Or had been deafened.

*So, time is moving on, you were getting no help. How Was Bill dealing with that, coping with that?*

He wasn't. He ended up going into depression and everybody else was in the wrong, he was right, everybody else was just winding him up as far as he was concerned. He was very difficult to live with. Very frustrated. No support from his work, his work didn't really believe he was deaf or deafened sorry, I used to fight with them as well because you were just banging your head off a brick wall.

[04:49]

*So what was happening with his job now that he was struggling to get back?*

He, to start with he went back to work as soon as he could once he got some hearing-aids. They weren't supportive, he couldn't answer phones, the drivers weren't very good with him, as in transport office. The office was far too noisy, and that caused a lot of the depression because he couldn't do his job he felt he was still in a new job and he had to prove himself. The kids were at the teenage years which is hard enough in their own right, he was shutting down. Completely shutting down from everybody and everything.

*What sort of a job did he have, he was transport manager, he had to use the telephone, was he organizing people from an office? On the phone?*

Yeah, he was based in an office in a big, big yard, where they have about 80 drivers so you have got constant guys coming in out of the building, the runs have to be checked, you have got customers on the phone, looking for their goods. You have got to deal with break downs, servicing the trucks, go out you're dipping tanks, checking fridges on trucks. A whole array of things. In meetings, morning meetings, dealing with different accents as well because we're central in Scotland so you have got Glaswegian accents, Edinburgh, Aberdonians, a whole array of different accents. And he was really, really struggling with no support from his bosses.

*It would seem to be no way he could do that job, how did he manage to get a way back in?*

Because it's a hidden disability, he felt he had to fight and prove that he could do the job. He had other people answering the phones, he got guys to repeat things or write them down, if it was too noisy he was lost and this is why he went off with depression. He just couldn't do it.

*So it was down to Bill to make all the adjustments and changes, nobody else would?*

Nobody else took responsibility. I had gone in originally, before he went back to work, I got a phone call to say to bring him in because he wasn't even allowed to drive until his other senses adjust which he found really difficult because he was HGV. And he used to get very angry because I was driving and 'why are you driving and I am not'. I would pull over he would be raging at me for pulling over, and 'why are you doing this'? And I would just point out the window. And it's an ambulance coming past. So for him, its having to accept there is things he could do and things he couldn't. And then we went into his work, and they told me to go and have a cup of tea, and they will talk Bill on his own. I said 'not on your life'. Because how can two hearing people talk to a deafened person who has no hearing-aids. I had to fight to stay in the room which I did, and he wasn't used to their voice, but he was used to

mine. We had learnt the levels we could understand each other. And I would repeat what they had said and they still weren't listening. And I gave her a load of leaflets I had, this is HR, and she turned round and said to me, 'it doesn't matter really anyway because our drivers know hand signals but I am too much of a lady to show you'. I found that so insulting, I thought it just summed them up. I said to her, 'if you want to know anything else just give me a shout, I will get the information for you'. And she said 'by your attitude I am sure you will'. So that gives you an idea of what they are like.

[09:24]

*So Bill was fetching these problems home as well, and it was affecting your relationship was it?*

Just a little bit [laughs] it was a big pressure you were no longer the wife, you become the carer. You became everything else and you became the go-between between him and the teenage children.

*So there were a lot of stresses at home. How did the children deal with all that?*

Erm, they just kept out of his way to be honest. He had this amazing look he would give you and it was like you were a piece of dirt on his shoe, I used to say him 'you can't look at the kids like that he didn't know he was doing it'. 'I am not doing anything'. But it was his way of just us, he couldn't communicate he would do these amazing facial expressions and occasionally he still does that which I am very quick to remind him of! But he just wasn't coping with the kids, with anybody. He wasn't coping with himself.

*So he was getting rather isolated at home, was that the case elsewhere? I mean could he still go out into the society to go to clubs and meetings or anything like that?*

No

*Or was he stick at home mostly?*

Stayed at home. It was easier to stay at home.

[11:00]

*Were there any solutions developing to this Bill had no help at that time was there any sort of, how did he actually sort of move on from there? Did he get any help?*

I think the turning point for us was when we moved house which was 4 years ago this October, and he was still very depressed, and we just moved in and he was going on to a night shift. The move went very, very well, everybody was fine, there was about 10 of us helping move us. And he was the only one who couldn't cope who was ranting and raving that when it really showed what was going on. So I gave him an ultimatum. You either don't go on night shift and you go to the doctors, or our marriage is over because we can't do this much longer. I would never have left him, but it was a threat I had to be extreme. And we went to the, to join the new doctors surgery, we walked in and explained our situation that there was definitely a depression going on, he needs help we don't know who to talk to, his work was getting him down, and the doctor pulled out a hearing-aid out of each ear of his own ear and said 'I totally understand you'. That was a turning point.

*It was really a case of finding someone who understood?*

Yes definitely

*In what way did that help?*

He put Billy on a course of tablets to combat the depression. The doctor got in touch with his own consultant, to talk about his hearing which we thought was really good of him, very nice of him. He was very sympathetic, and he managed to get Billy to go on the train by himself to go and see RNID and talk them about his work, employment issues. Billy was then put on the sick for about 6 months which was a major boost which made him step out and take time.

*All this should have happened sooner shouldn't it?*

I agree totally it should never have happened in the first place.

*Why do you think it didn't? Just chance of meeting someone?*

We should have had help from the hospital, they should never have sent us out the door with nothing. You know you can't be told you're deaf and be told go away, read a paper for 50 weeks before we can get you any hearing-aids to a young guy basically. To anybody. It shouldn't happen.

*Were there other places in your area you could have got that help and didn't know?*

We didn't know anything.

*But were there other places if you would have known could you have got that help but just didn't know about it?*

If it was for private hearing aids which that same consultant told us he could see is within two weeks in Edinburgh if we wanted to pay the money which again was very insulting we could have had hearing-aids then. I think we would have explored every avenue if we knew it was out there as far as we were concerned there was nothing out there.

*So this was the fact that there was nothing there, rather than the fact you just weren't aware of it?*

I think looking back now, there was probably bits and pieces out there, but we just didn't know at the time. If I had even the smallest inclination I would have investigated it. But nobody told us what was there. It's only now working with Hearing Concern LINK that we now know what is out there in our area. Again we have had to research most of that ourselves to help other people

[15:40]

*Does Bill have anymore medical help for his hearing now, is he still relying on his natural hearing?*

He has hearing-aids, digital hearing-aids, he has gone through the early process of tests for cochlear implant, but at the moment he has enough hearing with the hearing-aids that they won't do anymore just now.

*How are times at home like Christmas how did he deal with that, a lot of deafened people find that a difficult time to deal with, how did it work out in your house?*

He hid up in the study cos it was quiet, he would just get up from the table and go with no explanation. Nothing. We don't do mind reading in our house we had no idea why at the time. Mind reading sorry, my accent.

*So he was isolated and isolating himself perhaps as well?*

Very much. Yeah big time.

[End of Track 4]

**[Track 5]**

*In terms of other support like lipreading classes and so on did Bill get any help like that?*

No that's mostly down to his shift pattern. It wouldn't be consistent for him to go every week.

*So were classes available but Bill couldn't get to them?*

There was one class available that's all in our area. I think now there's only 2 available!

*How are things going on at work was he still struggling or ...*

He had one manager that came in and it turned out that his mother was deaf, so he was fantastic. Because we'd been involved with RNID, they had gone into his work and had meetings before Billy went back to work, and they got him a specialised phone, he got soundproof boards put up so he was more cocooned. So the noise wasn't too bad, the background noise. And he had a bit more confidence because he had the help and support a wee bit. We also were then in touch with LINK at the time, so there was a lot going on and he did very well with this manager. Unfortunately the manager then left, and it kind of has tapered off. He fights every corner. He's constantly fighting to save his job. And last year was probably the worst year that last lasted right through until February of this year where we had to have the unions involved and the disability rights people involved.

*So the story seems to be finding someone who understood?*

Yeah.

*Was the key to getting some help.*

Yep.

[02:23]

*Were you getting any sort of help with Access to Work or was it actually sort of through Government or just goodwill of a manager that happened to understand?*

I got in contact with Access to Work which was Glasgow, when he went back to work the second time. That was after we'd moved house we heard about access. I have to say they were fantastic I can't fault them. They were very, very good, give him everything he needed that was recommended to him. That gave him more confidence because he had that support behind him.

*You were doing a lot for Bill over this period of time, using phone calls, taking phone calls for him and so on, did that upset him? Did he accept that other people were doing it to help him or did he get annoyed because he couldn't do it himself?*

Frustration I think. I found it quite difficult in the early days because he would watch my facial expressions. I had a real to do with DVLA, because of his HGV we were told don't drive in the early days, and I had phoned them to explain this what do we do, and after about half an hour, they said to me 'we need to talk to him ourselves'. Which was horrendous. I am getting madder and madder he's watching me and I had to learn very quickly to control that because he was picking up the wrong things. Sometimes he was picking up the right things which I didn't want him to know about.

*How did you manage communications, was it all verbal, did you do any sort of writing, get to that stage or try anything else?*

We didn't do the writing until we had done the intensive LINK programme. We didn't think about it. It was, we were finding my level of voice which worked for him, and if he looked at me he lipread me. The children didn't do it, they didn't have time they were teenagers, so I would then translate what the kids had said. But mostly we managed by face-to-face and lipreading.

*So he was managing okay one-to-one?*

At home yes he was.

*But not with anymore?*

Not with anybody else, it was very, very stressful. Very difficult.

*Okay shall we take a break?*

Okay.

[End of Track 5]

**[Track 6]**

*The story we're getting so far is one of difficulties and lack of help, that's changed I think, how did that actually come about?*

Basically going back to the new doctor. Who as I said was very sympathetic, and between them, RNID, LINK came on the scene. And that's when we met our first deafened person. Which was quite an eye opener. We met up with a couple, who had been through a similar story to us, and it was gobsmackingly eye-opening to listen to them talk. And when his wife wanted her husband to stop talking she just gently touched him on the arm, and he knew that she wanted to say something. Obviously because he couldn't hear her speak. So that was a start for us of things changing.

*So this was the LINK intensive course?*

Yes

*You found that very useful?*

Found it very fantastic, I didn't want to go when it got nearer the time, I was very apprehensive about it. I didn't know what else I could learn, I think I was hitting my stress levels at that point, I think I was in need of help and I didn't know. Because I had been so busy looking after him, my husband and the kids, and doing things round the house and running my own business. I think everything was starting to take its toll on me. But we went, and it was, it was an eye opener it was fantastic.

*Did you get a lot of benefit from the other people on the course, the peer support?*

Yep definitely. To actually sit in a room with other couples, who most of them are in a worse situation than what we were, which although it's sad makes you feel that we're a bit better because they are worse off than you. We still had our jobs which was, we thought was quite amazing in itself. To listen to their experiences, and their way of dealing with things, we had not thought of. And we socialised with them in the

evening, we just laughed which we had not done for quite a few years because we were all suffering the same things, all making the same mistakes.

*So you feel you were making mistakes before?*

I think we have made quite a few mistakes. Now we can laugh at them.

*Before the LINK course, how were you feeling emotionally each day, how would you describe it?*

I think the first couple of years for myself, you took the challenge, you dealt with it, and you waited for the next one to come up. It was just the way our life was going to be. Nothing is easy but you get on with it. Then, we did the intensive course, and I think over the next couple of years I realised that actually I was his carer, and absolutely everything else. I no longer was his wife. I became angry, very angry about it. He was quite happy to sit back and let me do everything, and it was really starting to niggle away at me. And the last sort of year or so, I have come to terms with it. I have found my own niche in life. And he's more independent now I have taken a huge step back. Nobody's fault just the way its happened. So, we're doing okay.

[05:29]

*You had problems as a couple together communicating so on before the LINK course, how did you find Bill's deafness changed your sort of position as a peer, did you go out together and so on?*

If we did go out it was very strained, it wasn't fun. Bill's family have not seen him since he was deafened so isolation is a huge part. I don't have a lot to do with my family, so that has problems in itself I think. Because you have nobody to turn to, to mull things over with. We generally didn't go out an awful lot it was too much hassle.

*There are times you go out as Joyce, not as Bill's wife is that still the same, is that affected or does it affect you as an individual apart from your marriage?*

I have my own release away from him, and to be me, and that's my dogs. I have to keep my own identity, which I had not done for a long time since he went deaf. Its very hard to explain. I think now I am a better person, after going through what I have gone through. I would say I am a bit more understanding and I don't, oh God, I would like to explain this ... I think we're different people. I think he's different, and I am different, and I wouldn't say it's completely for the better.

[07:53]

*So you had some escape from deafness, perhaps Bill didn't have that?*

No, and I understand that to a degree. I do say to him you're not the only one who's been affected by your deafness. It affects everybody. And it took him quite a few years to understand that, and to be honest I don't think he will ever understand it the way I see it. And I can't understand his deafness the way he lives it. And he described it once as 'you could put headphones on for a year, and you would not go through a quarter of what I am going through because at the end of that year you will hear again I won't'. And I think that's well said.

*You went out as Mrs Jones, how did that affect things? People knowing that your husband was deaf, did it change things at all?*

Oh yes totally. People who didn't know us, would talk him as normal. Because its a hidden disability. And as soon as you would explain to him, 'my husband is deafened you need to look at him' they generally ignore him. And again, you become the go-between. You justify, reason with these people and try to get them to talk to him again. 9 times out of 10 they don't. Which puts a strain on myself and my husband. Frustration is just unbelievable.

*Did you feel that other people understood the battles you were fighting or..?*

Not at all, no way. My immediate family, my brother who I get on extremely well with and his wife, they have no idea. They think sometimes that Bill is being a bad

person, and they have no understanding what its like for him. Whereas because I live with him I have an inclination of what he's going through. And its again you're caught in the middle because you are justifying why he's done what he's done or saying what he's saying. And they think he's been very selfish. He can be very selfish. There's no doubt about it. I don't say that all deafened people are selfish but my husband can be.

[10:59]

*How did you see your prospects for the future before the LINK course?*

Oh very much doom and gloom. I don't know if our marriage would have lasted. We struggled. The kids struggled. As I said, Bill's family just ran a mile so there was no contact, and still no contact from them. I don't know. If we hadn't had LINK I can't honestly say where we would be right now. Probably a good possibility that I would have murdered him!

*Moving on to the present time now, how would you describe things at present? Have they improved a lot?*

Yes. The word is definitely yes. With a bit of knowledge you can generally deal with anything. Having the knowledge and getting the confidence, we're doing well. Not fantastic, but we're doing well. We're constantly learning. Things constantly change. We still fight the employment issues. That will never go away. We accept that now. Due to his balance problems he has had his licenses revoked. So I have to get up at 5 o'clock in the morning and drive him to work. And then I have to do my own job on top of that, and run the house, and do everything else and then I have to go back and pick him up. For him he has four days off after every four days he's worked the so he gets a rest, I don't. So it's still stressful. We still have our moments and we will always have the ongoing battles between ourselves, the deafness, and dealing with the deafness. With other people.

*Do you think there is more that could be done, do you feel that society could help you better?*

Oh yes without a doubt.

*In what way?*

I think the moment you go to your GP, for any sort of hearing loss, you should have a network of support to help you. It would make life easier to deal with, it would make it, and you understand what you're going to be dealing with. And I am sure with that in place the NHS wouldn't be under such strains with depression, suicides, marriage problems. It's just a whole array of things that just shouldn't happen in this day and age.

[14:46]

*After the LINK course, your communication is improved because you know a lot of extra skills and so on, how do you feel it is in a complete way. Do you still miss the small talk type of thing communicating is statements?*

I miss the small talk between him and I, I miss the personal talk that him and I have, as any couple would have that really upsets me. We have discussed it, numerous amount of times. You can't even walk down the street and make a wise crack that you don't want anybody else to hear, something you would say between two people, and it's not derogatory, maybe offensive at somebody but not you know, outrageously bad but you can't do that. And that's something you take for granted. And there's no way that's ever going to come back, and this many years down the line I am still wanting say these stupid things but I miss them. There's a lot of things I miss.

*At the LINK course, you found a lot of help from other people, peer support, do you still have that at all?*

Yes we're still in contact with these people. There was 5 lots of people there, there was a young family from Inverness I don't have contact with them, but there's people in Ireland, an older couple that we are in good contact with. Another couple who are now outreach volunteers like ourselves with Hearing Concern LINK, and

there is two other people on that course who are out reach workers as well with LINK so we're in constant contact. Not seeing each other every other week and things like that but we know each other is around. And they are like us, they have come on leaps and bounds as well.

*So through the people you met on the course have you got any local contact, people you can make face-to-face contact with regularly?*

As in deafened people?

*Yes*

No. We meet people now because we're outreach volunteers and we do quite a bit for Hearing Concern LINK Scotland sorry. So we meet a lot more people now, and give advice, and help, and if we can't help them we find somebody who does. But we don't have people very close to us who are deafened.

[18:06]

*You presumably do your voluntary work primarily to help other people, but do you find it helps you as well?*

Definitely. We can give back something that we got from LINK.

*Apart from giving something back do you think that other deafened people give something to you as well?*

Yes I think so. I get to sit back sometimes and watch Billy doing his thing, and he gets a lot of satisfaction out of it, and contentment. That makes my life a wee bit easier it gives him something else to think about, another wee challenge shall we say.

*Has all this helped Bill, do you feel he's more balanced now and relaxed with his problem, or is he still feeling isolated?*

He's definitely has more peace with the world, he still gets irate. I still see him lose the head at things that's just not worth it. And I find I am trying to negotiate with him, and bring it down. But I don't know if that's an age thing or if that's a deafness thing a lot of the time. But I would say in general, he's more contented with life. He's learned to adjust. And live with his disability.

*He was having problems with the children, that had not managed to make sort of contact properly since his deafness, has that improved now?*

Yes he's definitely calmer round them and they have grown up, they are adults now. I think teenage years is hard enough without having a depressed father round who doesn't want to talk to them, or understand their problems and it was all about him, it was never about the kids. And at that stage of their life it should be about the kids, you should be there for them whether they want you there or not. But no they get on really well.

*Also his own family you said he'd not met his own family since being deafened has that changed?*

Nope it's still exactly the same. And I also don't see that ever changing. He doesn't, he doesn't get upset about it now. He accepts this is the way things are going. And he also looks at it that they are not worth it if they can't make the effort to come and see him or even write to him, then they are not worth bothering about. I don't speak about it, I just leave the issue well alone.

[21:40]

*Do you think Bill is accepting his deafness better now, does he call himself deaf, does he admit I am deaf or does he still try to conceal it?*

No he's never concealed it, he just didn't know how to put it across to people I think. He doesn't like, if somebody else something to him and he hasn't picked it up he hates using the word sorry, I am deafened can you repeat the question. Because he feels he is apologising for being deafened. So, now we're at the level where if we go

anywhere, and the person talks to him, if the two of them are doing okay I step back because I feel he has enough confidence to do it himself. He goes out into the big bad world himself now, and he can go on the train, the bus, he has to be extra careful one because he has no balance, two he can't hear what's around.

*He's also disabled, would he use the word disabled?*

I described to it my doctor a couple of weeks back when I hurt my back, my doctor asked me 'is there nobody else to help you?', rather than you do the heavy lifting yourself, and my way of explaining it to him was 'my husband is disabled and he knows how to use the disabled word'. He knows when its a good time and when its not. So I think he's okay with using the disabled word. Usually to get him out of doing anything physical. [laughs]

*What single thing would you say has been most helpful in Bill's deafness?*

I think LINK. LINK has been the saviour for him I think he would probably say the same thing if he was asked the same question.

*Let's turn it round, what's the most single thing you think has been most unhelpful?*

Wow! ENT consultants. Yeah. That's the one I would use.

*Simply by the fact they did nothing other than medical help and not looked any further than that, is that the case?*

Yeah they didn't do anything. Didn't seem interested, didn't speak to him. So from the start, he was belittled. He had no self worth, he had nothing he viewed that for a long, long time. That's how he was. Because the health professionals spoke to him like that, it was just a knock on affect from there. So I will never forgive them for it! And yes I am bitter!

[25:36]

*You're not happy with consultants, ENT consultants, how do you feel about public attitudes?*

How do I feel about?

*Public attitudes.*

You can't tar everybody with the same brush I don't think. Generally, its unseen, you have to educate them. If they then choose not to abide by the rules shall we say, that's their choice. You can't force people. You have to accept that's what going to happen. If they talk to him and deal with it, great. Wow. We're having a good day. If they don't, don't take it personally, move on. They are not worth it, life is too short.

*Have you ever felt embarrassed or needing to apologise for circumstances that are not your fault at all?*

No. Because I am of that nature. That I wouldn't! Especially with deafness. Nobody has to apologise for anything. Lack of understanding I would have said more than anything else, but no. I wouldn't I would never apologise no.

*Do you feel that there's still a stigma related to deafness?*

Yes. Big time. It's amazing the amount of people who suffer a hearing loss of some sort, and it's also amazing how you can pick up the people who have a hearing loss of some sort, just by looking at them. Because you live with it 24/7, I have a neighbour who is in denial that he has a hearing problem, until we were sitting having a drink in the garden, and his wife said something to him and he said no he said 'I wasn't listening' and I told him 'no you have a hearing problem'. And he actually admitted in the end he did and he was in denial. The good always comes out of bad that the way we view life.

[28:17]

*Is there anything about deafness that's, Bill's deafness that left you feeling shocked, apart from the treatment with the ENT people have you ever felt surprised and shocked?*

One time I was shocked at the attitude of his employers. To not believe what they are being told, in the position that they were. I found that absolutely shocking. I was naive in the beginning to think that people would be out there to help us, and after the first phone call I was learning that that's not the way the world is not made like that, they are at there to help you. So I would say I was probably shocked at the very beginning and nothing shocks me now. Because I think we have seen it, we have lived it we have had to deal with it.

*Anything living with deafness that left you feeling frightened, scared?*

God I wish a had a list of questions before we did this I could have thought about it a bit better! Frightened? I suppose if anything ever happens to me he's left on his own. That frightens me. Because I don't know how he would cope. No. I can't think of anything else that frightens me.

*Is there any time you have ever felt like giving in?*

Oh yes!

*Why?*

I think there's quite a few times. I think even of late, you just think for God's sake give me a break, cut me some slack, I am a human being I am not this machine. Especially since I have hurt my back I have had to slow right down. And I think for him its all about him, and his deafness, and his disability, and when the table turned he couldn't cope. Where I needed some help, and I had to basically shut down for a couple of weeks, he was not dealing with it and I am thinking 'I have dealt with this now it's your turn. Give me a break'. And I have come close then to saying 'I can't do this anymore'. But feeling better, on the mend, I am bouncing back so it's very short-term.

*So it's the difficulty of dealing with this day in, day out, day after day that more wearing than the problem itself?*

Definitely, and most people don't see this, they think you're Bill's wife and your life is no different. They don't see the pain, the heart ache, and the suffering that you go through, and I don't suppose for one second I am any different from any other hearing partner.

[32:15]

*How do you feel that deafness compares with other disabilities?*

Sometimes I think it's the better disability to have, we have discussed what would you rather be deaf or blind, and he has still come back with being deaf rather than blind. I sometimes I think it would be better to be blind than deaf, because I have not lived the deafness side. I assume that's why I go with that thought. There is worse than ourselves out there. And I think if his disability stays at loss of balance and loss of hearing, into his old age, we can live with it. I think we have done okay.

*Last one on these, have you ever encountered any discrimination after Bill's deafness?*

At his work. Definitely discrimination there. I think Joe Public discriminates without realising. I think you get it in very walk of life its how you deal with it. Now we have the laws for employment the Disability Discrimination Act, and I think if it wasn't for them, he would be out of a job. Wrongly he would be out of a job. But because we got them involve, we know we have that back up, but they are not easy to access. You fight tooth and nail to get these guys in. We're lucky we have the discrimination act there. But no I think every day of your life you come across some discrimination of the deafness because it's so unseen. And people have this vision of how to deal with deafness, and now you can sometimes you can say it's actually quite funny the way they have dealt with it because we're confident to deal with it. But before, no it would be awful. And you would take it so personally.

*You mentioned earlier you weren't very confident as a child, but obviously that has changed, do you feel that Bill's deafness has helped that change, has it changed your character in anyway?*

Ooh ... my character ... I don't honestly know if have I changed anymore than what I would have done as I have got older. Because of his deafness, erm, this is a really hard question. I am trying to think how Billy would put this, what he thinks. No. I don't honestly think so. I think I am who I am because I have been like this for a few years now, as I became an adult is when I changed. And I think I am still as determined now as I was then, because its my belief of how to deal with life.

*Has your lifestyle changed because of all this? Do you see yourself restricted at all now or able to do what you want?*

In some ways yes, it has changed. I would love for him and I to go to New York, and I have said to him that I won't go with him while he's on a walking stick, because he has to walk everywhere. His hearing part is not an issue. Because you have to accept that, he's still at work we're still doing all the things that we had planned on doing, so in most cases no it has not but in our dreams yes it has.

*So it's not really restricting your plans for the future too much?*

I refuse to let it in most cases [laughs] I don't think you can live in the past, you have got to keep moving forward. He has a problem, you deal with it you move on.

[37:53]

*Have there been any points at which your sort of views have changed a lot?*

My ... views I suppose maybe in politics. I am not really into politics but having gone through what we have gone through I have more of an opinion. Because of the NHS, because we pay our taxes and all this sort of thing yeah it comes into the politics side of things. My views are quite strong on that now. I wouldn't know where to aim

them at, but if I had to do something I would be very focused I would go hunt the answers. I can't really think of anything else to say to that.

*We don't look for bad experiences in life, but they come along in the form of deafness sometimes, and providing we survive, experiences like that can strengthen us, did you feel that may have strengthened you in some way?*

Definitely. But I have not changed who I am, but oh God, erm, I think I am generally a strong person anyway. I am not your shy retiring type, so yeah you just take each blow as it comes, and deal with it. So maybe I am not any stronger than what I was before, I would need a lot of time to think about that and analyse that one! . [laughs]

*Okay I think that's probably the end of what we have got and thank you very much for talking to us.*

Thank God! I wish I had the paperwork beforehand to read it through and just have a right inkling what was coming that is so difficult to think off the top of your head.

[End of Track 6]

[End of recording]