



# Unheard Voices: interviews with deafened people

Jean Sneddon  
Interviewed by Colin Ellis

British Library ref. C1345/45

## IMPORTANT

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## Interview Summary Sheet

**Ref no:** C1345/45

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

**Interviewee's surname:** Sneddon

**Title:**

**Interviewee's forename:** Jean

**Sex:** Female

**Occupation:**

**Date and place of birth:** 1966, Fife

**Date(s) of recording:** 5<sup>th</sup> April 2009

**Location of interview:** The Bruntsfield Hotel, Edinburgh

**Name of interviewer:** Colin Ellis

**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:** 42 min.

**Additional material:**

**Copyright/Clearance:** Open. © Hearing Link

**Interviewer's comments:**

**[Track 1]**

*This is Colin Ellis interviewing Jean Sneddon on Sunday 5th April for Unheard Voices Project in Edinburgh. Jean, would you like to tell us your full name, when and where you were born and about your father, your mother and father and whether you had brothers or sisters and where your family came from?*

My name is Jean, Jean Sneddon. I was born in Fife. My father was a labourer for a long time then became a policeman. My mother has never worked and in employment but she raised us. I've got 2 sisters. I've got an elder sister who is very unwell. She used to be a school teacher. My younger sister is in Wales at the moment and is a lecturer.

*And when were you born Jean?*

I was born in April 1966.

*Did you know your, grandparents and about any of their family background?*

My father came from a huge family. He had nine brothers and sisters from Edinburgh. My mother was born in Fife I don't know a great deal about my family background I did know my grandparents for a while but they're deceased now.

*Do you know what their occupations were at all or was that never passed on to you?*

All I really know is my grandparents lived a life of extreme poverty, they were incredibly poor and had a very, very tough life I don't know a great deal about them at all.

*Would you like to describe your childhood experiences, your school, friends, what you used to like to do in hobbies, and what you liked or disliked?*

I was raised in Fife and moved abroad for a while with my father's job and I had a fantastic time in Malaysia really good multi-cultural up bringing really enjoyed it. Came back prior to starting secondary school and had quite a tough time really having an accent and a dark skin and I came back to a small mining village a village school. Found things really, really tough.

Then I went to high school which I loved. Really enjoyed high school. I like getting out about. I used to enjoy cycling and I would read. I read a lot of books as a kid. Enjoyed music. Played the guitar. I had a good childhood.

*That sounds interesting. So when did you actually go to Malaya and how long were you there?*

I went to Malaysia I was 7 or 8 came back when I was 11 or 12 thoroughly enjoyed it, paradise.

*Have you any members of Malaya at all you'd like to tell us?*

What I remember was the sunshine glorious sunshine. Scotland is really grey. Just being outdoors was nice. Parents social life with the locals had a lot of Chinese, Tamil friends, really enjoyed it.

[04:31]

*Can you remember Jean what were your first experiences of employment and did you have to have any further education?*

My first job was in ASDA stacking biscuits in a supermarket which I enjoyed. I did that part-time I then, one of the best jobs I ever had was working as a cleaner in a hospital. Thoroughly enjoyed that and I certainly didn't need any qualifications for it. But I then went and did a degree a science degree and then I got a job in a pensions office in Edinburgh. I then went back to university and did a post grad in town planning which again enjoyed I love cities, so I really enjoyed studying cities. And then I went back to pensions again in Edinburgh and now I'm working for the local authority.

*You indicated that you did a science degree. Would you like to tell us a little bit more about the university you went to and what led you to that decision?*

I love science. The degree I picked was a multi-disciplinary one so I studied things like chemistry, biology, maths psychology and the idea of the degree was to integrate these

subjects. Thoroughly thoroughly enjoyed it. But unfortunately in Edinburgh there is not a great deal for work for those sort of skills. That's why ended up in finance. I still to this day enjoy reading science and maths books.

*Have you got any memories of being at university on campus that you'd like to tell us about, happy times or sad times?*

It was tough. I do remember it being really tough. Very, very challenging. I enjoy studying. Thoroughly enjoyed it. Nothing specific at all.

[End of Track 1]

[Track 2]

*Jean, describe how you first noticed the deterioration of your hearing and your feelings to this about any related problems, for instance, did you have tinnitus or balance problems. Losing your confidence and self-esteem. And did it affect any relationships you may have had at that time?*

Yes I didn't notice my hearing loss it was people that surrounded me noticed it. What I did notice was my door bell stopped working, my television broke, my alarm clock stopped working I was having a lot of problems with my telephone I think I've always had tinnitus but I always thought everybody else had tinnitus. I then went to my GP and it took a year to get an appointment with the specialist and when I got my hearing test I got quite a shock because I didn't think I had a hearing problem really. So I got my hearing-aid and it was dramatic. It changed my life. It took a long time to get used to because I was hearing a lot of noise that I didn't want to hear. It made things difficult, using a telephone was hard, I did find my relationships had really suffered and I was surprised how much I could hear and also surprised - I think emotionally I would lose my temper with people, became irritable, it was hard, difficult maintaining friendships, so I think emotionally that was the biggest problem for me.

*What do you think contributed to it happening in your life? Or, perhaps was it hereditary through your parents or grandparents, perhaps your sisters may experience it now.*

I just see it as life. I don't think it's hereditary. Nobody else in my family has any hearing loss.

*What was the reaction from your family, your sisters, friends, and work colleagues. Did it affect your work or the progress to get better jobs or promotion?*

My family didn't react very well at all. My sister is incredibly ill and most of the resources in my family are focused on my elder sister. My friends have been mixed. Some are incredibly good took it in their stride some had a very difficult time dealing with it. My work colleagues that was difficult and it did make, work was the biggest impact. It was almost impossible to do the job I'd been trained to do.

[03:25]

*How did you go about getting the diagnosis and treatment and where? And was your employer helpful or ignorant of the fact?*

My employer was terrible. They were poor. They were poor from the top all the way down to the bottom. They expected me to be the expert and I didn't know anything at all. Eventually, they did make quite a number of big mistakes really and eventually they got RNID and they come into the office and were very, very good at resolving a lot of the conflict and I'm somebody who's never had conflict before in an office and that was difficult. I was seen as a problem. It wasn't my hearing loss was a problem it was I was the problem and it was really separating the hearing loss and me and them, separating all these factors out RNID were very, very good at resolving that conflict. But, working in such - I was working in finance which is very demanding very fast paced, people didn't have a great deal of patience, and I suppose I was quite impatient too because I was coming to terms with the hearing loss and I was having to make big adjustments.

*Did your hearing rate deteriorate to a point which you could not hear? And how long did this go on for?*

My perception of my hearing loss was probably different from perhaps the reality of it my perception was it seemed to drop 3 times quite dramatically. Without hearing-aids in I couldn't have a conversation one to one in a silent room. At the moment I had surgery 2 months ago and I've now almost got natural hearing in my right ear but I'm still profoundly deaf in my left ear. So, I'm now having to adjust back to being hearing.

*So we are talking of very recent diagnosis and surgery and was that with the NHS?*

Yes. I've also used the house of hearing. They were private, the hearing-aids that I needed were unavailable on the NHS at the time and the House of Hearing they were fantastic, absolutely spot on, incredibly good, I felt that the House of Hearing had a lot of time for me. They certainly didn't give me any sort of emotional support and advice but I felt they had a lot of time I felt they treated me as a person I feel NHS it was just part of a factory Assembly line. I feel that the NHS I waited 3 years to get an appointment to see somebody about

surgery. I've turned up taken a day of work and they've made mistakes with administration and I can wait for 3 hours waiting for an appointment. I've just been very disappointed with the NHS.

*Would you like to tell us more about this private company how you found them and did they expect you to pay for consultation and hearing-aids?*

I can't remember how I heard of the company but they've certainly got an excellent reputation which in my opinion is well deserved. My employer were more than happy to give a blank cheque to get the problem sorted out and the hearing-aid was incredibly expensive. And the House of Hearing they couldn't have done enough for me. I didn't have to pay for any appointments any check ups any hearing tests any adjustments, I didn't pay for a thing.

*Are they a national organisation or are they more toned to Scotland and Edinburgh?*

As far as I'm aware they're Edinburgh but people travel for hundreds of miles because they are so good. They are good.

[09:03]

*From this piece of conversation I understand that the NHS during the last few years have not been very good with their diagnosis of deaf people and that you had to find alternatives to get any help whatsoever.*

I don't know - I think the diagnosis was spot on. They certainly gave me hearing test that showed I had profound hearing loss. What was difficult was having to wait a year or 2 to get a hearing-aid then to have to wait for two or three years to get an appointment to get surgery. When I got my hearing-aids they were good when I got the surgery the surgery was good but there is no advice, no emotional support, there are no alternatives. Even the receptionist, they must deal every day all day with people with a hearing loss but they mumble they turn their backs they don't have a system to tell people that the doctor is ready to see them. And the thing that's what I've found organisation like RNID and LINK are incredibly good because these organisations seem to plug the gap that's missing from the NHS.

*So, was it your, how can I put it, the lack of time to get to see an NHS audiologist that turns you in this direction? Did the private people, did they recommend you to see a hearing therapist or lip-reading tutors et cetera?*

No. Nobody suggested at all that I get in contact with any other agency. When things became really bad at work when RNID stepped in I can't remember the word, to try and resolve the conflict between myself and my employer, that that's was when RNID suggested that there were other agencies out there that could give me help and support and advice.

[11:55]

*Would you like to tell us Jean by this time, which is very recent, how you felt about your social life and about your hobbies? How it affected you.*

That was the biggest thing. I found that I enjoyed cooking, enjoyed having people round for meals and all of a sudden I just seemed to be burning everything. I didn't know at the time but with hindsight I would be frying onions and doing my dishes and I couldn't hear the onions sizzling in oil. I was burning food all the time. People were calling at the front door and I wasn't hearing so they would go away and think I wasn't at home. People would phone me and I wouldn't hear my phone ringing. I would visit a friend's house and they would put a record on and I couldn't hear people talking any more. That became so frustrating I would just literally see red. I would get on a bus and the bus driver would speak to me and I wouldn't hear what the bus driver said. I would go to the petrol station to pay for petrol and the guy would make a remark and I wouldn't hear the remark. At work someone would stand up and shout across the office and I wouldn't hear it. There was one time I was at my desk and I looked up and there was no one else around me. Everyone had been called to a meeting; and I hadn't heard that they were all going to a meeting and no one had thought to tell me or they had but I hadn't heard them; so I just felt really marginalised I felt left out, I felt stupid, I felt thick, I couldn't follow things in meetings. I would want to write things down which held everybody up, people became very impatient with me I became impatient with them. It's not just words it is people's tone I wasn't picking up on tone; but all this is with hindsight at the time the world just went really strange I didn't think I had a hearing loss. I thought there was something wrong with the planet.

*Jean, do you have a partner, and if you do how did they react to your deafness?*

At the time I was in a relationship and the relationship broke up and I didn't know what was going on and I just think these small communication things, things were being missed things were being misunderstood I think that caused a lot of conflict I was having problems at work. I was having problems socially, having problems with all my relationships. And I think that all these things just compounded to make me not an easy person to live with. And yes, yes my relationship just crumbled really.

*Have you been able to amend this with somebody that does understand you these days?*

That was a big battle. What I did was when - I got the equipment sorted out, and at the same time I had a lot of work personally, I saw a counsellor who was a specialist in pain management. And what he did was he took me on a course it was six weeks and the first week was an introductory the last week was a sort of conclusion and in the 4 weeks in-between we looked at pain management to look at two things. First of all deal with my hearing loss and the second thing was to look at my tinnitus. I really learned to manage my tinnitus and come to terms with my hearing loss. After - that was dramatic, that was very, very successful. I then went and learned self hypnosis and that really, really helped. Then I think it took me 3 or four years but I did pick things up and then I started really working hard at opening up my social life again and meeting people, meeting new people. And it's sometimes easier to explain to somebody new to send me a text before ringing the phone, or I can't hear the phone ringing if I'm watching television, or it's sometimes easier to explain something to somebody new than to somebody who's known me for a long time.

[16:41]

*You mentioned getting a counsellor and getting equipment, who advised you about this area of consultation?*

My work have, they're very popular now, they have telephone help lines and it's to do with staff in general that have relationship problems or stress problems or work problems and they have these wee cards and everybody can phone up and speak to a counsellor and I said to my work I cannot use this because I cannot use the telephone and in my opinion that was

discriminating towards me that I couldn't use a service that everybody else in the office could use and I kept pushing it and pushing it and what they ended up doing was sending me to psychiatric evaluation. I was sort of stuck because I didn't think there was anything wrong with me medically, apart from frustration and anger, and I didn't think that I needed to see a psychiatrist about it. All I wanted was the option of speaking to somebody about anything I wanted to as my colleagues could if they wanted to. In a redundancy situation they were closing office in Edinburgh. Because I forced this issue my employer forced me to see a psychiatrist. I was quite open with the psychiatrist and I had forms and evaluations which I refused to participate in, so in the end he was really good and we ended up focusing on managing tinnitus as he would do somebody in chronic pain.

[18:48]

*Jean have you ever heard of LINK and what they do?*

Yes. RNID suggested that I get in touch with LINK because my understanding was at the time they were an organisation to support people like myself adjusting to acquired deafness.

*When was this Jean?*

Off the top of my head it would have been five or six years ago and I was reluctant to do anything about it and I resisted for two or three years and then when I went it was very, very good. I think I had to be ready to make that change.

*Do you think if you were better advised that you would have come to LINK sooner rather than later?*

Yes.

*Have you been able or would you have got on the intensive programme that would have helped you through the psychological barriers?*

That was difficult because it was presented to me as a week where everybody went with their partners, with their children and I didn't want to be the only single person in that sort of - that

was a huge barrier for me. Also getting arranging the time off work my employers were not keen for me to take time off work.

[20:45]

*What did you do to overcome these prejudices and discriminations that you've encountered in your life?*

I don't know if I do that very well. I suppose sometimes I just close down really. It's something that can feel a bit relentless just to keep asking somebody several times a day just "pardon" "excuse me" and sometimes it's easier just to duck out and not get involved. Other times what I can do is suggest to a friend that they can read something or talk about something.

*You mentioned having trouble on buses. What about railways or your own transport. Getting into certain areas?*

Travel was a big thing, that was a huge thing for me because, like I said it's quite easy just to close down a bit and I love London and I remember going to London, that was a huge adventure and I think that people enjoy showing off, enjoy talking about the city, so I just had to overcome that hurdle and I found people were fantastic if I asked about a train, how do a get to this platform where is this train leaving, people were fantastic. What is difficult with travelling is when they announce changes on the tannoy I don't hear the changes and I can't relax because I've always got to focus on the boards. And the same with flying really. It's not as relaxing as it used to be but I do find that people have been really helpful.

*During this interview, I get a hint that you've never been given information that you could get support from your local services or benefit agencies and were you aware of the access to them, in particular Access to Work?*

I have used Access to Work several times and it feel that Access to Work they seem to change the rules frequently which makes it difficult. I've been working with the Council for a year now and Access to Work have been very, very good and my new employer has been very, very good but previously I found Access to Work difficult because they seemed to be

cumbersome there is a lot of paper a lot of toing and froing but certainly this time round they've been very good I got equipment very quickly and I got information very, very quickly.

*Were you aware of the help that Social Services could give you and the fire services with regard to emergencies should you ever be placed in one?*

I work for the social work department and nobody there seems to know - they wouldn't be able to answer that question. So occasionally I do a wee bit of awareness in my office but I don't know a great deal at all about the help that Social Services could give me.

*Around the country, Social Services operate differently, for instance, in Southern England they call themselves Sensory Services, but they're there under the 1948 Act of Assistance to help you within your home. Have you not found any within your employment?*

No.

*Do you believe that you've achieved actually everything to give you better life whilst disabled?*

It varies. Sometimes, sometimes. It's making an effort. Have to make that effort really.

[25:55]

*During the last few years, you've talked about your employment and the discrimination you felt at times. Did this mean that you had to leave that employment and seek new, or was there any time when you were unemployed?*

I had to leave not only the job I was in but I had to leave the sector that I was in because there was too much verbal communication. There was not enough information written down. The sector, the financial sector that I was in was being squeezed so I had, it was one of the hardest things I've ever done was switch sector so I've now - I do a job using similar skills but for the social work department as opposed to the financial sector.

*I go back to a previous question about help and I wondered whether anybody had advised you of the benefits that you may be entitled to should your deafness be known as a disability.*

I'm assuming if you're talking about work I was quite upfront that I felt that my deafness was a disability. I don't think it had to be a disability. And I think that it's - the law is there to protect employers not to protect me. That's sadly that's my experience. I thought it was better for me to get out that sector, out that environment because what I was doing was fighting and like I said I was considered the problem, not my hearing loss. I was in a meeting with HR and they asked me why I hadn't considered taking early retirement through ill health and a year later I'm earning more money, I've got more responsibility and I'm doing more, and yet in that sector HR wanted to get rid of me.

*Have you ever taken advice from the Citizens Advice Bureau as to your condition and the way that employers might be treating you?*

Yes I did and I found Citizens Advice to be fantastic. They were really really good. But I think that employers can do one thing on paper one thing in theory but in practice it's very, very different and I found that my life was just becoming a battle about my hearing, not about with the clients or working with the computer system or project. Instead it was focusing on my hearing is a problem.

[29:41]

*You've revealed that now that you've found LINK and RNID them to be very helpful to deafened people or hard of hearing. Would you consider taking a more active role to support charities like HCL, volunteers, fund-raising, giving talks, whether to clubs or organisations about how to deal with people in your condition?*

I feel that I need to be in a certain place myself emotionally before I get involved in supporting somebody else, other people. I also feel that I'm so much more than just somebody with a hearing loss or somebody that wears hearing-aids and it's something that I live with every day all day and I would quite like to get away from that. I do a lot at my, in my work. People constantly talk to me about their aunties or grannies, their neighbours or Dads and Mums with hearing problems and I do a lot of support and education every day all day in my work. I think at the moment volunteering would just keep me immersed as somebody with a problem. That might change. I certainly think in the future I would be happy to do so.

*We've talked over the last hour or so regarding your life, and how you came up through school and that and your employment and your illness and how it's been treated. Is there anything else that you could think that you would like to add to your story for people in the future?*

I think it's about hearing loss it's not one dimensional, it's a problem with a lot of dimensions and for me it's getting that whole package in place, getting the technology correct, getting educated, getting knowledgeable about technology, and to me it's about keeping my life open rather than closing it down. That's been a battle. And I think it's about awareness. For me it was about self-hypnosis its about getting an alarm clock that vibrated, educating my friends, learning about email as a different way and learning about different ways to communicate I don't think there is one solution for everybody. I think people need to look for individual package for them.

*I'm going to ask you one final question. You very kindly told us your story this afternoon and you'll finally walk home thinking about this conversation, go indoors, kick your shoes off, have a nice cuppa, sit down, and take a big sigh. There is a knock on the door. It could be a friend, a neighbour, a work colleague, or even a member of your family, even distance, and they are in total distress. They are crying. They point to their ears and say, Jean, I've lost all my hearing and I don't know what to do. What would you suggest?*

That they talk, that they talk. That would be the first thing, talking and the technology, get the technology correct.

*Would you advise them to see doctors, get appointments to see audiologists and seek medical help through the proper governmental systems? Or what?*

I would suggest they do everything I would suggest they get in touch with NHS, LINK RNID, the House of Hearing, counselling, relaxation get on the internet get the equipment in. I would suggest everything. Try everything. Get as much help as you can.

*Well, Jean, it's a very interesting story and I think there will be many people wanting to listen to you and I want to thank you very much for coming along this afternoon and telling us about your life and about your illness and I wish you the best of luck in the future.*

Thank you.

[End of Track 2]

[End of recording]