



Unheard Voices: interviews with deafened people

Angie Lambert
Interviewed by Andrew Goodwin

British Library ref. C1345/20

IMPORTANT

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Interview Summary Sheet

Ref no: C1345/20

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Lambert

Title:

Interviewee's forename: Angie

Sex: Female

Occupation:

Date and place of birth: 1978, Worcester

Date(s) of recording: 13th March 2009

Location of interview: The City Inn Hotel, Bristol

Name of interviewer: Andrew Goodwin

Speech to Text reporter: Mirella Fox

Type of recorder: Marantz PMD660 on compact flash

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Interviewer's comments:

[Track 1]

Right. This is Andrew Goodwin, interviewing Angie Lambert on the 13th March 2009; for the Unheard Voices project in Bristol. Speech-to-Text reporter today is Mirella. Now Angie, there are a couple of things that I need from you as we start recording, can you tell me your full name please?

My full name is Angela Lambert.

And your date and place of birth?

15/06/1978. So I am now an old woman!

You are younger than me I wouldn't say you are an old woman.

But where were you born?

That's good to know.

Where were you born?

I was born in Roxford hospital in Worcester; I don't think it is no longer there any more.

So they broke the mould when you were born.

I think so, yes.

And can you tell me what your parents' occupations are? What do they do for a living?

My dad is a recovery driver, my mum is currently unemployed, but she is usually most, mostly -- my sister has just had a baby, she has been busy helping her out.

You said your sister has just had a baby? Or your mother.

Yes.

Congratulations.

No, don't say that, my mum will kill me.

Okay. Well, I like to have the start of these interviews if we can go right back into ancient history, can you tell me from I something about your childhood? For example, where did you go to school?

I went to Pitmaston primary school which is in Worcester and it was absolutely lovely school, and I remember my head teacher looking at me, because I was doing some worksheets, happy with my English. And I was trying to think of a word and it happened to be Tony, mentioned the school at the time, he helped me with the answers to that question. That's it.

So, this school was it the same school from primary and secondary onwards?

No, I had different schools. At first I went to Pitmaston primary school, then I left to come to Malvern because I was living in Worcester when I was little, up until I was nine. And of course, where was I -- yes. We moved around a lot. So I have lived in about nine or ten places by the time I was ten. So bear with me.

Yes, so I went to Pitmaston primary school, then I went to Summers Park which was in Malvern, in my secondary school was Dyson Perrins which is also in Malvern.

Where was your favourite school?

Pitmaston, it had a school pond. I don't know I had to say that but it really made, it was very cultural school, very loads of trees, loads of outdoor area, loads of interesting stuff. And all the teachers were really nice there.

Okay. When you went to when you moved to Worcester was it, what school did you go to?

I didn't move to Worcester, I moved from Worcester to Malvern.

I see.

Which is a really good place to move to I think.

What is good about Malvern?

It is a very pretty place to live. It has a small town, but everybody is really friendly. Pretty much everybody knows everybody, so it is good because of that.

Thank you. So what about the house that you lived in? What can you tell me about the houses?

Which one?

Any house.

My first house I remember was in Coventry Avenue in Worcester, and it was really nice. And I remember being friends with a girl called Zoe and a girl called Joanna, and I am sure there were loads of other people, I can't remember them all. And I used to like to climb trees a lot, I was a bit of a tomboy when I was little and I don't like wearing dresses and skirts.

[06:35]

What about where you live now?

I live in a place called Ranleigh Road, which is a supportive housing where everybody has got a brain injury or mental illness, I lived there obviously because I had an acquired brain injury.

Okay. I will be coming back to that in a moment. It sounds quite interesting. But you mentioned you have a sister, have you got any brothers and sisters?

Yes. My family is quite complicated. I used to have two stepbrothers and my dad has a girl friend who has her children so I have a lot of step brothers and sisters too, I guess they are my stepbrothers and sisters, it is all a bit too technical to go through it really.

But are you a close family?

Very close.

What can you tell me more about your family?

My younger brother has recently passed his driving test which is really good for him. I haven't passed mine yet so I have to catch up with him somehow. Also, my little sister Leah, she has a son called Bailey and he is really gorgeous, he is very polite and helpful and my big sister has just had a little baby called Lilly, she is a beautiful little girl and she started to crawl last week. I have to go and see her this week hopefully because I would like to see that part of her crawling. I think that's everybody.

Okay. So, living in a lovely village when you were little, what can you tell me about the village, what things you did at the time? Did you go out anywhere as a family?

We went on holiday. In Wales, and I threw up because I used to get really travel sick. And we went to a caravan in Wales.

It was raining the whole time so playing cards a lot. But I was really young when we went to Wales it was a long time ago.

Apart from Wales have you been anywhere else?

[09:42]

Recently I have, I went traveling so I have been around the world, yes.

Please tell me more!

Well, I went to South Africa. I volunteered in South Africa in a place called Worcestershire funnily enough. And it was with a little kibbutz setting so it was with lots of kids in the area they lived in was they had a history full of gangsterism and drugs and racism and apartheid

and stuff like that. So me and my friend, scrap that -- me and my friend went traveling to separate different volunteer placements, she went to a place a big place in Africa, which is really famous but I can't remember the name of it now but it was really good experience, yes. And everybody was really friendly to us. I worked in the nursery, and I taught the kids dancing, and just sit and talk to them and help them with, because I could use the computer back then. I had them learning how to use the Internet and stuff.

When did you do this traveling?

It was, I have been back for nearly two years now. So I must have been 27, until I was 28, 26, 28 I went traveling for two years.

Okay. So where else did you go apart from South Africa?

I went to Mozambique. I did the Garden Route of Africa, South Africa. Then we went to Thailand and we, I sat on an elephant because that was my dream to meet an elephant, which I did. Then we went to a place called Laos on a boat, but it was literally really slow. And a bit risky probably. But it was kind of fun in a weird way. When we got off the boat, there were Thai people and Laos people waiting to sell us all the tourists drugs, like I can't remember what they were now, but they were hard-core drugs I think. But not that I would take them. After Laos, we went to, we went back to Bangkok in Thailand, and then we went to Australia; which was really, really good. I loved it in Melbourne. And I went to the town of 1770; it is a small town, very beautiful place. And we had a go on Harley Davidsons. That was for my friend's birthday. And we stayed at a campsite called Captain Cook's. Then we went to New Zealand which was really beautiful place. It seemed really clean; it was really nice there. And a friend of my friend Katie had a best friend that lives out there with her boyfriend. And they put us up in the house for a little while, so that was really nice, yes.

Can you tell me what was the best thing about New Zealand for you?

Yes. There was, we went to a mountain, it was absolutely stunning. And the best thing about New Zealand was probably the beauty of it. There are so many trees, so many really nice walks. That's kind of it was really pretty countryside and stuff, yes.

[15:12]

So, you were traveling for two years, and then what happened?

Yes. I got ill. It was really bad headaches, I thought they were migraines. Then unfortunately they weren't migraines. They were symptoms of an acquired brain injury which I had no idea of, until I got home. Well I stayed with my cousin to begin with, and her little boys because I gave up my flat to go traveling. So my cousin Emma offered me a place at her place. So I tend -- sorry I tend to waffle on a bit.

Please talk until your heart is content.

Thanks! Anyway, I stayed at my cousin's place for about four weeks, and my cousin and my friend Faye noticed a change in me. After I had no idea what that change was but apparently I kept having repeated headaches. And I needed to have lots of baths to keep me cool, hot baths to keep me cool. And I was trying and do things like use the Internet and phone friends, stuff like that and I found it really difficult to do. Anyway, after four weeks they took me to my local GP, doctor Meredith and apparently he sent me to hospital; which at first was only Worcester Royal hospital, which doesn't deal with head injuries. It is just an A & E hospital really. So I stayed there for about three weeks. And I had lots of lumbar punctures which I don't remember. I also had bad dreams, really bad dreams of Freddie Kruger and Jason. So my mind was playing tricks on me. I also had a funny dream that my dad was dating Britney Spears. Don't ask me why, my brain was just doing what it wanted to. They couldn't deal with me at Worcester, so they referred me to Birmingham QE, which is Queen Elizabeth Royal Hospital. Not a very nice experience for me there. It was not the staff's fault. It is just because it took them so long to find the cause of what was making me so ill. And I had to take pills for my headaches, which made me sleep for hours and hours on end during the daytime and at night time as well. So I guess that was kind of helping me to recover, I don't know. But the worst thing about my time being ill was I spent my time in many hospitals, in all I think I went to, sorry -- I went to Ledbury, Evesham, Q E, I went to the Q E twice, and the Worcester Hospital Royal Hospital, yes. Because first of all it took Birmingham Hospital too long to find out what what's wrong with me because it is really difficult apparently to track down what, on my condition is now. They kept giving me lumbar punctures which I tell you they are really horrible things. And –

[20:16]

What are sorry I can't quite read it, what is it?

It is where they give you an injection in your spine. They take the fluid off with an injection and they can tell you what is on your brain. But they kept on getting the same results which happened to be protein, which the doctors weren't aware of. And they said we have to do another one, one more lumbar puncture and I said no way. I am not having another one, I hated them. It was my tenth or eleventh one. And I gave into the doctor in the end because I was absolutely really upset, beside myself; I was really frightened of another one. And I gave into him and it happened to be the best one I had ever had. I didn't feel any pain this time. So it was quite a relief, and this doctor I can't remember his name, but he was really funny doctor, and he told me there was protein there again. I was really disappointed with that because they always said this was protein there and I said maybe there is protein because they were just disregarding protein for some reason and I said maybe it is what, maybe we should take it that it means there is protein on my brain, whatever that means. And so they did. And it turns out that I had inflammation on my brain; which means I have a condition now called encephalitis. Don't ask me how to spell it, it is too difficult for me. And during my time in hospital, pretty much it was at the first stages of me being ill, they told me I had a vertigo, which is something to do with your ear I think, but I had no idea it was at the time or only just found that out recently. Because they asked my audiologist, and I had really bad attacks, like I was lying down on my bed and I would spin around. And they started to give me medication for that. They told me it might be something I have to live with for the rest of my life. But I actually happened to stop taking my medication now because I am determined to beat it so... also after much time in hospital, it was about seven months, about six or seven months, I developed a hearing infection. I was told it was a hearing infection. And to begin with, I was a little bit deaf and I blame that on wax because if there was an infection, so I asked the doctor if I could have my ears syringed. Because they kept giving me ear drops, and the first ear drops they gave me were apparently the wrong ones to give me. So, then they let me go and have my ear syringed, and I asked the lady that the doctor that gave me the syringe, if there was any chance I was losing my hearing and I could go deaf. And they said no, it is just because of your brain injury. So at this point, I was very confused. And I still hadn't lost my hearing so far as I was concerned. Not that I am a doctor, but I think it is called

false hope. And the doctors at the Q E hospital seemed not to like dealing with my hearing loss, or my hearing infection or whatever it was. They seemed to be a little wary of giving me my drops in my ears. But the ear doctor, audiologist, told me I should get a nurse to do it. And every time I asked the nurse to do it, they were busy with something else because part of it was a neurology ward; so there are lots of people who are very ill there. So I don't have any blame to them for that.

[25:44]

I also lost part of my eyesight. I have now an eye impairment in my left eye. I'm meant to wear glasses which I've got in my bag today. So anyway, I still hadn't got a clue I was deaf or I had a problem with my ears. So I was waiting to be moved to a rehabilitation hospital, which is good; which was good I should say. Because I didn't really want to stay in Birmingham because it wasn't that nice a hospital, not because of the staff just because of what was wrong with me and other people. And because I had a lot of bad memories because my mind was doing really silly things to me all the time. Anyway, so I went to a hospital called Evesham Community Hospital, which has been the best hospital I went to of all of them. Yes. Thanks to the staff being so cheery and really positive towards me, because I was really worried my brain tumour would come back because I had to still see people about it all the time. So it was a constant worry for me it was going to come back, I had no idea what was wrong with me; I thought I was going to die. And I thought I had Aids. I thought everything, because you know at first they couldn't find the cause of what was wrong with me, so I thought of the worse scenarios it could possibly be. So, anyway, Evesham, that was when I found out I didn't have a hearing infection. I had a hearing impairment. Well, at first, I was still pretty much deaf, and they gave me some tablets. They might be steroids I can't remember. And my left ear became a little bit better, so basically I got my hearing back in my left ear almost. My right ear never came back, it is still the same now. But unfortunately, my hearing has now deteriorated since I got my hearing aids, my first set of hearing aids. On the first day I got them, my hearing disappeared which is really disappointing because when I, the first person I spoke to was my support worker called Kirsten Brown, and she said I could speak and hear really clearly, it was really good to see. And I felt amazing because it was like I had my hearing back, sort of. It was really hard because hearing aids are a little bit strange at first. But I would give anything to get my hearing back now because I miss it obviously. Even though I am learning lip reading, and sign language, it's still nowhere near the same.

And, of course, all my friends and family have perfectly good hearing. So it's very difficult. I think my little brother find it is really difficult to talk to me these days. Or it seems like he has nothing much to say to me or it is because of my hearing loss. Maybe he doesn't know how to approach me now. But it really disappoints me because obviously when I was traveling I missed all my family and friends so much, and it was really nice to see them again, like it used to be. But they have to get used to the way I am now. I really did struggle with my hearing loss and still do. I really lost my self-esteem, my confidence. I suffer from anxiety for a long time, and I have had to take anti-depressants for the first time in my life and I am not a very big fan of them. Because I know people that have had Prozac -- mentioning no names -- because I don't agree with giving out Prozac to people that are really young, for example. Because it could be hormones or anything like that. Okay.

[31:27]

That is all really absolutely excellent so far. I am just going to ask you some more questions just to tease out some more detail. You were in hospital for about 7 months in total, is that right?

Yes.

So, can you tell me what support you had from your family, what did your –

Yes. My dad was an absolute star and his girlfriend and I am indebted to them for a long, long time. Because they came in every night virtually, to see me because I used to smoke very badly, don't any more. But they would let me go out for a cigarette with them and my dad and his girlfriend I was never allowed out on my own, obviously because of my vertigo and my brain injury. I was always trying to run away and disappear and stuff. So I can't blame them. But I was quite naughty in hospital. I always wanted to walk around and do stuff like, just to keep me occupied.

So they traveled all the way up to Birmingham to see you?

Yes, and they come from Worcester. And my dad works full-time. So he had to come,

obviously he had to come at certain times because of hospital visiting times. So it was very difficult for them. And I really, really appreciate what they did, because there were some really hard things for me to deal with, for example, there was this a person in the hospital called Jerry; he seemed to be obsessed with me. And he found me and my dad and his girlfriend one night in hospital, had to stop him from beating up this other man in hospital. And he approached my hospital bed and my dad had to ask him to leave and his girlfriend managed to calm this bloke Jerry down; obviously Jerry wasn't in his right mind. He had something that I called a cabbage on his brain, the size of a cabbage on his brain and he used to be in the army. So he was taking the role of being a soldier all the time, not his fault because he had a brain injury himself. But my dad was just being protective.

Can you tell me about your other family members? About how they dealt with you when you were in hospital?

Yeah my mum came to see me sometimes, but she worked full-time and my older sister and my younger sister, they had lots of things and my younger brother and she had lots of things to be busy with. And she couldn't drive up to Birmingham, because she doesn't like the motorway, and she hates hospitals and needles and stuff like that so I had, when I had my biopsy, I actually refused to have it. Because I wasn't allowed out for a cigarette obviously. And my mum signed the consent form anyway. But, to be honest, I am so glad now that she did. I wasn't at the time but I was frightened of it because I thought I could die or lose my legs, all sorts of things went through my mind.

What, you have mentioned that you got support from your family and you had support while you were at the hospital. Can you tell me about any friends?

Yes. My best friend is called Anna Elliott, and she helped me a lot. Since having come out of hospital and before I left hospital, she has her own problems to deal with, but she doesn't mind helping me with whatever she can. She also has a brother who had meningitis when he was a baby, so he has a mental disability and he has no hearing at all. So when I told her that the LINK programme helps me to learn finger spelling she said, yes that's a really good, I know how to do that. So she can help me sometimes and when I had my anxiety she would sometimes take me shopping when I really needed to get something. Like milk.

[37:20]

So, you have explained about actually being in hospital and you have talked about your father and girlfriend coming to see you, but can you tell me more about your own personal feelings? What was going through your head when you first of all went to hospital and you spent all that time there?

To be honest, I was confused. I also suffered from anorexia because that's a condition of encephalitis, so I have read. And so I guess in a way that was because I want to control what was happening to me because I felt I was out of control, there was nothing I could do to help me get better. And I was frightened, I thought I was going to die. I actually went through really strange emotions actually. My brain tricked me into thinking I was pregnant; which I obviously wasn't because I had been nowhere to get pregnant. So I actually lost my baby in my mind, I actually experienced losing a baby. So I went through all the emotions of that and I accused my mum of being pregnant again and she has had a hysterectomy. So I phoned up people and I was crying all the time, because I thought it was for real, and I thought my mum was tricking me because I asked her what has happened to my baby. She said she is in the baby hospital downstairs, I used my - somehow my brain was using the fact that I had a baby to get the pain away, I think. I don't know.

[39:30]

We will move on to dealing with the hearing loss side of things now. Can you tell me about a period when you realised that it wasn't just an infection, but you had actually lost your hearing?

Yes, well my mum was visiting me in Evesham hospital, and I broke down sobbed my heart out and I said, I think I have lost my hearing mum, and she phoned the Q E hospital and they said it was an infection. It was my hearing that had gone. So I think I was completely gutted. And then I went to see another hearing doctor in Evesham hospital; he was really friendly and helpful. But I still have my hearing aids, it is long time since I got them. I had to wait 8 weeks out of hospital and 8 weeks before that I think. So, I was totally confused and annoyed and upset because I had been told my hearing was fine. And it wasn't and to my friends and family told me my hearing was going to come back, not that I blame them but they were

being helpful for me. So, really, I don't think I ever come to terms with my hearing loss. Because one thing I don't want anybody to think badly about the Q E hospital because they were really good to me in their own way, but nobody ever mentioned I might lose my hearing, my eyesight, or anything like that. I knew of a patient who had lost his eyesight and was completely blind; but that's the only thing I knew about and I never considered I was going to lose my hearing. And I was really frustrated because it was the last thing about being in hospital that I lost and my whole life depended on my hearing; because I was trying in performing arts. Which you obviously need your hearing for. So I am still gutted and was gutted.

So, when you realised that you were not going to get any hearing back, what help did you get to start off with?

First of all, a lady came to visit me when I moved out of hospital to my home in Ranleigh Road. And her name was Kim Edmonds, Edna, sorry. And she is training to be a social worker. I didn't know that at the time, not that it matters, but she came with all this equipment that was meant to help me and we did somehow manage to get me some communication with people. And it was like a headset, and it did help a little bit but it was really difficult to get the tone right. And obviously when I first got out of Evesham hospital I had a little bit of hearing. So I thought that would be it. But it wasn't. Because in June of last year 2007, or July, I got my first hearing aids and lost the rest of my hearing. And I completely cried into my pillow nearly every single night, I was completely overwhelmed, frustrated, didn't know what was going on. So, the fact that Kim helped me was really good. She said it was okay for me to cry as I had lost my hearing, but my mum used to tell me to stop crying because she thought it was making me worse. But she didn't know I was actually grieving for my hearing loss. I didn't know I was grieving for my hearing loss. But at least I know it is normal to go through that kind of behaviour afterwards. Because I just thought I was crying all the time for no reason. I had no idea I was grieving for my hearing.

[45:24]

And you say that Kim bought some equipment. Did she offer any other assistance?

Yes, she also gave, because I was worried about my hearing obviously, and there was a door

bell on my door and it kept making a really loud noise which you think I would be happy about with no hearing, but it seemed to stay in my left ear for a long time after it was buzzed. And I asked for a new buzzer and she gave me a vibrating buzzer for my door. So I hook that on my jeans now and that's really helped me a lot because now it doesn't ring so loud, not that it would matter now so much but it means I can gain my independence a bit more. She also introduced me to a Typetalk phone. As you know, I have lost the ability to make phone calls on a normal phone, which really distressed me as my mobile phone was my main means of communication. I am now a text addict. But the Typetalk phone, even though that is a bit tricky sometimes, has given me some means of independence, like making my own doctor's appointments for example. Organising trips out with my friends stuff like that.

Can I ask why is Typetalk tricky?

It is tricky because of my memory I think or my brain isn't as good as it used to be because I don't always remember to press VT or I press it too much. VT, I don't know what VT stands for, I can't remember. But when it works it works perfectly. When I work, it works perfectly I should say!

Okay. I am just conscious of the time. Would you like to take a short break?

That would be cool, thanks.

We will just break for a few minutes then.

[Break in recording]

[48:05]

Okay. We have just had a short break and we are now going to continue. We were just talking about the period when you realised you didn't have a hearing infection, but it was more of a hearing impairment and you just mentioned the equipment you got. I would like to ask now what was the reaction from your family?

That was a mixed reaction. Basically my two sisters had been perfectly fine, my best reaction

has been from my nieces and nephews. In fact, my niece Jessica asked me to carry a bag down the stairs and I couldn't do it because of my balance. And my mum had a little word in her ear and she said Angie has been a bit sick she can't do things like that. So she carried my bag all the way out to the car and I thought Oh wow that is so sweet, kids just don't judge you, they have no conception of you being deaf or hard of hearing or whatever. They just love you for you don't they? So it is good. My other nephew Bailey my little sister's boy, he told me he loved me, and I taught him in sign language and he did it back to me. Which I think is so cool. He is such a lovely little boy. And also my nephew Jordan has been really supportive and caring and my cousin's two little boys, Sam and Lewis, just give me lots of big hugs and they also taught me they had been learning they told me, sorry, they have been learning sign language and they showed me how to do "sorry". So that was really cool. And that was really impressed and it also got me thinking, because I actually want to work with children like in the future, I want to go back to university or to college and do a teacher training course. If I am up to it. But I have always had this ambition to go to university. And I am really determined that one day I will do it and it has made me think I always assumed I would have my hearing forever, and I guess everybody does, and I probably would like to mention to the government somehow that hearing loss -- no, sign language should be taught at primary school by law or by a kind of rule of some kind. Because I was told recently sign language is the language of people that were born deaf. But had I known I was going to lose my hearing, quite young, I would have needed to learn sign language when I was young because obviously you retain it a lot better. Sign language is quite difficult to remember when you are a bit older, it is like languages like French or German. It is much better to learn them when you are young, than it is when you are 11 or 12 or 13. So that's something I would like to address one day maybe.

Okay. Can you tell me, let me rephrase that. You started to tell me the reactions from members of your family, you told me so far your reactions from your nieces and nephews were quite positive. Can you tell me about your sisters and your mother?

Yes. My little sister Leah, she's absolutely been my rock. Because when I first came out of hospital I went to live at home for two weeks; to see if I was okay to move and live on my own, obviously I was getting to the age when living with my parents would have been a bit embarrassing anyway! And my sister would come round to visit me and we both, we all lived at Ledbury that point, so it was easy for her to get to Ledbury and come and see me. And she

was gutted for me too I think. And she was very positive and she showed me lots of love and support and I used to have two sticks to walk about. And I had to go on the field where we lived and practice my walking without my sticks. And she would set me a target and I would try and do it. So she helped me with things and my older sister was at home in Malvern, with her little daughter Jessica who I mentioned, and her little boy Jordan who I have also mentioned; and then she was also carrying a baby Lilly at that time. So she was heavily pregnant. So my older sister didn't really have much to do with my hearing loss at that point. My mum, however, did. I felt also mentioned that when I began dealing with my hearing loss I was always crying and my mum asked me to stop it. Not horribly but she just, it was just confusing and horrible for her to see. She used to cry a lot because I was ill, whatever. And I have to say it is not, I can understand why now I am not as ill as I was. But she seemed to stay positive for me. My dad, however, has been extremely positive for me; especially by being at hospital but my hearing loss was as frustrating for him as it was for me, because he was so positive about my hearing coming back. And still is. Which I guess is my fault because I am still positive it will come back one day. But they say positive thinking, you never know, do you? And it was a very strange way for me to lose my hearing anyway. Also, I mentioned my little brother Kelvin. I don't think he has coped with my illness or my hearing loss, or he doesn't know how to speak to me these days. Maybe he is frightened that he will do something wrong, I don't know. I hope he doesn't read this and think Oh my God, my sister is being horrible to me but I just miss that we don't talk to each other like we used to. Stuff like that.

How old is Kelvin?

19. So it is quite a big age gap between us. And he has also got a girlfriend recently and I had never met her during, I didn't meet her until after my illness. So I don't know really.

[57:02]

Going back to the period when you lost your hearing, when was this? When did you actually realise you were going to lose your hearing?

Last year in June I think.

June of 2008?

Yes.

What has happened since then?

Basically, apart from crying my eyes out, and trying to be as positive as I could, a support worker where I live took me out one day to a place called St. Ann's Wall in Malvern, which is a beautiful place and we went for a long walk which obviously I didn't do when I was deaf, when I am deaf because I had anxiety about the cars and stuff. So it was really nice for her to take me out somewhere, get some nice fresh air as I was confined to my flat most of the time. So I had a chance to cry really, really cry and talk to someone and explain that I really wanted to do stuff with my life and I don't think I can any more, I don't think it will go on now. I think my life is over etc.etc.. but I know it is not now. Thanks to my, my support worker Kirsten, who has been really helpful towards me and my friends and my family which I have been really lucky with, nobody else really turned against me because I assumed everybody would treat me differently because of my hearing loss and they did I suppose but not in a horrible way. Just like, for example, my dad being, having found a boyfriend pretty recently, which is quite surprising, he, I confided in my boyfriend that I think my dad treats me like a child but he said no, he just speaks really loud because he thinks you can hear him better. But I thought he was maybe shouting a bit at me. But he wasn't, well he is not apparently, he is just trying to make himself really clear for me. Maybe I have to tell him myself he doesn't need to do that, I don't know. But I don't want to upset him because he has been really, really supportive. And he was really worried about me getting the brain injury again, as am I. I think it is one of those things that you always think you are going to get it again because it was so bad an experience.

I hope you don't mind but I would like to go more into detail about you mentioned you were feeling confined to the flat. And that you had these anxiety attacks. What can you tell me about that? Why didn't you go out?

Basically, I was confined to my flat literally. I wouldn't go to the shops by myself. I couldn't go outside by myself.

Why not?

Because anxiety attacks -- it is really hard to explain because my friend suffers from anxieties attacks, but they are for a different reason and it is quite different I think. The only way I can explain it is the fight or flight syndrome in that we are all programmed to have the reaction of danger and it is really overwhelming. I was terrified of people not being able to understand me or help me, or bump into me or knock me over. Or short-change me. Or I had to hold someone's elbow all the time. But I have recently discovered that the more you do it, the better. So it isn't the same any more, although it could be coming back because I will have to stop taking my anti-depressants one day. So I guess it was really difficult for me because at first there was a kind of support worker named Maggie somebody, sorry Maggie, and she came to visit me at my mum's house in Ledbury as I kept leaving my flat and staying over at my mum's in the spare room that they made up for me when I left hospital. So I kept leaving my flat and getting my mum to pick me up as I was too scared to stay in my flat because of my anxiety; it was extremely similar to vertigo attacks. Everything was spinning around; I would be still and the telly would be spinning. And I really couldn't read my subtitles for example, as my vision became blurred which really made things difficult because I've got an impairment in my left eye and with my hearing loss as well. Made me very confused, it was really overwhelming and I really, really thought when I cross the road for example I figured I would get run over by a car. In fact I thought that is the way I was going to die; by a car hitting me on the road.

[01:04:03]

Thank you for that. But how long were you living in your flat, are you still living in your flat now?

I am still living there now. I have been there a year in April.

Is this the same flat where you received all that equipment?

Yes.

Okay. I am just checking my notes because you have come up with so much so far... right.

The support worker, was that to do mostly with your brain disease?

I am not sure. I think she is a support worker; she pops in any way she can.

Who arranged this worker?

She works where I live, so she arranges herself really. She has just been really helpful towards me and she just noticed how badly I was suffering from crying and anxiety and stuff and noticed I need a lot more help than usual. And she has also been taking me to my cochlear implant assessment places. Will we talk about that now?

Well, before we get on to the cochlear implant, you have mentioned the help you have had with your balance. But what help did you have regarding your hearing loss? Did you have any help?

Not specifically with my hearing loss, I don't think so anyway. I might have, but I am not sure if it was to do with my hearing loss but I have not had any help since I had re-ablement team. I had a re-ablement team; they helped me with my cooking, my cleaning, showering, stuff like that. Because I couldn't shower by myself as I couldn't stand up straight and stuff like that, so I haven't really had any support in my home apart from that, no.

Okay. Thank you. So.

Can I just add to be fair, where I live, all the people there have helped me in any way they can. And they have also not experienced working with somebody with a hearing loss before, so it is like for me blind leading the blind I guess. Don't know idea about what I needed or what I need or anything, but they have been trying to find things out for me, for example. And also Kim, I mentioned before, has got me some information about the Deaf Direct which I have recently found out is an agency that I can use. It is quite close to me in Worcestershire.

And what do they do?

Basically, they are a charity that work with deaf people or hard of hearing people or deafened young adults. I didn't realise deaf had lots of different meanings as it does, like deaf,

deafened, hard of hearing, stuff like that, but anyway, they organise volunteering jobs. They organise sign language for people, they offer worksheets to people and newsletters for people, stuff like that.

Okay. Thank you. Are you working at the moment?

No I am not, no.

I don't think I asked, were you working before you went traveling?

I was, yes, I love working, I love being busy. I am really upset about that because I am not very good at doing nothing. I have to, I am meant to take my convalescence period all the time, which is not very good for me as I am naturally a busy person, and I used to have two or three jobs at a time. And had a very busy social life, had a large circle of friends. Still do luckily. So, by not working I have realised I have to re-train myself in stuff like sign language, lip reading, other things.

[01:09:30]

Where do you learn things like sign language and lip reading?

I actually found out there was really hard because I live in a small town called Malvern, I looked everywhere including the Internet and the library. And I couldn't find a lip reading class anywhere locally. The nearest was Evesham, which is at least half an hour on the train. And at that point my anxiety was a problem, so going to Evesham on the train was for me a very big deal. It is like maybe somebody else going to London or something. So anyway, I found, no I didn't find - somebody found for me, I think it was Kirsten again, the lip reading class in Malvern; which I can walk to, it is that close. So I am really privileged to have found somewhere I can go to and I go there every Wednesday and it is for two hours. Yes.

And how do you feel about that class?

The class is really great. The tutor is called June; she also suffers from a very small hearing loss. So do the other people but no one as severe as mine. But the class is really, really

helpful. And I went to a hospital recently for an examination of some kind and they told me that my lip reading class is paying off. So I am really pleased about that. And I also like, for example, I learnt the days of the week this week in my lip reading class in sign language. Obviously I can't learn too much at once because I won't remember it, but I can remember Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday.

Just for clarification, you were just showing me the signs there. Excellent.

[01:11:59]

Can I, before I move on from all of this, were there any other support networks that you were involved in? Apart from your family and the support worker, was there anybody else involved? Or groups?

Recently my boyfriend Jake has been, we have been learning sign language from a book together. Apart from that, I am afraid not.

Can you tell me more about your boyfriend?

Yes. He is really, really supportive. And I really didn't think I would meet another boy friend after my illness. Especially a hearing person but he has been so supportive and I am so lucky, so I surprised myself to be honest and he surprised me. I guess I was being rather judgmental and rubbing people off before they had a chance, like I expected people to do to me. So I am just as bad as, I have to slap myself. So yes, Jake has been so normal about my hearing loss. It really surprised me. Especially when I wear hearing aids, they can't be very attractive can they? But maybe that's my own perception of them, as I have only been deaf for six months or so. So I am new to it as much as anybody else is new to it.

What do you feel about your hearing aids?

I am very gutted with my hearing aids. I shouldn't be really because it was my hearing that was the problem, but when I got the first lot of hearing aids I was gutted because my hearing went. I was really happy with them on the bus home from my appointment which my sister, Leah, and my mum came to with me and when I got back to where I live, Kirsten, my support

worker, was working and said, Oh my goodness, they are such an improvement in your hearing, you can hear me and we can have a conversation. And it was true, I could. On the way home on the bus with my mum and sister were chatting away, it was lovely. I was so happy. So, after I got home my hearing aids, obviously very strange because they echoed and a bit like a microphone, they give you feedback and stuff. And I was watching TV and I could hear it and I was like Oh my God, it is too loud. Which is obviously understandable as I wanted it to be so I could hear it. But unfortunately the next few days I kept going down and down and down. I had an appointment with the audiologist which was a few months later. I thought it would take me a long time to get used to them. So I blamed my hearing aids, wrongly, for my lack of hearing. It was my hearing had disappeared. I should have worked that out for myself because before I lost my hearing I could hear without my hearing aids on a little bit. And after I couldn't, so that should have told me it wasn't my hearing aid, but I needed some confirmation it was not my hearing aid. It was me.

[01:16:20]

So just to recap then, you had lost some of your hearing, you got some hearing aids so supposedly to allow you to hear again, and then you lost more hearing?

Yes.

Is that the stage you are at now?

Well, I don't know, because apparently according to my audiologist, my hearing fluctuates. But I wish it did because it would, that means it would go up and down, but at the moment it only goes down. So I don't know what point I am at. Also I asked somebody recently what the likelihood of my hearing to come back is and they said if it has gone for longer than 18 months, it is very unlikely to come back at all. So I am not sure what to think to be honest.

You mentioned a little earlier cochlear implant. Could you explain what is a cochlear implant?

I could try to, yes. Basically, it is an implant that is put inside a cochlear part of your ear; there is in your implant there should be fine hairs on it; is that right so far? Anyway, I

recently have been referred by somebody, I don't know who yet. And I was very surprised because I am still so young, having a hearing loss and still very young in terms of the time I have had my hearing loss, to have an assessment of a, for a cochlear implant. But I am having - I have had a few appointments now, and I am still not sure if it would be something I would want anyway. As the first thing you have to be aware of, you have to be willing to let get your piece of hearing you have got left to go and that's really frightening to me and apparently cochlear implants are not a cure to your hearing anyway. So what is the point in using one? So, also I don't really know enough about them yet. I only learned about them recently on my LINK programme in September 2008. Because to be honest before my LINK programme, I had didn't know anything of the equipment or anything about strategies or anything to help me with my hearing loss.

[01:19:25]

Can you tell me what the LINK programme is, please?

Yes, the LINK programme, it basically you meet people that have a hearing loss, just like yourselves. Some worse, some the same, some better. So we are all in the same boat. We all have or have anxiety. We all have similarities, and we have made a life-long friends from these people and this programme. Also the LINK programme gave me confidence as I came by myself, which I was really nervous about and totally relaxed at the same time. Sorry. I was relaxed once I got here. But my support worker Kirsten drove me here and drove me back. So I wasn't completely on my own. And to be honest, there was one thing I wanted to learn from the programme and that was communication to help and they taught me finger spelling which I never knew about. They also taught me some sign language. They also gave me instructions about the RNID, also they taught me about the Tynetalk phone. I had never even heard of before, so I could now see a future in my life which I had given up on completely. Also, I was a bit concerned about the programme at first; because I was, apart from Becky the daughter of Jenny, who are both lovely people, I was the youngest person there and I thought how am I going to get on with this. There is nobody here that is the same age or anywhere near my age. Because I need to know things like would I still be able to have children, would I still be able to cope with having children if I have no hearing, will it be hard and I know it's hard anyway but would it be harder. Things like that. But the LINK programme is part of the reason I am here today because I have to give something back

because they gave so much to me. They basically gave me my life back. Because it was going nowhere. I was giving up and I know now that I have to try and keep going for myself and my friends and family. And my boyfriend Jake.

So, where do you see yourself going in the future?

Well, due to the programme, I see myself able to go to university now in the future but my problem is I am way too eager to do things. And I have to take my time which frustrates me a lot. But I really want to go to university and study teacher training. Primary school children, if I am allowed. I also want to pass my driving test one day with a deaf aware driving instructor. Now I have told people all of this, I will have to won't I? So I have to pass my theory test now. It is just - I recently read in a newsletter, because I am part of the Encephalitis Society now, that it is really hard for people with encephalitis to gain driving lessons because your perception of cars, of different speeds, is really quite difficult to ascertain. So I may not be allowed to go for my driving lesson, I do not know yet.

[01:24:37]

Is there anything else you would like to share with us?

Actually, yes there is. Until I went to the LINK programme, I didn't realise there were other people like me. There are because where I live, it is a very small town. It is very village town type of town, but until recently until this programme I didn't realise there were people my age who not only lost their hearing but have children, partners and also I didn't realise that a deaf person could drive legally if they wanted to. I thought a deaf person would mean no driving, no nothing. Am I talking too fast for you? So I am really grateful for the LINK programme for that and I would like to say thanks for all that they gave me.

So, how did you find out about the LINK programme?

It was because I used to have a physical therapist who helped me with my walking outdoors, and crossing roads. And a lot more things she helped me with, but she also mentioned about the LINK to me quite early on. She told me about this course going on in September which I thought it is only June, September is ages away. And it wasn't obviously, it crept up with me.

So it was quite good and I got referred to the programme by my doctor my audiologist I think. And several other people, I can't remember now. But I am really grateful to them because it was really imperative for me to have gone to the LINK programme. I wouldn't have got where I am now if it wasn't for them.

Can I ask you to remember when you were first told about the LINK programme, what were your feelings about it?

I had a mixture of feelings. I was a bit confused because in handouts she gave me she said it was about at that point people who were deaf or deafened and I was still hearing a little bit, so there is no way of getting accepted on that. And also I didn't expect to get the funding but I did, which I am really grateful for and it is well spent money. So I am really glad about that.

Okay. Is there anything else you would like to share before I close the interview?

I don't think so, no, I just want to say thank you to all the people that have really supported me and helped me. I have been really lucky in that way.

In that case, then, I am going to stop the interview at five past 3 and thank you very much indeed for coming today.

You are welcome

[End of recording]