



# Unheard Voices: interviews with deafened people

Emily Owen  
Interviewed by John Newton

British Library ref. C1345/52

## **IMPORTANT**

This transcript was created at the time of the interview by a Speech-to-Text Reporter. The summaries were completed by the interviewer after the interview using the STTR transcript.

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## Interview Summary Sheet

**Ref no:** C1345/52

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

**Interviewee's surname:** Owen

**Title:**

**Interviewee's forename:** Emily

**Sex:** Female

**Occupation:**

**Date and place of birth:** 1979

**Date(s) of recording:** 31<sup>st</sup> May 2009

**Location of interview:** The Westminster Hotel, Nottingham

**Name of interviewer:** John Newton

**Speech to Text reporter:** Cate Oates

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

**Recording format :** WAV 16 bit 48 kHz

**Total no. of tracks:** 1 **Mono or stereo:** stereo

**Total Duration:** 1 hr. 25 min.

**Additional material:**

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**Interview notes:** The first section of the interview was not recorded although there is a full STTR transcript.

**[This portion of the interview was not been recorded]**

*This is John Newton, interviewing Emily Owen, on 31 May for the Unheard Voices project in Nottingham. The speech to text reporter is Cate. Can you read this? Now you have to tell me your full name and your maiden name if appropriate?*

No, I'm not married.

*This is just for the record.*

Emily Louise Owen.

*And your occupation? What do you do for a living?*

No, I don't work.

*And your mother's occupation?*

Housewife, I suppose.

*And your dad's occupation?*

Dad is a maths teacher.

*I don't know why they want that, but just to identify this tape afterwards.*

That's fine.

*Anyway, so that's just the preliminary. I couldn't help noticing when I was reading your brief details that it was your 30th birthday last Sunday?*

It was, yes. I've now entered the realms of being 21 again -- every birthday I'm 21 again!  
*How did you feel about it?*

Fine actually, fine.

*Well, the decades, the tens, always seem to be a problem for people, I'm not sure why.*

It's not a problem for me. Actually people think I look a lot younger than 30, so I had in my head that once I am 30 people thought I would look mature, but the other day somebody thought I was 23, so obviously not very mature!

*Anyway, as you know, what we are supposed to be talking about is the experience of deafness. So obviously the thing I would first like to ask you to tell me about is, tell me about the time when you went deaf?*

The day when I went deaf. Well, it's difficult to remember the exact day, because I had a brain tumour, so I went into surgery hearing and came out deaf, but I mean I can't really remember all that because obviously I was quite poorly. I do remember waking up and hearing absolutely nothing and being terrified, very scary, seeing people around me talking and moving. Somebody would come into the room and normally you would hear the door open but I didn't until they were right in front of me and that made me jump. So, yes, it was scary.

*You had no warning? You had no warning of this?*

Oh yes, I knew when I went into surgery that I would come out deaf, but you can't really prepare for it. I tried to prepare, but you can't really, until it's actually happening.

*Tell me about the period before that, when you presumably became ill and then you –*

Well, I became -- I was diagnosed with NF2 and brain tumours when I was 16 and I had surgery on one tumour, so I was deaf in one ear but I could hear fine in the other ear. At that time I was told in the future I would need the other one removing so I would lose all my hearing, so in the interim I prepared as best I could, I learnt sign language and I had about four sessions with a hearing therapist to learn about lip reading. So I prepared as best I could.

*Tell me about your actual domestic circumstances at the time, at that time?*

When I was 16?

Yes.

Well, I was obviously living at home, I was going to school. I had three younger sisters so they were all at home and then my mum and dad plus a dog and goldfish and pets, but my three sisters and mum and dad.

*Tell me about the school you went to. Which school were you at?*

Just the local comprehensive. I was there -- well, it was a 11 to 16 school so I went there and did my GCSEs, but then I went to a sixth form college to do my A-levels in Leicester.

*That was before you were diagnosed or after?*

Well, I started to be symptomatic as I was doing my GCSEs, so I would go to the doctor -- I basically had lots of very bad headaches so I kept going to the doctor saying I've got these headaches and he would say, "Oh, it's migraine or it's because you are stressed about your exams", and I wasn't stressed, so he gave me migraine tablets which I took and didn't help, so I went back again and in the end, as I say, I was diagnosed. So I had this surgery one term into my A-levels.

*You mean into your A-level year? When you say into your A-level, as soon as –*

Yes, I was symptomatic during my GCSEs, but I was finally diagnosed part-way into my A-levels.

*How did you feel about it?*

What, about being diagnosed? Well, it was all a bit of a shock because, as I say, my GP had kept giving me loads and loads of different tablets and at the end he said, "I will refer to you

a neurosurgeon", which he did. The appointment came and I went basically on my way to college, I called in for the appointment, so I had all my school books and everything, and I went into the hospital, had my appointment and they said, "Oh no, you've got these massive brain tumours, you can't leave the hospital, you need to be admitted, you need to have brain scans, this, that and the other". So it happened very quickly. So there was almost not time to feel anything because it was just bang, bang, bang.

*Were your parents with you at the time?*

Well, my mum came to the appointment with me and when I was admitted obviously it was a big shock so we phoned my dad, and dad, as I say, is a teacher and it happened to be his lunch time so he nipped in to see me during his lunch time. So, yes, they were with me, I wasn't on my own.

*How did they feel about it?*

I think probably similar to me, I don't know. I mean my dad is being interviewed, he will say how he felt, I don't know, but I think at the time it was just a case of bang, bang, bang, bang, all of this stuff happening and we just had to deal with it really.

*Just to get it clear in my mind, tell me again what the actual timescale was?*

The timescale, okay. I went into hospital, to this clinic, I think I was diagnosed on I think it was 15 April and I was kept in hospital for a week on high steroids and they said to me, "You need another week on high steroids or another few weeks on high steroids, but you don't have to stay in hospital for that, but go home and just lie in bed, don't do anything because it will aggravate the brain tumours and before we operate we need to get you stable, so keep taking the tablets and just don't do anything", and then after about -- I'm not sure how many weeks it was, but I eventually went to Nottingham hospital for surgery on 21 May, so about a month after I was diagnosed I had the surgery, yes.

*How about your friends at school, your school pals?*

What, at school?

*How did they react?*

My friends -- I'm trying to think. Yes, they stuck by me. I mean some of them would come to visit me in hospital and this was particularly when I could still hear, I mean I used to have loads of friends popping in and in the end I used to take over the day room in the hospital and I would entertain my friends in there. But, yes, they were very supportive. But that was before I lost my hearing, because communication was fine, yes.

*Yes, okay, what about after?*

When I lost my hearing, one friend in particular stuck by me. I had been friends with her since I was 5. The rest of my friends -- I'm trying to think. They did stick by me, but I think in some ways I was a bit stand-offish. I guess I probably retreated into myself and I didn't make the effort to contact them and perhaps they felt awkward and didn't quite know how to be with me. So now a lot of -- well, most of my friends are friends that I have met since I've lost my hearing who know me as a deaf person, rather than as a hearing person who now is deaf, you know, they know me as I am now.

*That's interesting. What sort of relationship did you have with the doctors?*

With the doctors? Well, I have been really fortunate, my doctors have all been fantastic. I know from speaking to other people that they haven't always had a great experience but my doctors have always been -- I mean I can't fault them, they've always been really good.

*Is there somebody particular you have in mind, a particular doctor?*

Well, no, I mean as I say all my doctors have been really good. The surgeons that I see are fantastic. I have to say, actually, the ENT surgeons that I see are now getting better with communication. The ENTs used to be the worst at communication, ironically, I used to think they would be good but they would mumble, but they are getting better. Actually one doctor who I saw when I was in hospital when I just lost my hearing, so I was very scared, I was lying

in bed and the doctor came round and started talking and I said, "Sorry, I'm deaf", so he leant down on the bed, one hand each side of my leg, face really close, and started shouting at me, so that was scary. But that's the only experience I have had of that, really. Mostly they are all very good.

*Did you have any long-term contact with any particular doctor?*

Yes, I tend to have -- yes, I do tend to have a doctor or a team of doctors and -- well, certainly the first doctor I had who diagnosed me here in Nottingham, he was excellent, fantastic. Then I was moved up to Manchester and again the doctors there were lovely, very, very good. I was moved up to Manchester because they have the top surgeon for my condition so I was moved up and again, yes, very good.

*I don't know much about your brain implants, tell me a bit about the actual technicalities?*

That was why I was moved to Manchester, because Nottingham couldn't do the implant, so I went up to Manchester to have it. But I sometimes think that people think it is an easy decision. I was told, bearing in mind I was still hearing and they said to me, "When we do the operation would you like us to implant something into your head that would give you noise?" and most people would think, "Oh yes, go for it", but my first reaction was, "No, I don't want that, I don't want something in my head". I mean, to be honest, I thought I would be fine, I don't need it, and this happened when I was about 21, but talking to family and friends, they said, well go for it. If you don't like it you don't have to use it, but if you don't have it you will probably always wonder what it would be like if you had had it. So in the end I did have it. But it was at the same time as I had the tumour removed, so it wasn't extra surgery, it was just being done anyway. So they put it in and after, I think it was about three months, I went to Manchester for the big switch-on and I was in a little room plugged into all these machines and lots of doctors in there and people standing there, all looking at me, and they said, "Right, when you hear anything let us know, or if you hear anything", so they start twiddling the knobs and I'm sitting there feeling the pressure because everyone is looking at me, and then I heard a noise and I thought, "I will just check", and I heard it again and it was a noise, and I felt so depressed because it sounded terrible. I said to them, "I heard a noise". They were all ecstatic, jumping around going, "Yes, you've heard a noise!" And I'm sitting there in the midst of all this thinking, "It's

not good, it sounds awful!" But in the end they sent me off and they said, "Just wear it as much as you can, go out for a meal whatever, go into the town and keep it on as much as you can", and I went out there and it was terrible, the noise and everything was just awful. I had to take it off, I couldn't stand it. But then I went back the next day and they twiddled a few more knobs and gradually I got to be able to wear it. I mean I went home and they said, "Wear it as much as you can", but I couldn't wear it, I was better without it. I mean, in the end, mum said to me, "Start off with just trying to wear it for a minute". So I would put it on, I would look at the clock, watch it tick around for a minute and then take it off, because it was terrible. But gradually, really, really, really gradually, after about 18 months, I found I could wear it most of the time. So it was a long, hard struggle, really.

*What was terrible about it?*

The noise was just so different. I mean I think the problem was that I was comparing it to hearing. So if we were out and I heard a noise and somebody would say to me, "Oh that's a bird", rather than learning that that was how a bird sounded, I would think, "Oh that's a bird, what does a bird really sound like?" and remember what it really sounds like, whereas it's nothing like what it sounds like with my implant. So the breakthrough came after about 18 months when I finally accepted that I would never hear as I had before. I would have to learn to hear in this new way and from then, you know, it improved. Now, it's really great, I mean I would not want to be without it, it helps with lip reading, it helps with environmental sounds.

*Initially, during this initial period, did you get any use out of it, out of the noise?*

Not really, because I just found it annoying. I guess probably if the doorbell went, I would hear a noise and I would think that was it, but lip reading, it didn't really help. Because it was just this noise. I actually found it offputting, I found it distracting. It's almost like if you put it on I would try to ignore it but I felt good because I was wearing it, but I would try and ignore it. Whereas now, if I put it on with lip reading and the noise together, I've learned to use the two at the same time, rather than independently, really.

*Could you describe the noise, what the noise sounds like?*

What the noise sounds like now?

*Yes.*

You mean when somebody is talking?

*Whenever.*

If somebody is talking, and if I'm not looking at them, I will probably know they are talking, but it often sounds like -- you know when you are at the railway station and there is an announcement over the tannoy and you know somebody is talking but you haven't a clue what they are saying, that's what it sounds like to me. It's almost sometimes frustrating because I know they are talking and I can sense the words but I don't know what they are saying.

*Right then, so -- oh, yes, I remember something I wanted to ask you about what sort of student were you before and after?*

Well, all through school, to be honest, I have been a bit of a geek, I have to say. I really enjoyed school, I enjoyed learning. Unfortunately I didn't like maths, my dad is a maths teacher but I did not inherit that! I don't like maths. But I loved things like English, languages, really enjoyed them. So when I did my A-levels I was doing English and French and psychology, and obviously I had the surgery during these A-levels. Afterwards, when I went back, the hearing side wasn't particularly a problem, because I could still hear out of one ear. What was a problem was things like memory, but they were a result of my brain surgery, not the hearing. So I guess, as a student, I was probably the same as I had been before. But then I went to university, and half-way through my first term at university I had to have more surgery and that affected me as a student. I didn't go back to being a student after that.

*Tell me a bit more about the additional surgery?*

Do you want to know about the initial surgery? Because it's not particularly to do with hearing, but you still want me to tell you?

*It was unrelated to your hearing, was it?*

Well, the initial surgery -- I was left very, very poorly. I was in intensive care for ten days and my parents were told that they would have to switch off the machine, because there's nothing that could be done, but when they did start to switch it off I started trying to breathe for myself, so they switched it back on. Then it was a long recovery, I couldn't do anything, I couldn't move, I couldn't talk, I literally couldn't do anything, so then it was rehabilitation, which took about three months but that was over the summer. So after the summer I decided I wanted to go back to college. My parents said, no, wait, but I said, no I want to go back with my friends and I wanted to go back.

*Back to college, that was for your final A-level year was it?*

That was my final A-level year, yes and then I finished my A-levels and went to university, yes, so the hearing side was fine but I was affected by the surgery because I had been so poorly.

*You say the hearing side was fine, but how did you cope at school?*

Because I could still hear in one ear.

*I see.*

If I sat in the classroom -- say, if I made sure I sat on the right side then I could hear what was going on. I mean it was difficult in a sense because obviously I had to adjust to only hearing in one ear, I had to learn about making sure I was on the right side of somebody but now having lost all of my hearing, I know losing just the hearing of one ear was fine. But at the time it was a bit difficult.

*So at what point did you lose all your hearing and have to rely only on the --*

That was when I was 21.

*It was after university was it?*

Well, it was after university but I didn't finish university because when I was 19, halfway

through university, the tumour I had had removed grew back, so I had to go in for more surgery, it was on that side. So I could still hear in one ear. But after that surgery, again, I wasn't too well, and I didn't go back to university after that.

*Before all this happened, what were your ambitions?*

What were my ambitions? Oh, to go to university, to get a degree in English literature, possibly then do a PHD, possibly become a teacher. I mean I didn't really know, but I knew I wanted to go to university and do English literature.

*And at what point did you find you had to modify all that ambition?*

Well, basically, as I say, after I had the second brain surgery. When I had the first brain surgery, I refused to acknowledge that anything had changed. I thought well I'm fine, you know, I can go back, carry on as normal, same ambitions. But after the second surgery, that was when I began to realise, actually, I'm going to have to adjust things here, I can't carry on pretending nothing has happened.

*You say you began to realise. Do you have any particular recollection of that period?*

You mean when I realised that I couldn't carry on?

*Yes.*

Basically, not such a recognition. I think it was more of an acceptance that I couldn't keep pushing myself to do this. After the first surgery I pushed and pushed and pushed to keep going and do it. After the second surgery, I guess it's more of an another knock-back and it takes more to come back from it and I think I just realised that -- I think, as well, my confidence was knocked. Whereas after the first surgery, I was just -- my confidence was knocked but at the same time I was determined to carry on, after the second surgery my confidence was knocked even more. So I think it was just easier in a way to say, I'm not going to keep going, really.

*What role did your siblings and your parents play in that sort of thinking?*

Well, they were supportive. As I say, my mum didn't particularly think I should have gone back to college when I did and do my A-levels but in fact the whole family thought it wasn't a good idea, but I thought it was a good idea and I mean, at the end of the day, it was right for me, I went back with my friends, I did my A-levels. But afterwards they were very supportive. I mean my whole family, when we knew that in the future I would lose my hearing, we all went and learnt sign language together, stage one, so mum and I carried on, so we've done stage two as well, but my family and -- sorry, my dad and my three sisters they learned level one, so they know finger spelling, they know a little bit of sign language. They were all really, really supportive when I lost my hearing. I mean I remember my younger sister, who was about nine at the time, would sit and read me children's stories, but just read them to me and see if I could understand what was said. She also did that before I lost my hearing but with no voice, so she would read the story with no voice so I could practice understanding not being able to hear. I mean, so, yes, my family were really, really supportive.

*How important is lip reading to you now?*

lip reading? Oh, crucial. Because none of my friends -- well, when I say none of my friends are deaf, none of my friends who live in Leicester are deaf. I do have deaf friends who I've met since I have been deaf, but my friendship group in Leicester, they are not deaf. They don't know sign language. So I have to lip read them. But they are very good at speaking clearly for me.

*Can you recall the period during which you were learning to lip read, how long did it take to get up to speed, can you remember that period?*

Well, when you say learning to lip read, I mean I went to four sessions where I was one-to-one with a hearing therapist -- this was before I lost my hearing -- where I would learn thing like techniques. So if the person you are trying to lip read is sitting in front of a window it's difficult because you can't see their face. So things like that and making sure of different techniques of lip reading. So I went to four sessions. But one thing they told me there was that although you can learn to lip read to a certain extent, a lot of it is basically some people have an affinity to be able to lip read and some people don't. So from then on I prayed desperately that I would be able to lip read and fortunately I could. I mean, lip reading wasn't too difficult for me actually.

I mean obviously it improves, but right from when I woke up from the surgery it wasn't too hard. But one thing I do find is that, when I'm meeting new people, one thing I find is it's really good to be able to talk and the fact that I can speak -- when I meet someone I say to them, you know, I'm deaf, but I can lip read you and if I don't understand you it's not your fault, don't worry, and I can try and put them at ease. That took a while. I can do it now, but for probably a good two years afterwards I wasn't confident to do that and it took me a long while to even be able to say to somebody "I'm deaf", because to say those words was really difficult. But now I just say to them, "I'm deaf, I can lip read", and I try and put somebody at ease because it's scary for somebody actually, because if I say I'm deaf a lot of people think, "Oh no she as looking at me, looking at my lips", so, yes.

*So what do you attribute your confidence that you gained to?*

I think a lot of support from my family, initially, encouraging me to do it. I mean, I remember at first I didn't really want to go out on my own, but I remember there was a particular thing, going to the post office, and I was not confident to go into a shop at all, but my mum gradually encouraged me to go. Like the first time I wanted a letter posting, mum took it and the second time I said, "Can you post a letter?", and she said, "Well, you come with me", so I came in the car but I stayed in the car while she went in and dealt with whatever needed doing in the post office. The next time we went together and she came in with me and she did the talking, but I was standing there, and then the next time she came in with me but I did the talking and she was there, and then the final time she said, "Okay, off you go", but she was waiting outside. So it was just a real gradual encouragement from my family and now I can go in on my own and I think my confidence as well -- I mean I'm a Christian, so God is really important to me, and I think the fact that although an awful lot changed when I lost my hearing -- my relationships with other people, you know, talking to people was difficult, I couldn't pick up the phone, but because I've got a strong relationship with God that really helped my confidence. My relationship with God was just as it ever had been, God doesn't speak with a booming voice into my ear, I can pray to him anyway. So I think that was a big thing. And gradually, I mean going to church was probably a big confidence thing. I mean I had always been to church, but after I had lost my hearing I went to a new church so people only knew me as deaf and that was really great. People didn't know me as, "Oh, this is Emily, oh poor thing, she lost her hearing". People didn't know that, they just knew me as I am and that really helped with the confidence and how they were

accepting and gradually my confidence got up. I mean now I would stand up in church, and I go around different groups talking, you know, sharing what's happened to me and how it has affected different relationships. So, yes, I would say a big thing is God and church that helped my confidence, really.

*Tell me a bit more about your religious background?*

Well, my parents are Christian, so obviously they brought me up to believe in God, but when I was really quite young I realised that it was more than just, "Oh my parents believe in God, I'm fine", it was actually I decided to have a personal relationship with God. I guess I had always been brought up to understand that basically, you know, we all do wrong things, we do, but that actually Jesus, God, can forgive us those things if we say sorry to him. So when I was very young, maybe about five, I really understood that for myself, so I said sorry, I prayed to Jesus and he forgave me my sins and ever since then I have had a relationship with him that always, always grows and that's everything that, as I say, has really helped me through all this experience, because I know that whatever happens God is with me, and actually I must admit I look around and see other people going through similar things that I went through and I think, "How can you do it without God?" because God is absolutely crucial to me.

*Just for clarification, have you always -- during your life -- lived in the same place? Have you always lived in one place?*

Well, I've always lived in Leicester.

*You have, yes.*

I mean I moved house within Leicester. I moved house when I was very small, when I was about three I moved house, but ever since then I have lived in the same house.

*So what about your church, tell me more about your local church that you attend?*

When I was little I went to a very small church and then when I was about 14 I moved to another church near me and then, as I say, when I was about -- well, I didn't move churches straight away

when I lost my hearing, but when I was about 24 I moved to another church locally, which is where I met all these friends.

*What denomination?*

Baptist, well, Baptist now. The other churches are Brethren. I don't know if you've heard of Brethren church.

*Explain!*

It's just different denominations, I mean brethren churches, they are quite -- it's quite hard to explain. Brethren churches believe that men should have the leading role in the church, so the elders and the leaders of the church are men and the people who speak and preach and lead the services are men, whereas Baptist churches believe women can do that as well, can lead or speak or pray out loud. So it's just -- it's the same God, it's basically the same, it's just a slightly different way of doing things.

*And the Brethren was originally your parents' church was it?*

Yes, yes.

*And are they still involved?*

Actually they now go to the Baptist church as well, because my mum actually interprets for me, so during the sermon mum will interpret for me in sign language, because lip reading can be quite tiring, so to sit and lip read for an half an hour, 45-minute sermon is quite tiring.

*So your parents' sign language is good enough to interpret is a church service for you?*

Well, when you say my parents, my mum's is, my dad's isn't, bless him. No, he is quite good but my mum can, yes. She doesn't interpret BSL, she basically interprets in sign-supported English, which is what I prefer, because if it was BSL, it's difficult to change the whole word structure, but sign-supported English, it's basically the same as what's spoken so that's fine.

*How do you cope with the sermon?*

Because mum is signing it, fine.

*How do you feel about the sermons?*

What do you mean?

*Well, do you get -- do you understand it 100 per cent?*

Now I do, yes. At first, when mum first started interpreting, I would miss out bits or she would miss out bits, because fair enough, she was learning. And then she got to the stage when she could do it but she found it so tiring, afterwards she couldn't remember anything that she had interpreted because she was so tired. But now she interprets fine and she can take it in and I can take it in. Actually I find that she is really good and I do get it all and if I go to something, like a big Christian conference where there is somebody at the front signing a big meeting, so I'm watching the professional interpreter, I find it more difficult because they sign in BSL and I know it's missing out some bits. I mean obviously with my interest in language and English literature I like to know the words that are used, because some words -- the same word has different connotations, so I like to know exactly what's said, whereas for BSL one sign can be used for lots of words. So the sign, I don't know which specific word they are using. But mum is very good, she tells me the exact words.

*Tell me more about these conferences?*

Basically it's just a massive -- they are hundreds and thousands of all over the country Christians come --

*Where?*

Well, sometimes we meet at Skegness at Butlins and there is one in the summer down south.

*Isn't there one in Keswick?*

Yes, and there's one called New Vine down south where we go camping and again there's meetings and different seminars, and seminars are basically you know if you are interested in something you go to a particular seminar, or if you want to find out more you go to a different seminar, or if you are needing help with a different issue there will be a seminar about that. So you pick and choose what you go to.

*And you find you can follow things?*

Yes, I can. I can follow -- I must admit music is a bit of an issue, because at these there's worship bands, singing, music bands, and I don't particularly enjoy that anymore. I used to be very, very keen on music. I used to play the flute and the piano and the accordion and I really used to like music, so that is something I do find a bit difficult at these conferences, the music. I don't really -- I can't really enjoy it. But what I find in church, because obviously there's music in church, but what I find is I actually start making up my own tune for a song and we have the words on a Powerpoint, and I sign along, so I'm singing and I have a tune in my head that I make up. It's quite interesting sometimes. I say to mum, "This is a lovely song, isn't it?" And I will sing it to mum and my mum will say, "What are you singing?" And I say, "I'm singing my tune", and it's completely different from the real tune! So that's fine.

*That's fascinating. I wonder if we ought to have a short break?*

I don't mind, I will keep going.

*It's for Kate's benefit.*

I could rabbit on forever! We had better press pause then.

*And it gives me time to think about what I should be asking you next ...*

**[Track 1]**

This recording is going to be so funny. When somebody listens to this they'll hear us saying 'have you pressed the button'?

*Right. I wanted to take you up a little bit on the music, which means going back, so before all this happened, you know, when you were a teenager, tell me about your musical experiences?*

Well, I love music, I started to learn to play the piano when I was five. Music has always been a part of my family. My mum plays the piano and my sisters play various things, and also listening to music. I was always a bit -- when all my friends were into all the pop bands I'm afraid as I said I was a geek and I liked classical music, but, yes, when I was about -- I think it was 11, just got to secondary school, started to learn the flute and I really enjoyed the flute, I would play in various bands and orchestras and different things. I played at church as well for people to sing to. The accordion I learned because when I was about 15 I went on what's called beach mission and it's where a team of people -- it's a Christian thing again, where a team of people go to the beach during the summer and they basically run a thing for children, so there's different games and singing and stories and quizzes and I went on this, because I used to love doing stuff with children, telling them stories and things, and I went but to do the singing they have an accordion and I went on this team and they didn't have an accordionist, there was no to play the accordion so I said 'well I can play the piano so I will learn', so I quickly learned to play basic on the accordion so I would stand on the beach, play these songs and the children would sing them. So, yes, it was nice. I mean that was probably what I miss most. I probably miss music the most since I've lost my hearing.

*Now step forward ten years, do you go on -- apart from music in church and associating with your religious activities, do you go to concerts as well?*

What now?

Yes.

Oh no, because I can't hear the music.

*No. Your parents are interested though?*

Yes, actually, one of the hardest things not just for me but for all of us, every year, about in November or December, the run-up to Christmas, every year our family tradition is to go to a performance of Handel's Messiah, we go every, well we used to go every year, and they still go, I wouldn't want them not to go. But I always find that a little bit difficult, I would like to still be able to go.

*Do you ever look at the score?*

Yes, I mean, I can look at something, I can remember the music in my head. I mean, if I -- it's interesting about the score, I mean one time, going off on a bit of a tangent, as I said sometimes I will go and speak at different groups, not just about this, but maybe about the bible or different talks and my mum will sometimes do the same and one time I went with my mum because she was doing it but she wanted -- we often find actually when we go to these because it's often quite old people and they like it if you sing them a song or something and my mum wanted to sing a song, because she is quite good at singing and she thought she would sing this song to them but she said I need someone to play the piano, will you come with me and this is when I was deaf, so I said okay I will do but obviously beforehand I practiced and I went and played and very interestingly I didn't realise this had happened I played it but then through playing it I got the tune. So I was singing it -- I think I was washing up or something and just started singing this song and mum said to me 'how do you know that tune?' and I said, 'well, is it the right tune?' and she said, 'yes' -- obviously give or take a few notes but she said basically it's the right rhythm and up and down the right tune and that was because I played it on the piano and it's interesting, if somebody else is playing and I watch their fingers I can tell the basic tune because I know if they are playing up there it means it is high and if they are playing down there it's low so it's quite interesting.

*Very interesting. When you are playing the piano, what do you hear?*

What do I hear? Actually the best way to play the piano for me is to take my implant off because it's just a bit of a noise, it doesn't sound nice. But if I take it off, particularly if I'm playing something I know I can hear it in my head and as I'm playing I kind of hear it in my head and

play at the same time.

*And you are reading the score?*

Oh, I can read the music, yes, I read the music.

*So you are reading the score, and imagining the noise?*

Yes, but particularly if it's something I knew from having heard it before. Or, as I say, if it's something new I tend to work out the tune as -- but it's not the same I can't do it very often, it's not the same.

*It would work even if it was a new tune, would it?*

Yes. Well, yes, because this song that my mum sang was a new tune but because I played it I got it.

*Right. That's absolutely fascinating. I will tell you afterwards why!*

[06:48]

*Right, let's go on to -- at some point you decided to drop out of university?*

Yes, that was after the second operation.

*Tell me more about that decision and what happened?*

Well, that decision -- it's really hard to say. That decision, I guess, was taken because, as I say, I had a second operation, I could still hear, but it's a neurological thing, so everything was affected, it was more difficult for me to walk and I think in some ways I think I was tired of fighting to keep going, you know what I mean? It was an effort to -- it was an effort for me to do the assignments because my previous surgery had left me very tired and basically my memory had completely gone but my mum would come and visit in the hospital and I would be lying in

bed and talking and she would say 'I'm just going to the toilet' and I would say 'okay', and she would go for two minutes and I would say 'nice to see you I haven't seen you for a while', so I had no memory so I had to retrain the whole thing. So it was difficult. Doing the A-levels was pushing and pushing and one of the things I found hard, I guess, to be honest, I mean this might sound a bit bad but I had always been very good at English Literature. By the time I got to my A-level there was still parents' evening and my parents went to the interview and basically the English teacher told them that I was the best student she had ever taught.

*Which university are we are talking about?*

Sorry, this is back at A-levels, because this is the lead-up. Back when I was doing my A-levels the English teacher said I was the best student she had ever taught and I loved English, I got really good grades and then I went to university after -- we will have to go even further back, sorry I'm waffling, I had the surgery halfway through A-levels and then when I did my A-levels, I passed. I did pass, but I was really disappointed because I didn't get an A in English and before the surgery my English teacher had said "she will get an A no trouble, she is great at English" so I felt really disappointed although everyone else was saying you've done so well that is fantastic and I can see why they said that because obviously I had had this surgery. Then I went to university and my assignments were okay, you know, B pluses type of thing, but afterwards I thought -- again it was probably a stupid pride issue but after the second surgery I thought I'm going go to go back again and get even worse and I don't know if I really want to do that, if I really just want to be getting okay grades, which would have been really good for me, but when I could have done better so I think I just thought leave it and to be honest I thought well I can still read a book, so I don't need the grades to prove it.

*Which university?*

I stayed in Leicester, De Montfort University in Leicester.

*So you were still at home?*

Yes, I stayed at home. That was another thing; I had been determined -- my dream had been to go to Durham University and obviously again that didn't happen. I couldn't have gone away

from home because I needed all the support, I was poorly physically, you know.

*So ten years on, how do you feel about those decisions you made ten years ago?*

About not going to university?

*Yes.*

I feel fine about it. It was difficult -- I'm trying to think - around about when I was 22 and maybe mid- twenties then a lot of friends I had made obviously had been to university and a lot of them were kind of like why don't you go back and carry on or haven't you got a degree and it was all very much -- I mean I can understand it because basically I had been exactly the same, you know, degree all the way through, as soon as I could understand about what university was I wanted to go and they were all like you should go and get qualifications and you should do this, that and the other, but as I said, fortunately, particularly with my relationship with God I've got that inner confidence where actually I could say, actually a degree does not define who I am, I don't need a degree. I'm still who I am, I'm still legitimate, I don't need a degree. So now I'm fine about it, I really am, and I haven't got a degree but so what.

*You could go back now if you wanted to couldn't you?*

I could if I wanted to and interestingly now I think I could but now I'm thinking what's the point?, I'm actually fine. It's not like if I don't get a degree somehow I'm not intelligent I mean it makes no difference. People often ask me are you going to go back and study, but, no, I mean I can do what I feel God wants me to do, I can do that anyway, I don't need a degree.

[12:21]

*So what have you been doing since then?*

Well, I have been -- let me think. It's hard to say. As I say I'm quite involved with the church, so I do various things like I go along to a weekly what's called a community bible study, I'm the coordinator for that, so I deal with the money and who's coming and posting out lessons each week for that. I have been teaching -- well, when I say teaching, I mean in the church one thing

I particularly -- I don't do it anymore but I did do the children's work, so I would have a group of children and I would tell them stories and do activities and do all this stuff and actually the children are fantastic about me being deaf. It's not really -- they don't see it as much of an issue. I just say to them, 'by the way, my ears don't work properly', and they are like, 'oh, okay', and they carry on. Particularly when they get to about maybe six or seven they understand that they need to look at me if they are talking to me. I mean actually one little boy who is only four saw someone talking to me and he came over and this person was looking away and he came over and he said 'you need to look at Emily when you are talking to her'. So they are really, really sweet, yes, they really are. Actually I've got quite a lot of them are my godchildren now, it's really nice. I think it's four godchildren now, so I have a bit of a brood of them, I've got quite a few godchildren but they are all really very good. One in particular, if I don't understand what he said he will just repeat it and they are really good at tapping to get my attention, they are, they are fantastic. But I think they don't really understand because -- when I say don't understand, they accept that they need to look at me but I don't think they understand the full extent and to be honest I don't want that, because I don't want them to start feeling scared because it's different, it's just -- I want them just to say that's how Emily is, rather than, oh, you know, Emily is different, Emily is deaf, they just understand that's how I am.

*Do you feel different?*

What do you mean by do I feel different? You mean different from everybody else or different as a person? Which do you mean?

*I don't think I can expand on that, I mean obviously everybody is an individual, but do you feel set apart in any way?*

Well, as a person, in who I am, I don't think I've changed particularly, any more than I would have done if I could hear, you know, I'm still -- I'm quite confident in who I am. I accept who I am inside. But obviously things have changed outwardly, I mean I'm standing in a group of people whereas before I would be in with all the conversation now I probably won't follow the whole conversation. You know, sometimes I have to wait for somebody to say, oh we are talking about this. So obviously that has changed, yes.

[15:56]

*I couldn't help notice that you are slightly physically disabled.*

Yes.

*How does that affect you?*

Well, it affects my walking, but that is a result of the condition that I've got which was the brain tumours. I also grow tumours in the body and my walking with the stick is as a result of having two tumours removed from my spine a year last May, so just over a year ago and after that, basically I woke up -- well, they told me before the surgery, you might not be able to walk afterwards, you know, you might be paralysed so I was as prepared as I could be for being paralysed from the waist down and after I woke up I just couldn't move my legs at all and I just thought well that's it. But they said to me you can't move your legs at the moment, but you may be able to recover some use. So again, I mean, it has been a year and I still can't walk properly, but it has been slow, slow, slow rehab. I have had intensive physiotherapy, I was in hospital for I think it was six weeks, three weeks of which I think I just lay in bed and then three weeks of having physio gradually, you know I walked with a zimmer frame and then crutches and then finally the stick but what I can do now compared to what the prognosis could have been is fantastic really.

*You are describing experiences which most people consider nightmarish and yet you seem quite -- not content, but you seem quite cool about it?*

Well, I mean, when you say content -- I am content, it doesn't mean I like it. I don't like the fact I can't walk anymore, I can't hear anymore, I don't like it, but it seems to me you have to accept it, otherwise you go crazy. I don't have to like it but I do have to accept it and say, okay, this is how things are now and like I say I'm a Christian and my faith is so important to me and actually when bad things happen, God doesn't just say 'okay I'm walking out', God is right there with me the whole time, so that's what gets me through.

*So you will anticipate your next question, I was going to say where do you get your strength from?*

Yes!

*Yes. We are talking about quite a long period, you are 30 now, last week, aren't you?*

*Yes, I'm, actually do you mind if we pause for two seconds? Can I have a bit more water, would that be okay?*

[19:22]

We were talking about my disabilities, disfigurements, another one clearly is my face, half of my face was paralysed and that was because when I had the tumour removed the nerve it was on the was the audio Friday nerve obviously but that's really close to the facial nerve so there is a chance the facial nerve will be severed. The first time it was removed it was fine, my face was fine, which was great because I had been so -- I was more worried about my face going than about losing my hearing. That would have been a nightmare, you know, 16 years old, school and looks and everything, I just did not want my face to go and it didn't. Then the second time they told me it might go again and it did clearly, I mean my facial nerve went, and that was really quite tough. But again, you know, God -- I read in my bible and I find verses that just speak to me so much. I mean the one particular verse I read not long before my facial nerve went was: "Man looks on the outward appearance but God looks on the heart:" And I was like that's so fantastic for me, because people will be looking at me, and it's true, not so much now, but it used to be when I was walking down the street people would look at me but you have that reminder that it didn't bother God, you know, he didn't care. But walking down the street with people looking at me, that was harder for my mum, actually, than for me. I mean I didn't particularly notice people looking but my mum would see people staying at me and that was really hard for her. But for me, I don't know why but I just didn't notice them, I was probably concentrating on walking or something, I didn't notice it too much, but I was conscious of it. Basically I was very conscious of my face, I didn't like it at all and then it was suggested that I could have -- it used to be worse than it is now, it used to be kind of -- obviously that's not going to show up the palantype, but it used to go dragged down, but then I had an operation which is a nerve graft, they took a nerve from my tongue and grafted it into my facial nerve, which is amazing and gradually my face lifted. So it's still paralysed but not as bad as it was and that was a big decision for me because it meant having surgery that wasn't essential and it was hard for me after

having all the surgery I have had to say I'm going to choose this surgery.

*They call it elective surgery don't they?*

Elective surgery, that's the one.

[22:17]

*Yes, it's fascinating. There's something I wanted to ask you. Oh yes, you must have times of doubt?*

Times of doubt about what.

*Where you feel low and you don't feel as confident as you obviously are now? Do you? Does that happen?*

Oh yes. Particularly at the beginning. Particularly when I first lost my hearing. When I first lost my hearing I didn't want to go out of the house, I didn't want to see anybody, I didn't want to -- I mean I didn't really want to do much at all.

*What about now?*

Oh now I don't mind seeing people. Now I can't really go out now because I can't walk but that's not because of my hearing. No I'm quite happy to see people. I'm much more confident about you know saying to people, "I'm deaf" and actually what I find is people are really, really nice. People are lovely, they really are. I mean I've never had anyone be aggressive to me because I'm deaf or ignore me or shove me, people are really nice. If I say to somebody, 'oh I'm sorry, I'm deaf' -- I mean I've said 'I'm sorry I'm deaf what did the announcement say?' or 'can you tell me where something is?', but people want to help, they are so, so nice, they really are and people will sometimes even go the second mile. You know, if something is being said and I don't get it or if I'm in the shop and I'm saying where's this, they won't just say oh it's down there, they will say oh come on, I will show you. People are really, really nice. But I think a lot of that -- because I mean I have friends who are deaf who they haven't had the same experience,

they've found people to be not so helpful all the time, and I think I'm just fortunate in the people that I happen to have met are really nice, but I think as well it's about your own attitude, you know, it's about putting people at ease straight away, saying -- and what I often say is "I might not be able to lipread you but it's not your fault" because people think oh if she doesn't understand me it's because I'm doing something wrong but I just say it's just me, I can't lipread all the time, so it's me, don't worry about it, it's not you and I think that's a lot of it, putting people at ease, really.

*Some people might say it's also attributable to your genes?*

Oh, I don't know, it might be.

*Have you thought about that?*

No. What do you mean?

*Well, your parents, your personality.*

So when you say genes you don't mean literally, you mean family life?

*Mm-hm?*

I mean, yes, I have had a very secure family life, my parents are together still, a lot of my friends' parents have split up and I know that has been difficult for them but yes, it's about family life and it is about -- I don't know, yes, having the support, and I think feeling valued. I've always felt valued, even when I lost my hearing and some people think, oh that's it, you know, disabled, or whatever, but I've always felt valued. It's not only in my family, although they are crucial, but it's my wider friends, I've got some lovely friends, really, really nice and I think that makes a difference.

[26:03]

*You now reminded me of what I was trying to remember to ask you about and that was tell me*

*more about your relationship with other deaf people?*

With other deaf people?

*Mm-hm?*

One of my best friends is deaf, I met her through -- there's a kind of group of people who have got the condition I've got but it's quite rare, so they live all over the country. We meet up maybe once a year, there's a weekend where everyone goes to the same hotel, but one girl I met there we became really good friends, she lives in Bristol but we sometimes meet up and it's fine. I mean with her, I just use sign language, partly because I guess it's difficult to lipread me and partly because it's difficult to lipread her and partly because sign language is her preferred way of communicating. So I will sign for her. I mean some of my friends like me to write it down, so I write things down for them or some of them -- yes, some of them can lipread me, it just depends really.

But it was quite interesting once, because I was talking with a group and there was -- I think we were all deaf, but it was quite funny because one of them was speaking without using sign language and the other one couldn't lipread and needed sign language so it was very ironic, I was interpreting, it was so bizarre, because I'm lip reading and trying to interpret, but you know, yes, we get by.

*Do you use email?*

Yes, oh yes.

*Do you participate in, what do you call them, social forums by email?*

No, not really. My own social forums, as in I email my friends, but not the organised groups where you get together and talk, no, not really.

*You don't?*

No. I don't know why I don't and I don't know why people do. Do you know what I mean?

Maybe it's -- because I mean I email my friends.

*What about texting, text messages?*

I mean I often say actually if I had to lose my hearing then the time in which I'm living now is great. If I had lost it, say, 20 years ago, all the email and the texting wasn't around. So, yes.

[28:43]

*I'm amazed at your facility with British sign language. I live in Preston where there is a big university department for sign language, and I commonly I see groups of students, deaf students learning sign language in the supermarket or something and they do it so fast, young people who use it, that I can't imagine how you could follow it.*

No, I mean I can't follow it -- sorry, clip your microphone back on.

*It's alright, I'm not saying anything anyway!*

I can't, if somebody who, say, is born deaf and sign language is their first language is signing I can't follow it, I don't understand what they are saying. I mean what I do basically is get by with Sign Supported English more than -- because if you are born deaf and do this with sign language, no, I can't understand it.

*Can you remember your first contacts with other deaf people?*

I don't know. I can remember -- I don't know if it was my first but I can remember a contact with deaf people. It wasn't that great, actually, because I thought -- I thought, before I lost my hearing, when I thought oh I'm going to be deaf, I thought that's it, I'm in with the deaf people. So I went to my local deaf centre and thought, okay, I'm going to go along to -- I can't even remember what the group was but I went along to something and I can remember one of the deaf people, born deaf people, saying to me, "you are not deaf" and I'm like, "yes, I am", and they said "but you are talking, you are not deaf" and I'm thinking, actually I'm more deaf than you because they were hard of hearing, I'm 100 per cent deaf, and I'm thinking, I'm more deaf than

you but it's because I could talk and they think you are not deaf because you can talk. I can understand why they think that, because they don't talk, so it was quite difficult and I realised that actually there's deaf and there's deafened and actually there's deaf, there's hearing, and there's deafened stuck in the middle because you are not deaf and you are not hearing.

*So how about meeting other deafened people?*

Oh that was fine.

[31:35]

*Tell me about what you remember about your first contacts?*

I think my first contact would have been at LINK, when I came to LINK, but I think the first time I came to Link was before I had lost my hearing -- I had only lost it in one ear, I could hear in the other ear but LINK said I could come to learn what it would be like when I lost my hearing. So that was the first contact with deafened people and it was really positive. But it's slightly different, as in we were all together for a week and the people were so nice, they were really lovely, and we just got on really well.

I'm trying to think -- I went to Link again after I had lost my hearing and again, a very positive experience for deafened people. In fact I would say every deafened person I meet, it's positive.

*What was the age group of the people you met in Eastbourne the first time?*

I would say -- it was a long time ago, it's hard to remember. Probably some were 60 and some were 30, yes, maybe 30s to 60s.

*They weren't all old cottagers like me then! Codgers!*

No, they weren't as old as you!

*Yes, that's interesting. Who paid for you to go to Link?*

Leicester Health Authority.

*Did you have any trouble getting the money?*

No trouble at all. When I first went to Nottingham hospital, I told you I was referred there for the first surgery and I saw an ENT surgeon and actually in that first consultation he said, "I think you should go to LINK" and referred me and I went and the second time no trouble at all.

*That was the first time you heard about LINK?*

First time I heard about LINK, yes, from the ENT surgeon and he referred me straight away and there was no trouble with funding and then when I wanted to go a second time, no trouble with funding.

*Did your mum go with you?*

Yes. The second time we wanted my dad to go with me but he was at work, so he couldn't because we thought it would be really good for my dad to help him understand. I mean, to be honest, I wanted my dad to go because of the headphone thing, you know when the hearing people put the headphones on and there's noise playing, so it's like they've got tinnitus and they can't hear anything, I wanted dad today to do that but he didn't go.

*Why did you?*

So that he could understand what it's like.

*Was that based on some incident or behaviour of your father?*

No, just because I wanted him to know, to understand really.

*But you must have had some feeling that he didn't understand fully then?*

Yes, I mean often -- I mean that was then. I mean now he is much better but he would often

mumble or talk while he was walking out of the room, and actually it got my mum, she was say "oh, she can't see you!", but I mean he has got a beard and a moustache and he is good at keeping them trimmed. He is much better now but just at first, I think my mum as well had found it so enlightening to do the earphones thing that she wanted dad to try it. I mean it doesn't matter, it's just a little thing.

*You persuaded him to trim his beard, did you?*

Yes -- well actually, when we went to LINK the first time someone told us that beard and moustache are not great and mum and I thought 'oh dad's got one', so we said, 'oh dad's going to have to shave his off' but my mum said 'I don't think so' because apparently just before they got married, dad's sister persuaded dad that he couldn't have a scruffy beard, he had to shave it off so he shaved it off and mum said it didn't really suit him. So she said he's keeping it, but it's good, it's trimmed and I can see his mouth and that's fine.

*So he has had his beard for a long time then?*

Yes, he has always had a beard, yes.

[36:17]

*On this list I've got here, subject areas, it says politics at the bottom.*

What do you need to ask about politics.

*Are you a political person in any way?*

I'm from -- I'm not a strong political person, but I take an interest, I mean obviously -- I mean to be honest I've got a bit fed up with the whole expenses row, I mean I think it's pathetic.

*I suppose we should avoid that, otherwise we will be here all day! Are you a regular newspaper reader?*

At the weekend we get The Times and I do tend to read particularly the supplements, I like reading the Times magazine, and I like watching the news, I like Channel 4 news and probably at this election I will vote Conservative, I think, best of a bad bunch, really.

*So your enthusiasm for literature is basically focused on books is it?*

Books, oh I like reading books, yes.

*Do you find any sort of reflection of your own situation in literature?*

No. I can't say I have, no, not really. Maybe I just don't read the right books, but no, not really.

*What are you reading at the moment?*

At the moment I've just finished reading a short book, The Boy in the Striped Pyjamas, and I always like read the book before I see the film and my friend who is staying with us this week she has got the DVD and I said 'don't watch it don't watch it I will watch it with you when I read the book', but of course she forgot the DVD. The same with lots of books I don't know if you know *The Reader*, the film with Kate Winslet, I wanted to read the book first before I watched the film and of course the if I am many wasn't subtitled at the cinema. I like reading I like the classics, I like Jane Austen, I really like Jane Austen, a bit of a fan of Jane Austin so I like reading.

*Do you do any writing?*

Oh, I write particularly kind of poetry and meditative readings, often if I'm doing a talk somewhere, I'm doing it about a particular, say a bible passage or a topic, I will write, if I feel it's the right thing to do, I will right a meditation type thing to read as part of that talk I'm doing.

*For whom?*

Well, sometimes for myself, but often I will write it and then I will read it in church or mostly in the Christian group I'm talking to, something like that, but no, I do enjoy doing that, yes. I keep thinking one day, one day I will write a book. But everyone thinks that.

[40:04]

*What do you see for the next ten years then?*

I don't know. Maybe I will write that book. No, I do think perhaps I will write, because I mean the poetry and stuff that I write, people always like it and I do keep thinking, well maybe I should put it together and do something, but at the same time, I mean I really don't know. Probably, realistically, in the next ten years I will probably have operations. I mean for the last 13 years I've averaged at least one operation a year, I have lots, I have them all over, I mean I have had them in my leg, in my shoulder, I have had them all over. At the moment I've got a particularly big tumour in my leg, at the back of my thigh, which will need operating on at some point but the surgeon says we will leave it as long as possible because when it's removed it's on the sciatic nerve, so my walking will be even worse than it is now.

*What else would you like to tell me about the experience of deafness?*

The experience of deafness. One thing actually that's quite good about deafness is that you can -- if I'm reading a book or something, there's loads of noise going on around me, I can take off my implant and just read my book, which is really nice.

*I forgot to ask you about your speech perception, has it improved with the implant?*

What do you mean do I lipread better with the implant than without it.

*Yes, but since you have had it, does your speech perception get better with time?*

What, you mean perception with lipreading.

*Well, just understanding speech, what I'm saying to you, yes?*

Yes, basically it has improved as I get used to the implant. Every year I have to go -- I guess you are the same -- I have to go to have tests where you have a computer screen and you have to watch a man speaking and then you have words or sentences spoken without lipreading and yes,

that improves, that does get better. But I find it's a controlled environment when they do that, it doesn't -- for me it doesn't really reflect how life is really, because when I'm there and it's all quiet and they are playing the noise straight to me I can often understand what's being said. But then you go out into life in general and there's noise going on and you know, I might understand or I might not. So I never rely on just what I've heard, I always have to lipread.

*How long have you had this now?*

Nine years. Actually, you could have worked it out, because I had it put in when I was 21 and I'm now 30! No, nine years, yes. So it's gradually improved.

*Do you go back every year, do you, once a year?*

I go back once a year unless I start to have problems with it, say the sound starts sounding more different, different than it actually is, but I mean I'm very fortunate again with this, because it works exceptionally well. I mean when I went for my last hearing test they said that I was in one of the top two in the world for results so I'm really fortunate. There's no rhyme nor reason to it, it's not about how the implant is put in or anything, I said -- I was asking the audiologist 'why' and he was asking me 'well why do I think my mine works?' and I said well I don't know, and he was saying could it be to do with intelligence or this, that and the other and I was like, well, I don't know, I really don't, but I'm just glad that mine works but I do feel really sorry for people who have it put in and it's switched on and they don't hear anything. That was one of my fears about having it put in in the first place.

[44:47]

*You are obviously a very bright girl, do you think that's related to your coping mechanism?*

How am I supposed to answer that! I don't know. I think for me, and it is just for me, I'm not saying this should be for everyone, for me a lot of the coping is mental, is about telling myself I have a choice, I either accept what's happened and do the best I can or I go into myself and I never go out and I never do anything. I find that you always have the choice in life, you always kind of say, 'okay I'm going to make the best of it or I'm not' and I decide to make the best of it. Yes, sometimes it's making the best of a bad situation because I wouldn't choose this, but it's

happened and you've got to get on with it.

*I just wonder whether your emotional energy is in some way related to your intellectual gifts, if you like?*

I don't know.

*Have you ever thought about that?*

I've never thought about that, no. What do you mean by emotional energy?

*Well, coping with the nightmare?*

Well, I don't think -- well, I don't know the answer to that. I mean I think -- I think in some ways it's to do with not competitiveness but the fact that always -- I mean I used to do sport and I used to love running and I always wanted to go as fast as I could, or as high as I could and get the best score I could and I wonder if in a sense it's a challenge, it's a challenge to say, right, this is happening, I'm going to make the best of it. I mean I don't know, I've never thought of it before, but maybe it's the challenge to say, this is what I'm faced with, I'm going to do what I can. I mean, I know I keep saying it, but I can't get away from the fact that it's because of God and all the time God gives me -- he gives me the strength and I can rely on him. I can't run away from that.

*Can we pause for a moment.*

[47:28]

*Yes, I remembered one more thing I want to ask about and that was in your little CV you did for Sarah, you mentioned that setting up a local support group?*

Oh yes.

*Tell me about that?*

I didn't know whether to put that or not because I did, but it's not happening anymore! So I didn't know whether I should put that or not.

*What happened?*

Do you know, I don't really know. I mean we started off meeting, and then to be honest I think I probably had to go into hospital.

*I see, so you were interrupted? Was it your initiative though?*

It was somebody else as well, the two of us were doing it together.

*Another deaf person?*

Oh yes.

*How did you meet them?*

I think it was through LINK, I think LINK actually said, can you do this with, and, yes.

*How important is contact with other deafened people to you?*

To be honest, not that important. I mean it's important as in some of my friends are deafened people and it's important for me to see them because they are my friends, but it's important for me to see my hearing friends as well. I don't feel that I need to be with deafened people per se.

*No, no. What about this whole event today?*

What about it?

*Well*

Oh I'm quite happy, it's fine, we are having a nice chat.

*I mean do you enjoy this sort of -- this event?*

Oh yes, and I mean I enjoy chatting to people. In case you hadn't guessed! No I mean when we go out and about I enjoy meeting people and talking to them.

*Whether they are deafened or not you mean be?*

Yes, exactly. That's what I'm saying, I mean obviously I have friends who are deafened so I love seeing them but not because they are deafened, but because they are my friends.

*But you did say earlier that after the traumatic loss of hearing, most of your old friends drifted away and you got a new group of friends?*

Yes, I found making the friends since I've lost my hearing -- but as well, I don't know if I'm being a bit harsh on my old friends because it was at a time when everyone was going to university and stuff anyway, so we might have drifted apart anyway. I mean as I say, one friend, one friend, she has stuck with me, as it were.

*Do you still have -- do you have any of your old school friends -- are you still in contact with any of your old school friends?*

Yes, that's this one friend.

*Just one, yes. Well, I think I've come to the end of my questioning.*

Oh have you, you can't think of anything else.

*I think it's absolutely fascinating talking to you, and one day there ought to be a book in this.*

Well, I did just say didn't I, one day I will write a book!

*We don't have to wrap this up in any formal sense, do we, so we just stop.*

I don't know. Is this the first interview you've done?

*No, no, but I mean I don't remember the details!*

Why don't we say, "Here ends the interview"!

[End of recording]