



Unheard Voices: interviews with deafened people

Andrew Goodwin Interviewed by Sarah Smith

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IMPORTANT

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Interview Summary Sheet			
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[Track 1]

This is Sarah Smith interviewing Andrew Goodwin on Wednesday 1st July 2009 for the Unheard Voices Project in Eastbourne and we don't have a speech to text reporter here today, and Andrew will be lipreading me, I'm sure. So Andrew, could you just state for me your full name, your occupation or former occupation and your date and place of birth please?

Right, will try to remember all of that! My full name is Andrew Lewis Goodwin, born in Bushey Heath, which is North London. 27th September 1971 and my former occupation, because unfortunately I am as the actors say, in between jobs, I am resting at the moment sorry. My previous occupation was project assistant to the Deafened Awareness Project for the LINK Centre for Deafened People.

Ok Great. Could you just spell your middle name for me please?

Lewis, that's L-E-W-I-S.

And if you could just tell me your Mum and Dad's occupations please?

My Mum, Marsha, she's now retired, a lady of leisure, but she used to be a, um. sorry she's done lots of different things, the last thing she was doing was a healer, an alternative therapy type healer. She did Reiki, crystal healing, angel healing you name it she did it and was quite good at it actually. My Father is currently a salesman in a furniture store. He was working in that kind of field ever since he was 16 years old. I think he was 21 when he was made manager of his first store, and for the next 40 odd years was made manager and then when my parents split up, almost 10 years ago actually he decided to go off travelling around the world, came back and thought what is he going to do for a job, tried a few other different things and then ended up working as a salesman. But this time, because he was in his mid fifties he decided not to, basically he didn't need the pressure, let's put it that way. Didn't need the money, didn't need the pressure so he was a salesman. He went into where he was working, temporarily and seven years later he is still there!

And is that here in Eastbourne?

It is yeah, he's working for David Salmon which is one of the very few independent furniture stores still left in the country. It's the sort of place you go to buy a footstool and it costs you £15,000 but it's the sort of thing that you'll hand off to your grandchildren. Its quality furniture. But somehow, still manages to keep going.

You sound like you could be quite a good salesman yourself actually!

Well I have been a salesman in the past.

Could you tell me a little bit more about your Mum's last job I'm particularly interested in what angel healing might be...

Well right you have to understand that my mum has always been interested in the esoteric. And partly because I was born with a severe hearing loss she has always been trying to find out ways of healing me. I'm trying to resist putting my hands into the quotation marks position, because you obviously can't see that when you're listening. But it was always that kind of interest. She got involved in faith healing I think maybe when I was 2 or 3 years old and it kind of developed from there. And she found that she had certain talents and angel healing in particular involved invoking the names of angels so that they are standing round you while you are giving healing to this person. The idea being that it is not you that is not doing the healing it is the angel. And there are people that will quite happily pay lots of money for that. Jolly good for them! There are other things however, things like Reiki which is a Japanese kind of art, which she trained me in, and I am what you call a Reiki master. And stripping out all the mumbo jumbo, the fact is if I lay my hands on someone and do the certain visualisation exercise I can definitely feel something happening and the person who I am laying hands on definitely gets better from whatever condition they've got quicker than they would've otherwise.

And what does that feel like? What do you feel?

It's a bit like pins and needles, but not painful

In your hands?

In my hands and there's a sense of total calmness over me while the healing is happening. The important thing to stress again it's not me who is doing the healing. The practitioners of Reiki believe that, they believe in God they are quite sort of spiritual but they believe that God isn't necessarily a being, but its an energy which you can then tap into and you're just simply a conduit for it. So that's one of the very few things my mum has ever done that I've actually got involved in. Because she had her own healing centre for a while, for five years in Brighton. Which went very very well and you get to meet so many, I was about to say weird people, but so many interesting people lets put it that way.

Wow, well that was a bit of digression, but very interesting nonetheless! So can you just tell a little bit about you?

Me? I'm six foot four, four hundred pounds and devastatingly handsome, no. What do you actually want to know?

What do you want to tell me?

[06:27]

Oh God. I don't really know where to start to be honest.

Okay, how about you start with your childhood, your family, what makes up your family, that kind of thing.

Right, well apart from my parents and myself there is my younger brother Nicholas who is 18 months younger than me and while we were all growing up, up until maybe early nineties we were a very close family, we did all sorts of things together and a lot of that was from my parents perspective, they were very determined that no matter how my parents felt and no matter what my brother and I were planning on doing we were always doing things together as a family, even if it was doing boring things together like playing board games, you know monopoly and scrabble and stuff like that we made it a fixture of our lives that we did things together as a family. Holidays were always taken together we went out every Sunday afternoon and went for a walk things like that. So we were a very strong family. Maybe one of the reasons for that, is that as I say I was born with a severe hearing loss and right from the very

get-go my parents had to spend a lot of time with me taking me to hospitals things like that and my brother was also involved once he was old enough to start talking himself he was very much involved in the communication side of things. And one of the best pieces of advice my mother in particular was given when I was still a baby was to keep talking to me. So we always talked, you could say talked none stop, but communication was a big thing in the family.

And was that everybody?

Yes

They weren't all just talking at you, you were talking a lot as well?

I'm afraid so yes!

That's ok!

I mean, for example dinner times, you could say it was very traditional in some ways. But my father even changed jobs on some occasions to ensure he was home for dinner and that he didn't work on Sundays so that every dinner time we would sit down together as a family. And we would be expected to talk about our day and what we have been up to, ok my brother and I mostly limited to well we maths and double English and we hated it that kind of thing you know, but my father in particular has a very interesting outlook in life and he's a great storyteller and for most of my young life he worked for a company called Queensway which in fact were the first company to start opening regularly on Sunday and the money they used to make far outweighed any fine.

Sorry, what sort of business were they?

A furniture shop and because they continued to make so much money they then made it company policy to open up on Sundays and because of their actions leading to other companies following them that's the reason why in the country today we have Sunday trading hours.

So how did that work then with your Dad who had always made it a priority to be home on a Sunday, was that a difficult thing?

Very difficult thing. He basically had assistant managers. And he worked out the deals with his assistant managers that they would work on Sundays. He had to work occasional on Sunday but then eventually the pressure got too much and he the moved to a different, I think it was Times Furnishing, could be wrong. But the majority of times he was home on a Sunday and we would do things together, but then I know towards maybe late childhood, early teens that became more and more difficult and he'd been working on Bank Holidays and stuff like that. Which traditionally was a Monday so we just got used to it really.

So you're all sitting around the table, and you're say what 6? And how much can you actually hear, or what sensation have you got of what's going on around you?

Well, the best way to describe it is this, even though I had a severe hearing loss I wear hearing aids and even though they are nowhere near as advanced as what we have now they were enough that I was able to get quite good hearing or a semblance of hearing in my right ear, my left ear has always been very, very poor I can only hear low pitched sounds and em...from what I could hear, I could use the telephone in my right ear with the hearing aids in but em...but my parents particularly my mother spent an awful lot of time with me right from when I was a baby teaching me to lipread which was quite fun cos she always tried to remind me of the things she went through as a mother. You know all mothers do this they say "Hey do you know what I went through with you when you were a baby, the things I've given up for you" and all the rest of it, but then she explained it, this is what I have to do with you hours and hours every day.

[12:11]

And what did she do?

Well, she used brightly coloured balloons she'd blow them up and then she'd make you look at her and she'd say a word like, like balloon for example she would mouth the word pointing at her lips, so I'd be looking at her lips and then she'd hold the balloon against my cheek and then speak into the balloon and then I'd feel the vibration of the word, then she would point at her lips again and say the word till I recognised its shape and the b sound and that the 'l' sound, there's no real vibration from that and the 'u' sound, again, there's no vibration. But the 'n'

you can't really see, so I was actually getting 'balloo' if you like but then I've recognised that that shape I would hear that kind of sound and that it meant this brightly coloured thing next to my cheek.

So how did she know how to do that?

I don't really know because nobody ever taught her, this is something...I'm incredibly lucky to have my parents as my parents because my mum just sort of created these little exercises, nobody taught her what to do and she was just absolutely determined to do what's best for her little boy and of course when my brother came along she did exactly the same thing for him even though he could hear perfectly well

She taught him to lipread as well?

Well, no, she spent a lot of time with him, with his speech and in getting him to talk so here we're talking quite young...but she also wanted to make sure he wasn't feeling jealous. He needed to be included in what was going on so yes, that's how she taught me to lip read, and of course, when my dad was home, he'd also be speaking to me as well which is probably one of the reasons he's such a good story teller. So getting back to the dinner table thing, so we would sit 'round an oval table and...it was almost instinctive I suppose but it would be very rare that we would talk over each other and again, almost subconsciously, I picked up on the things my family did before speaking we all have a little "tell" if you like, that before someone...if someone's been sitting down and just eating, before they're going to say something they do a movement even if it's just raising their head or putting their hands down or something like that, they would do something and so I picked up on that so I would know, even if it was just out of the corner of my eye, that somebody was about to respond or say something so yeah, that's how we communicated around the dinner table.

So you are becoming like a very skilled communicator from a very young age then?

Yeah, but it was then also drummed into me that I didn't really have much of a choice because of school – school was pretty tough, let's put it that way. It was made clear that there were only two choices: either learn to lip read and try to appear as normal, if I can use that word, as possible or I can use sign language and not take a full part in society.

This was made clear to you by school, or at home?

Well, it was made clear by society if you like. My parents were talking about it right from a young age, maybe eight, nine, ten years old at that period when you become almost self-aware they were talking about – we had people who tried to teach me sign language and there was a lot of discussion about whether I should learn sign language or not, and my parents' position at the beginning was no, most people speak English, very few use sign language. They wanted me to communicate with the majority rather than the minority so therefore learn to lip read and do the best you can. I also have to say, again, that I'm very lucky that I've got the kind of brain suited to lip reading. I have the ability to concentrate, to quite high levels, for long periods of time, there are other people I know, who, how can I put it? They can't concentrate for as longer periods of time, and they find it far more difficult to lip read than I do, but because I've grown up with it, it's been difficult for me to understand that. Which is why, again, I'm lucky, because I was brought up learning to lip read quite comprehensively, and almost instinctively learning all of these different techniques just to get along, when I went profoundly deaf in 2002 I already had some core skills so that I wasn't completely lost in way.

[17:33]

Do you feel that they took the right decision for you to not learn sign-language?

In a way, yes, because I can lip read, and I can lip read well, when I left school I was able to get a job the fact that I had a hearing loss was completely irrelevant. When I was at school I had, the first school that I went to ----- school they had what was called a hearing impaired unit attached to it so they had a little place where there were teachers of the deaf who would liaise with the normal teachers there would be special classes run for the hearing impaired children. Because my parents spent a lot of time with me, my lip reading skills were slightly more advanced than the other children even though I had the worst hearing loss of that particular class or that particular year so consequently I was always getting pats on the head "isn't he doing well" and all the rest of it but then my parents would ask them, my dad in particular, he would ask the teachers, "so how is he doing compared to non-hearing impaired children?" And they always said, "you can't ask questions like that because he's hearing impaired, he's special,

a special child," so my parents then took the brave decision of taking me out of that kind of environment and putting me into a standard mainstream school with no special unit attached

At what age was this?

Eight years old, secondary school. And I had this 'communication support worker' I think she was called, who came in every week, next to useless, could barely understand what this lady said.

Why was that do you think?

I don't know. It was just, her lip pattern was very hard to follow. I have to admit, that after the first couple of visits I completely lost interest in what she had to say. So it's as much my fault as anybody else's. And then when I went to high school, I went back to a mainstream school with a hearing impaired unit attached because I did have some problems at my secondary school, I couldn't follow what was going on.

Is that just because it's so much bigger, or new subjects...?

Mainly because the teachers were unaware how to deal with me and I didn't have the skills or the confidence to say: this is what I need. I was only eight years old. So, when I went to high school we did have some very good teachers both mainstream and teachers of the deaf one particular lady who's name I've now forgotten, I can remember her first name: Helen,

It'll come back to you.

It'll come back to me, yeah, but she was very good at making sure teachers were aware of what they needed. I have to say, however, I was a completely and utterly useless student

In what way?

I'm not academically inclined, I'd much rather mess around, read books, than actually take part in lessons.

I'm not sure I'd call reading books messing around.

[Laughs] Well it is if it's more of a fiction book and you're supposed to be taking part in physics

Mmm true. So the teachers that were teachers for the deaf, so you went off to a different class..?

That's right, yeah, we had a special room for us to go into which was called 'the unit'.

The unit?

Yeah, I dunno why it was called that, but where some other students would have free lessons we would then go in for extra lessons and I don't think I ever had a single free unit the whole time I was at high school.

And how did you feel about that?

It was fine, because up until that time I'd never actually had a free unit so it wasn't as if I'd lost anything. But thinking about it, I'm beginning to see the extra level of schooling I did need just to receive a basic level of education. English, I was quite good at mainly because communication was a big thing and my parents were very good at speaking and grammatically correct. Every single dinner time, my dad, bless him, would fire questions at us saying: "what's seven times three?" and I'd say "forty-eight", "no, twenty-one" ok; but then he'd also do spelling contests as well, between my brother and I, which we'd also get wrong as well how he'd ever ---- I'll never know, but he'd always do things like that so, certainly when it came to English we were a bit more advanced. And because I found it easier to have my nose in a book than to make friends, my reading age was always slightly above normal. But the weird thing is with high school, I did mix with hearing and deaf kids, I never really had a big group of friends it was always just "oh I've got enough people, that's enough" I had about, maybe six or seven friends and that was all I really needed, the rest of the time I had my books so I was happy.

[23:42]

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So you said you found it easier to read than to make friends, is that because, I mean did you try

to make friends, or is it like you say, you felt you had enough?

I always found it difficult to make friends. And there was always the anxiety: "Am I going to

be able to understand what they say"

This is from what kind of age?

Beyond what I can remember really.

So always?

Yeah, so I would say always. There's always, even now, there's always an anxiety before I speak to someone, am I going to follow what they say, am I going to look stupid and it's that fear of looking like an idiot which restricted my social development if you like, I'm not saying I'm completely an idiot now, but certainly when I was younger, I always found it very difficult to approach people and say hello. When people approached me, because they were the ones to start talking and I've had that extra second extra of listening to them rather than them listening to me that always helped and by the fact that they've come to me that means they're definitely

interested. Imagine being a shy teenager, but ten times worse. I sound pathetic don't I?

Yes you do!

Thanks...

No not at all. And what makes the difference do you think, with people that you can understand ok and people that you can't?

Well, if I'm able to follow what they say I will then, I know it's going to sound terribly arrogant, but if I can't follow what people say, sorry let me rephrase that, if I can't follow what they say and I've made the attempt to say to them: "I have a hearing loss, I need you to repeat or rephrase or whatever" and I still can't follow, either because they have a very strong accent or they can't be bothered, then I in turn can't be bothered to spend any more time with them. I

know it sounds very arrogant but it's almost as if my ability to communicate with someone will decide what sort of relationship I have with them.

Because communication is important in any relationship.

Absolutely, yeah.

Have there ever been any people that you would really, for some reason whether its work or friendship or whatever, would like to have a relationship with them, but the communication is very difficult, so that's a frustration rather than just a 'oh well I won't bother?'

Yes. For example, my mother has recently remarried, and the person she's married to, Richard, is, I'm sure, a very nice person. I've only ever understood three or four words that he's ever said. And he has a strong Scottish accent and he has the inability to understand that he needs to look at me before he starts talking, and continue to look at me while he's talking. So, even though my natural inclination is "Well I can't be bothered if you can't be bothered." I have to make continued attempts because he's my step father if you like.

And how does that feel?

Incredibly frustrating! Because he's been married to my mother for almost a year now, he's been seeing her, if that's the correct term, for four years before they got married and I still don't know what this guy's like. I don't know...I don't know his background, I know he's got some children, he's been married before obviously, I don't really know where he's from, what sort of job he's done for a living, what sort of hobbies he likes, what his aspirations are, I know very little about him...even though he's now my stepfather.

And I mean I find that quite surprising because your mum has always been so into making sure communication flows. How does she respond when you and him are together?

I know certainly at the beginning she was, "Richard, you need to look at him...Richard you need to do this", I think she's given up as well, basically.

Because she's tired?

Yeah.

She's been doing it for a long time?

Yeah. She's an old lady, bless her. No she's not. I think all of us, we're all human and with the best will in the world, even if you work somewhere as wonderful as Hearing Concern Link, see I said it right this time, and even if you work somewhere like this place and communication is ingrained in the very things we do we still slip up, because we're all human beings, so even though I still don't know very much about Richard, I won't be giving up, I will still, every time I see him say to him "you need to look at me, speak a bit clearer, speak a little bit slower, try to lose that ridiculous Scottish accent considering you haven't lived in Scotland in a very long time"

In your opinion then, what do you think it is about people that make them not communicate effectively with someone like you who has a hearing loss? What stops them, even when they've been told, doing it better?

Fear. Especially...it's the age old situation – if it's something you don't know, or are unsure about, rather than look an idiot you will try to walk away from the situation or avoid it completely. And it's exactly the same situation as when you're talking to someone in a wheel chair or you see someone in a wheel chair that needs help. Unless you know exactly what to do, you would rather walk past that person, rather than asking if they need any help because you would be afraid of either giving offence, or looking stupid yourself and I'm sure that's the same reason about not really doing communication properly with people who have a hearing loss whether they've been explained or not. That's one possible answer. The other possible answer is laziness. We are all lazy people, if there's an easy situation or solution for anything we will use it, it's that simple. Without making it sound as though we're living in an absolute hell of an age, people have gotten used to lazy communication. Even if you're having communication between two people who can hear perfectly well, it's very rare that we actually look at each other, we always have...we're living in a very fast age so people want to talk as fast as they can to get the information out and...I'm not against America, but America has a lot to answer for, in that they use a lot of phrases that are a hindrance to good communication, such as the word "like" or "know what I mean" so all of those sorts of things are frustrating if

you like. But they do lead to breakdown in communication or make it more difficult. In my humble opinion.

[31:26]

So, your opinion is very much wanted today! Just, if I can just go back to thinking about this lovely family sitting around the table. First of all, can you tell me about where you lived, just so I can picture where you are?

Ok, sure. I was born in Bushey Heath, but then my parents were told, they were talking about future education and things like that and they were told that the only school suitable for me at the time was a place where they sent mentally ill people, it was a mental institution. My parents thought "we're not having that" so they moved to a different borough of London called Pinner and because we moved to a different borough we were under a different sort of NHS system and my parents were brought into contact with a doctor called Dr. Bickerton who was a pioneer of deafness issues, if you like, in the early 70s. And I believe she was one of the people who came up with the idea of having a hearing impaired unit at schools and she was always banging the drum about getting proper equipment, proper services for children, for deaf children. Anyway, so we were living in Pinner, which at the time was a very white neighbourhood, a lot of Jewish people living in the area, my mum's parents lived in Stanwall so we were quite close to them, my dad's parents had just moved down to Seaford on the south coast. Yes, it was a nice little house, a semi-detached, tree-lined road. We had a very strange road, I've never seen this kind of road anywhere else. It's your standard row of semi-detached houses on a slight incline, a slight hill, but at the top and the bottom the road split into two. To curve round an island, I've never seen a traffic island in the middle of -not a main road- a small residential road, it was very bizarre. But on the middle of this island we had some very big trees, or they were big to a little kid so instead of having to spend ten minutes walking down to the nearest park, I could play, with my brother and other small children living in the area, literally outside my front door, it was fantastic.

So did you live in Pinner until you left home?

Not quite, In 1988 my parents, my dad, got a better job down in Brighton. So we moved down to Saltdean, which is a bit further away from Brighton and at that time I'd just left high school

and then I went to college in Brighton. My brother was half way through his high school, but he was just like me, not exactly academically gifted, so giving him the opportunity to go to a better school, well, he used to come home with some fantastic stories. One story in particular which I think perfectly encapsulates my brother, he's a very, very, very bright guy, I would say he was a genius, we don't know what IQ he's got because he cheated on his IQ test

How can you cheat on an IQ test?

Well he got a well below average score, and there's no way he would have got that

Oh you think he made himself look not as clever? Oh right that's interesting

Yeah, absolutely. That's how clever he is, he knew that if it was proved how intelligent he was then better things would be expected of him.

I see, sneaky!

He's a very clever guy. But yeah, he, when we were both in high school he went to a high school much closer to where we lived than I did. I had to get a bus which was a fifteen, twenty minute journey away, and he only had to walk maybe five, ten minutes away.

Is that because you went to a school with a Deaf unit?

Partly, yes. I think also, I could be wrong, but I think when it was time for him to go to high school maybe there wasn't a place at mine. But anyway, my dad realised one day that every single day I was coming home half an hour before he was even though he would go to school much closer, so when he asked him he said, "why were you late home today", "I had detention", "what about the day before?", "I had detention", "what about the day before?" "detention" "do you have detention everyday?" "Yeah" "Why" "Things aren't working out" Apparently he'd had one of his teachers say to him "You haven't handed in your homework, that's terrible, you're having detention tonight", he said, "I'm sorry sir, I can't fit you, I can't have detention tonight because I'm already doing detention" "Well, you're having detention tomorrow" "No sir, I'm sorry I've got detention already from Mr. Jones." "What about Thursday?" "No, sorry, doing detention for Mr. Smith." "Well, this is ridiculous!" "Yes, I

know" And he gets out a little book which shows him which classes he's got on which days, starts flipping it through and says: "I can fit you in in two weeks time"

That's brilliant. What a cheeky guy!

But then of course, once he left school, that was the time we found out he'd got dyslexia, so as well as being incredibly bright, so therefore bored at school, he was dyslexic.

[37:31]

Right. Can I ask you more about your brother and your relationship with your brother?

Because you were obviously a close family as children. What was your relationship with your brother like right up to the present day?

Well certainly when we were children he was my younger brother, so his prime role in life was to irritate me. As my prime role was to bully him, that was our relationship really. However, having said that, we were close, we played together, and he had his own friends and went off and played with them, as did I and went of a played with mine. If I look at other families I wouldn't particularly say that we were necessarily closer than other people are with their brothers and sisters, but I would say we were close. Not really much more I can say about that.

And do you still see each other now?

Well, not as often as we would like. He now works and lives in Brighton, and he keeps himself very much to himself, he's a very private person for reasons that would take too long to get into now. And, whenever we do see each other we always have a fantastic time, because he's so sharp, he makes us all laugh, he's so quick, but at the same time when he's having a conversation with you he's already seeing how this conversation's going to go, three or four minutes down the line. So if there's anything which he doesn't want to disclose then he will change the conversation way before it gets there. He's a very private person, but as long as you don't try to find out what's going on in his life, he's a fantastic person to have with you.

So he tells you the things that he wants you to know. So you still spend some time together in combinations of your family?

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Yeah. I would say I see him two or three times a year

In a family, so like with your Dad or is it just the two of you?

Usually with my dad or my mum for example. Last year I saw him a total of four times in one year and that was only because my mum got married and my dad's mother died. So, if those two things hadn't happened I probably would have only seen him on his birthday and my birthday or my dad's birthday or something.

[40:08]

Okay just before we have a little break, can you describe for me some of the kind of hearing aids that you had growing up as a child, what they were like, things that were good about them, things that were bad about them?

Ok, now when I was growing up, certainly with the first few hearing aids I had, you've got to remember this is the 1970s, it's only thirty years ago but it's like prehistoric compared to what we've got now. Don't forget, personal computers weren't invented in those days so everything was still on a big scale. Now if you can imagine a child maybe two years old, think about how big that baby is; we didn't have what we call "behind the ear" hearing aids in those days we had a little box which was, on an adult, strapped to a belt. On a two year old child it covers the entire chest area.

What it hung 'round your neck?

Well, I had this little strap so I put my arms through and then it was tightened round the back. But because the back of it was made of metal, which was freezing cold, even during summer time, so I always had to wear a vest I looked like Rab C Nesbitt, the whole time.

So you had a vest and then the box over the top of the vest?

Then the box over it then I had these two little wires coming out the top which came into my ear moulds and these were huge great things, there was no way you could avoid seeing them,

even though it was the 1970s so I had a 70s hairdo, really, really funky sort of curly hair which covered most of it, but they were so big, they stuck out so much you could easily see them and the wires as well.

So the bits that went in your ear were quite big?

Yeah.

In which bit of your ear did they go?

Well they went into the centre part of the ear, but then they covered most of it. It was about the size of a two pence coin

Right.

Imagine a two p coin, but a cylinder sticking out of your ears, then attached to sort of beige wires going down to a beige box, that's what I looked like, up until, I've got a feeling I was sort of nine or ten years old before the first behind the ear ones came out, or rather before they were powerful enough for me to be able to use them.

Right. So how did you feel then about this box?. Obviously it was cold. Did it get in the way of doing things?

Well, it did. Certainly I don't have any recollection of wearing it but my mother told me that certainly at the beginning I was forever knocking the wire, it was coming out but there was nothing you could do apart from pick me up and stick it back in again. I didn't, apparently, object to it that much because I was a baby. But the sensation of sound, and it was meaningful that I had it in, so my parents were always constantly putting it in. I do remember having ear moulds made, mainly because when you have ear moulds done they squirt into your ears like plasticine, obviously cold and then it sets hard and then they take it out and they've got an impression of your ear. Well, they always made a bit too much of it and they gave it to me to play with and that would keep me quiet for a while, and I used to make all sorts of shapes and weird things, it was very clever.

That's good and does it harden then? So you could keep whatever you'd created.

I could keep it for a while, but then it started to smell, it would be discretely "lost" on the way home somehow.

So the behind the ear ones. Can you remember what age you were roughly when you started wearing those?

I think I was eight or nine. About that kind of age. So we're talking sort of, yeah about, 79-80, that kind of era, when they were certainly powerful enough for me to use. And that was great, because I didn't have to wear this vest anymore. The weight loss was huge as well. The only problem was a whole new set of problems because when you're a kid your running around screaming and yelling doing all these kind of things so quite often they would fly out.

And did they get broken? Or was it a case of putting them back in?

Occasionally. Again, because I'd had all this equipment with me from a very young age, my parents always telling me to be careful, I then was conscious that I couldn't be as wild as I wanted to be. So I was always...if it was a hot day and there was a water fountain in the street, I knew I couldn't play in that because I didn't want it to get broken. Sounds terribly depressing doesn't it?

Well no. But it's interesting. So you think....

Well I've always had this knowledge that I have to be careful with my equipment whatever it was, again, that's as early as I can remember. I had this...not fear, but I always hated being told off for when I was doing something wrong or something had gone wrong and it was my fault or whatever I always hated that, even now, I still do. But, that I suppose made me make sure that I looked after my equipment so therefore it wouldn't break so therefore I wouldn't be told off

And do you still do that now?

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Yes, even if it's raining for example, I will take my hearing aids out, put them in an inside pocket just to make sure they don't get wet

Really? And is that something that everyone would do?

I would assume most people would because if any water gets inside your hearing aids then they break down, you can't use them and you have to wait for them to dry out which could take several hours because your not allowed to put any heat source near them otherwise the plastic will melt.

Gosh. It's a complicated business. Shall we stop for a break.

[End of Track 1]

[Track 2]

So we've talked quite a lot about your early life, about your home life and your family relationships and school we talked about three different schools that you went to.

Yes that's right

So then when you were sort of sixteen, was that when you moved to Brighton?

That's right, yeah.

OK, and then do you want to tell me about your education from then on?

Right, well I went to Varndean Sixth Form College.

Which one?

Varndean

How do you spell that?

V-A-R-D-E-A-N [correct spelling VARNDEAN]

Oh, OK.

Which is in Brighton. And that was a very strange time for me because I was a teenager now, I'd completely left the area in which I'd grown up, gone to a completely new area of the world and it was almost like a fresh start. So moving into a new area, a new school, I was then determined to change some parts of myself I didn't like.

Which were what?

I wanted to be more sociable. And I was always told that when you go to college and then on to University you meet so many new people and it kind of defines you as a person and all that, so

I was determined to start again, get everything right this time, make lots of friends and have a good time.

What did you felt that you'd done wrong?

Well I was, it's in my school reports, "Andrew needs to make new friends, Andrew is too quiet, Andrew spends too much time reading books" and even though I was quite happy with it at the time, I thought to myself, as we made the decision to move down to Brighton, that perhaps I ought to do something about it

Did you feel that in yourself, or was it just a response to what other people were saying?

It was just a response to what other people were saying. I'm one of those sort of people who I am perfectly happy with other people chatting away, and equally I am perfectly at home with my own company. If I have a day at home with nothing to do, I'll be quite happy reading a book or reading a paper or going out for a walk, it doesn't make any difference to me. But, I think, when I moved down, I had this...almost an urge to try and see what else was out there because it was all new, new town, new city nearby, so I had to make new friends. So I had no old friends at all, so with that in mind, I was determined to make lots of new friends and try and not be so closed, if you like, to new opportunities. So when I went into College I had to retake my Maths GCSE, which was understandable really, I have to I was in the first year, when the GCSEs came out, one of the guinea pigs.

Oh really?

Yeah, one of the reasons why I did so bad. But yes, I had to retake my GCSE in Maths and then I did Art, English and Computer Science A-Levels. Partly because I'm, again, still not academically inclined, I didn't do very well. Also, I didn't have any communication support, but we didn't know that these were the sorts of things we should ask for, and this is also pre disability discrimination act, so there was no requirement of the college to provide anything for me in the first place.

[03:59]

So knowing what you know now...

Yeah.

What would you have liked to have been in place then?

If I was at college now, I would say that I would need a note taker, or "swifty??" text, or I'm sure I would have asked for extra tuition. So one-on-one tuition every so often, just to make sure that I know what's going on, because it wasn't until end of year exams and things like that, that I realised just how much I'd missed. So, and of course my dad would say that I just didn't concentrate...

Your parents sound like they were quite hard on you.

They had to be! I'm a lazy whatsit. So, they needed to push me, they were doing it for all the right reasons. They knew I had to be twice as good as anybody else just to be equal, and that still applies today, that still applies today in that I have to work twice as hard as anybody else just to be the same, or to be treated the same way. And so my parents had to push me, and there was no question about it. But one of the good things that did happen at College was I did become more sociable, I learnt all those little things that you do so that you get to meet people and so on. I joined the amateur dramatics group, fantastic time there! Really, really good time. I can remember when we finished the first production I was the prop manager and I also helped out with the lighting and the writing of the scripts and helping the actors with their lines and, I did all sorts of different types of things. I'd never had so much fun, but it had an unexpected side effect: that I became friendly with so many people, I had thirty, forty people I can say, I can go out with, have a good time with, which was unheard of, before, at the most it was six or seven people. So that was an amazing time for me.

That was a good move.

Oh yeah. One of the funniest things, one of the funniest side effects was I was introduced to alcohol.

Uh oh. This was at age...?

I think it was at seventeen this particular event happened.

Ok, so nearly legal.

Mmm...not quite, but let's put it this way: I'd always stayed away from alcohol because I knew that if I started drinking I would not be able to concentrate, so if I can't concentrate then I can't lip read. So, from an early age I avoided alcohol, I didn't particularly like it anyway. I also have to mention that I was brought up Jewish, so that on most of the traditional holidays and Sabbaths and things like that, we had this particular wine that you have to drink which was absolutely vile so as soon as I was able to I swore to myself that I would never drink wine, which I've kept to this day. But at this particular event, we'd just finished the run of the production and it had been a great success so a whole bunch of us then went off to the pub, and the older looking students brought round the drinks. Before I could say "I'll have half a pint of coke", they brought me half a pint of bitter. I went "Oh", "What do you want to say 'oh' for?" I didn't want to say I couldn't drink alcohol because I didn't want to look stupid in front of my new friends so I said "I've never had bitter before", "oh try it, you never know, you might like it". So of course, up until that time I'd only ever drunk soft drinks, I didn't know you were supposed to sip these things, and I was thirsty, so I knocked it back in one go. And I went, "yuk, that wasn't very nice", "what else have you not tried?" they said. "I dunno, what is there?" They said, "have you tried lager?" "No", half pint of lager. I was still thirsty, knocked it all back.

Oh dear.

Beer, ale, all these various things. So by this time we were all getting quite merry. So they tried to ply me with various drinks, and I'm just knocking it all back. So we started on the bottles on the top shelf, I'll have one of those, one of those and one of those. The evening passed very quickly, I have no remembrance of the rest of the evening except that we were all very happy. The following morning I wake up on top of a double decker bus at the Shoreham Bus station. No idea how I got there, still don't know to this day. But I can assure everybody that I do not drink on a regular basis

Not anymore.

No.

[09:03]

You mentioned a bit about being brought up Jewish, can you talk a bit more about that and how important or not it is to you?

Well, thing that's quite interesting is at the beginning, I hope of got this right, my parents reformed, and I think it was decided we would join a liberal synagogue because then it would be easier for me to follow what was being said as they tend to use more English, they tend to speak in English rather than Hebrew all the time.

This is your whole family, so your mum and your dad?

My mum and my dad, yeah.

Ok.

Because my mum comes from a Jewish family, and my dad's family, my dad's father was Jewish but not very religious, my dad's mother was Christian. They didn't really bring their children up in any particular way, my dad's older brother and sister were brought up kind of Christian. But my dad and his next eldest sister, Cindy, when they were about seven or eight years old, that kind of age, my nan was finally converted to Judaism, and then so my dad was brought up Jewish. So he'd been brought up Christian and Jewish...very confusing. But there's a funny little thing we found out recently, my father and several cousins had got interested in family history, and we, when my nan passed away last year, came across a whole load of documents – Wedding certificates, things like that – and my dad's always been told that his parents got married in 1932, no sorry, 1931, and my dad's eldest sister was born at the end of 1932. Well when we found the wedding certificate, we found out actually, my parents got married in 1932, so my Auntie Joan was actually bor- actually conceived, out of wedlock. Shock horror! And that is apparently one of the reasons why it took my nan so long to be converted to Judaism, partly because if you want to be converted you have to apply to this religious body called the Bethdin, that B-E-T-H-D-I-N, and, because obviously, you can't

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actually admit that you've conceived a child out of wedlock, when my grandparents first applied, we've still got the piece of paper, the form they filled in, it's got a copy of the marriage certificate quite clearly stating that they were married in 1932, and it's got my dad's brothers and sisters, but not my Auntie Joan on it because otherwise that would be damning

Poor old Auntie Joan, is Auntie Joan still alive?

She is, she emigrated to Australia when she was 21.

So has this news been broken to her?

When we knew about it, I believe so, yes.

Ok.

evidence.

Obviously she knew about it because she was old enough. But yeah, she emigrated to Australia when she was 21, with a man who my grandparents never approved of. In fact, my grandparents were with my brother-no sorry, my dad and his sister Cindy, they'd gone for a week's holiday in Torquay. Meanwhile, my Auntie Joan was getting married to this guy they never approved of, had a street party, all the neighbours and everybody else was invited, and then when the whole family came back after the holiday, the sister has moved out and is living next door with her new man!

Fantastic! Your family's wonderful

So many of the stories of our family are fantastic

So your upbringing then, you had this close knit family

Uh huh

Around the table

Yeah

And the Jewish faith was strong through all of that

Mmmm, we nodded our head towards it, put it that way. We did celebrate the Sabbath, my mum did tend to do the roast chicken and the blessing of the candles and things like that. And on religious holidays, went to a synagogue, stuff like that. But when we moved down to the Saltdean area in '88, the nearest synagogue was in Brighton and it was a very different synagogue to the one we were used to. When we were living in Pinner, we belonged to the Northwood and Pinner Synagogue which had a congregation of what seemed like thousands of people, in fact on religious holidays we had to go to Wembley Town Hall because that was the only one that could fit us all in. In contrast, when we went to Brighton there was hardly anybody there, most people were very old and we didn't really feel like we belonged to it, so for one reason or another, we kind of lapsed as it were. Also by that time, all of us for various different reasons, were not feeling particularly religious. As we were not part of a big community we didn't really observe all the holidays and things like that. I confess I started eating bacon.

And how was that Andrew?

Lovely, oh my god!

Can you remember the first time you ate bacon?

Oh yeah! It was fantastic. Bacon butty...I was out with some friends and they all went to a café, bacon butties all round and I thought, sod it I'm gonna have one.

And apart from the actually feeling from eating the food, I mean, were there any emotional feelings going on there? Did you feel guilty?

Surprisingly not, no. I always knew that the reason you shouldn't eat bacon was because pigs were supposedly dirty. But even from when I was at Sunday school I used to argue with the Rabbi and say "look this is ridiculous, it's perfectly healthy, they're kept clean and all the rest of it" and he'd go, "yes but these are the rules" and suppose that if you are going to be religious

you have to accept all the rules, you can't sort of pick and choose. And because I had questions about Kosher rules, questions about certain elements of the Old Testament or the Torah, if you can't accept the whole thing and believe in it and be faithful to it then you can't really follow it. Of course Judaism, there's the other aspect, in that it's also a race as well as a religion and there's a certain culture surrounding it. I still appreciate the culture even though I don't necessarily appreciate the religion. I'm still picking and choosing I suppose.

[16:41]

Yeah well that's ok. So when you moved to Brighton remind me how old you were?

I was turning 16.

Ok.

We moved down in August and I turned 16 in September.

So that's the kind of time when you might have been think along these lines of "what do I actually believe in" and that all kind of coincided with your family deciding they didn't feel strongly enough to go to this different kind of Synagogue.

Absolutely, yeah.

Ok right. So you were ok with that were you?

Yeah.

It fitted in with your plans?

Yeah my plans for world domination.

[Laughs] Ok, so you were at college in Varndean, and what about your friends there – oh your amateur dramatic friends –

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Amateur dramatics, and I did lots of other things after college as well, and built up quite a large circle of friends. But the nice thing is, once college finished I was still in contact with quite a large number. And even now, and it makes me shudder when I say this, but twenty years later,

I am still friends with three of them. Twenty years later, oh my god I'm an old man!

That's fantastic. And what are those three people's names?

Michael Saunders, Nick Harman and David McGonagall.

And they all live in Brighton do they?

Michael is, he moved to London funnily enough, because he wanted to train as a psychiatric nurse, which is what he does now. He's been doing that for ten years now, and currently he's on a beach somewhere in southern India with a girl he's met who comes from New Zealand.

Wow.

Fantastic

[18:31]

Good, ok. So we're kind of moving towards the time when you had another change to your hearing.

That's right, yes.

Are you ready to start talking about that?

Yeah, sure. The situation was, this was 2002

So you were how old?

Thirty years old, I was general manager of a jewellery store in Brighton, it was an independent chain, only three stores. I say I was a general manager, I'd actually been promoted from

running my store to just sort of a general running of the business. It was a small business and we didn't really have titles as such so I just made up the title gra- general manager.

Grand manager you nearly said there

Freudian slip! Oops. So yeah, I did all kinds of things like the administration, the banking, but also designed the website, ran it, did the online shopping. I supported the two managers we had of the two different branches in Brighton and I did my bit for the one up in Yorkshire, I did all sorts of different things, it was good, good money. I had my own little flat in Peace Haven, which was half way between Eastbourne and Brighton, and I was having regular holidays, good social life, a large circle of friends. I would say there were about fifteen twenty people I used to go out with on a regular basis. I used to go up to London at least once a month to see my friend Michael, and we'd invariably go to the West End theatres, because we discovered the half price ticket booth. So we'd stay over at his place overnight and we'd get tickets to go and see whatever show, up in the gala somewhere so it'd be really cheap. Saw *Les Miserables* and all the rest of it, and used to love going to the Cinema, I'd go to the pub occasionally and have a Coke – I have to stress that I wasn't drinking. Yeah, I had a decent life and in May I met a girl and started going out with her, life was pretty good.

Just remind me what your kind of hearing level was at this time?

Well at the time I still had a severe hearing loss in both ears, and I was wearing hearing aids in both ears. But in my right ear in particular, I was able to hear, with a hearing aid, quite well. I was able to use a telephone, I developed this weird knack, and it is very weird, I thought it was perfectly normal until I started talking to other people, and they said "that's weird". What it is, is I can visualise someone's face when they're talking to me over the telephone and of the sound that's coming in, I will be able to comprehend maybe 50% of it, but I'll at least be able to tell what the sound is. And I can then visualise what the lips must look like to produce that sound so therefore I then lip read the visualisation of someone talking.

I can see how that would follow from what you were saying about the things your mum taught you

Exactly, yes.

So the vibrations of what you're hearing

Yeah

Translate into what the lips look like

Yeah

That's quite interesting.

So I kind of had to lip read over the telephone, if that makes sense. So anyway, with my hearing aids out, you could scream in both ears and I wouldn't be able to hear a dicky bird. So that gives you an idea of just how good the hearing aids were. So with good hearing aids, good lip reading ability, good awareness skills, I was able to "function", if you like, in normal society. Then on the first of June, 2002, I woke up, put my hearing aids in, and couldn't hear anything at all in my right ear. My left ear was still perfectly fine, but my left ear I can't rely on because it's so poor, even with good hearing aids, and that's still the case today. So my right ear, for some reason, was not functioning at all. I changed my batteries, still nothing happened. You know when you've been flying, you go on a plane and the pressure changes, you blow your nose, clear your throat or whatever to try and change the pressure in your ears well I did the same thing. My next door neighbour must have been wondering what was going on because I was making all the weird noises, started banging the table, things like that. I knew my left hearing aid was working because I could hear things through that ear but nothing was coming through my right. So I used my spare hearing aid and that still didn't work, so I thought to myself, oh I must have something wrong with my ear, since there's nothing wrong with my hearing aids, so therefore I need to go and see a doctor. So I went to where my phone was and found that my balance had gone because I fell out of bed, stumbled. It was almost as if I was standing up right, but my ears were telling me I was leaning over one way or the other. So it wasn't necessarily as though the room was spinning, it was just what I was seeing didn't correlate with what I was feeling. So I then went to the telephone, picked it up and started dialling my doctor's number. Then I realised I was being a bit stupid because I can't hear, so I put the phone down and thought what am I going to do next?

So you wouldn't have been able to hear with your left ear on the phone?

No. No, with my left ear I can only hear low pitched noises. I can tell when people are talking, but if it's a particularly high pitched voice, it wouldn't even register, so it's not enough to be able to distinguish even between various words. So I depended purely on my right ear, which was the ear that wasn't working. So by this point, I was starting to panic because I'm living by myself, what do I do? I can't ask somebody else to ring the doctor for me, I think it was a Friday, and I was due to go into work, and it was my responsibility to open up the shop, turn off the alarm, get the shop ready for the day. So I thought, I better ring my boss to let him know, ask him if he can come down and open the shop for me, and I can go straight to the doctors. So I picked up the phone, and started dialling. Then I thought, *you're being stupid again*, and put the phone down. So what am I going to do? I thought that if I went into work and waited until the staff came in, I can get them to ring my boss, then go to the doctors. Sounds logical, so that's what I did. Got dressed, went to the bus stop.

Was your balance still very bad?

Still very bad, so I ended up having to run my hand over the near wall when I was indoors. I was in the first floor flat, so that when I went downstairs to go to my front door, I came downstairs a little bit quicker than I was expecting to...ouch. So I had a nice collection of bruises before I left my front door. So I then walked to the bus stop, by this time I was able to try to ignore what my ear was saying to try and concentrate on what my eyes were saying and also I was holding onto a wall where possible. Got to the bus stop, and of course if you go to the bus stop on a regular basis, same time, same day, day in day out, you get to meet all the other people who do the same. And I had to say, straight away, "I can't hear what you're saying so please don't talk to me", and all of them, without exception, had a weird expression on their face and I realised I was shouting, even though I couldn't actually hear my own voice.

Right.

I'm just going to blow my nose. Thank you.

So, I then got onto the bus and I had this weekly ticket so I didn't need to say anything to the bus driver, and then I discovered something really cool. I'm on the bus, I can't hear anything,

so I can't hear all those other people talking. I was actually able to read my book in a bit of piece and quiet for a change, so that was rather good.

But did you really feel that calm?

I wasn't calm, I was rather panicking, so it was good that I was able to have a bit of piece. That's the way I was looking at it, rather than keep thoughts running through my head about "what am I going to do", because I had lots of work to do that day, what's my boss going to say? Am I going to be able to get an appointment? What's wrong with my ear? Is it only temporary? Or whatever, I was able to just, because I couldn't hear any sound, I was able to block it all out and concentrate on reading my book, that was fine. Got into work, had another mild panic because I couldn't hear if the alarm had gone off or not. And it was only the absence of anybody, any big burly police force coming in through the door that actually reassured me I had turned it off properly. Then I waited, I think it was an hour, until the staff came in, they rang up the boss, they asked me lots of questions which I couldn't follow so they wrote things down for me, which was good. Got on the bus, went back home, because where I was living the doctor was just round the corner. So I had to go on a half hour journey on the bus from my home all the way into work, stay there for an hour, then come all the way back and walk round a corner for five minutes. Anyway, the doctor was somebody I had never had occasion to go and visit. I had registered with him because I needed to be registered with a doctor, but I'd never actually visited him because I'm not someone who actually likes going to doctors. And he reaffirmed my belief that GPs are useless because he had no communication skills whatsoever. When he came in, the nurse I have to say was excellent, because the nurse came and got me when it was my turn to be seen, and they made an appointment for me there and then because I said "I'm staying here until I get an appointment". So when I get into the doctors, the doctor spends maybe 30 seconds looking in my ears, then he writes on a piece of paper and indicates it's time for me to go, that was it. So I'm looking at the piece of paper, and it's some antibiotics, so I'm thinking he must think I've got an infection. It's a two week course, so I then go round to the pharmacy, get my prescription, go home and then I think, now what am I going to do? I need let my boss know what's going on. Fortunately at this time my mum was living a 15 minute walk away from me, so I went round to her, she was in, I explained what had happened, she was rather worried for my sake. She rang the doctor and got a full answer from the doctor and the doctor thought I had an infection. Stay off work for two weeks, come back and see him. So the next two weeks were the most boring weeks of my life,

mainly because I couldn't hear anything I couldn't go out, couldn't make any phone calls, couldn't arrange to meet anybody.

[31:17]

And what's going through your mind through those two weeks?

What's wrong with my ear? Why isn't it working? Is there a blockage? I've had an infection before, but usually when I have an infection it's all red, it feels painful. But there was no pain there, there was nothing visible to say anything was going on. So I took all the antibiotics and kept myself busy by reading books, tried watching TV. I don't know if you've ever watched daytime TV with the sound off and subtitles on...Richard and Judy was the program, daytime TV, they were the king and queen of daytime TV. With the sound off and subtitles on they are utter gutter trash

[Laughs] Some might argue, Andrew, that with the sound up and the subtitles off they are also that.

Right, but with the subtitles, because it was being shown live, the subtitles were always 4 or 5 seconds behind, which may not sound that much, but then what comes up bears no resemblance to what's happening on the screen and the technology is not that good, there are spelling mistakes, it's just totally and utterly bizarre.

Did you use subtitles before that time?

I did, yeah. Because it makes it a lot easier to follow. So they were two very boring weeks, I didn't see anybody. I had a lot of trouble cooking because, I love cooking, I don't cook baked beans on toast, I cook proper food, I love oriental like Malaysian, Thai, Chinese, Japanese. But I found that when I was cooking I was burning things, I couldn't hear the pans whistling and stuff like that. And going shopping was horrific because since I went to college I've made the effort to become a very sociable person, so when I went shopping normally there'd be people who I'd be bumping into who I'd say, "hello George", have a five minute chat and then get on with my day. People kept coming up to me, and I kept having to say "I can't hear what you're saying" or people would be behind me talking to me, then they'd tap me on the shoulder and

they're shouting at me because they're angry I haven't heard what they've said, and I'm going "I didn't hear you, I didn't hear you." I'd explain, then they'd calm down, but still, when someone's shouting at you for no apparent reason it's not very nice, especially if you can't actually hear what they're shouting. All you can see is this angry face and spittle in your face.

You sound like you reacted quite calmly to them, is that really how you were? Did you feel calm?

I was living in a total state of panic and anxiety, and because of that I couldn't react to anything. I would then, for example when I went shopping three or four days later because I ran out of food, I'd have these things happen, then I'd get home and the shock would set in. Then I'm angry and frustrated and I'd, I wouldn't say cry, but I'd be extremely upset for a while, which made me then very keen not to go shopping. In fact my mother and my dad both did some shopping for me because I wouldn't go out. The only times I went out were when I went out for a walk. You can only sit down and watch TV for a certain period of time, and I don't like doing nothing, so I used to go out for a walk everyday to get a bit of exercise and a bit of fresh air. Peace Haven's got a nice long stretch of grass, it's got a cliff with a lovely sea view, so I used to go out for a walk so long as it wasn't raining. But that was the only time I went out, the rest of the time I stayed in, I kept myself to myself. Of course, after the event, much later, I found out people had been trying to contact me, they'd been ringing me up, or trying to invite me out that night but I hadn't heard the phone ring. People had come round to my flat and rung the doorbell and knocked on the door, but of course, I didn't know. So, well in fact, my parents arranged to come and see me, we had made arrangements about exactly what time they would turn up. So I would then have to sit at the bottom of my stairs looking at the front door, waiting for the shadow to come across it and that would be the only way that I'd know that they were there. So that was two weeks of boredom and hell.

And not seeing any change in your hearing?

[36:36]

None whatsoever. So after the two weeks, this time with my mother

Sensible.

Yeah. I mean, I'll try and get something across, I'm thirty years old, I'm a very independent person. I'm now having to have my parents cook and do the shopping for me and come with me to the doctors, that's a very big step back. We were talking earlier on about how my parents were always pushing me to do my best and here I am, back to square one again.

And what did that feel like?

Horrible. I felt as if my identity had been stripped away. Like I was a little baby again. Anyway, we went back to the doctors again, the doctor said –to my mum- there's obviously no infection, you may have a blocked ear. So go away, have these drops in your ears and they'll fish out any wax...which was a total and utter waste of time because if there was any wax in my ears he would have been able to see it, and the fact is there was no wax, he'd just run out of ideas. So my mum contacted work and let work know, and I have to say my boss, Andrew Bird, was really very good about it. He gave me the time off that I needed, and I had another week of shear boredom and hell, and by this time I'm wondering what my friends are all up to, so I write to a couple of them saying this is what's happened, and a few of them do respond, which was very good of them. So a week goes by and we go back to the doctor's. This time I am beyond panicking, I am scared that I'm not going to get my hearing back, that I'm not going to be able to go back to work, not going to be able to have a life again. This time I'm seen by the nurse, the nurse takes one look in my ears and says you haven't got any wax in your ears, what we're going to do is send you to hospital. So I was then referred to the Royal Sussex in Brighton, this is towards the middle of June, similar sort of weather to what we have now: very warm, about 26 Degrees. And I've gone in to the doctor first thing, got sent to the hospital and we're there about 10, 11 o'clock in the morning, seen by the triage nurse and I'm hooked up to a drip, told to wait in the corridor because they're going to try and find me a bed in the audiology department so they can then observe me.

Are you with your mum at this point?

My mum is with me, she makes various calls. My boss, bless him, he comes into the hospital to see how I am, which I was really appreciative of, that's one of the advantages of working for a small company, the boss really does take care of his staff he was absolutely superb. One of my friends, Ian Brockwell, who was living just around the corner of the hospital, he popped in to

keep my mum company. Then about eight hours later, I was sitting in this very hot corridor, attached to a drip with no water and no food, I become severely dehydrated.

Do you know what the drip was?

No. My mum told me that it was because they think if I'd had an infection of some kind if they hooked me up to a drip then it could kind of flush out any infection that was in there. That's the thinking behind it. The fact of the matter is I wasn't attached to the drip properly, or it wasn't running through enough because I got severely dehydrated, so much so that the fluid which you have round your eyeballs, there wasn't enough there so my eyes because ultra sensitive to light and I couldn't open them. So I was sitting there completely deaf, and now I'm going completely blind because of their incompetence. I thought I had panicked before hand but this was just beyond unbelievable. I can't recall personally what happened, but my parents- my mum- told me later that I'd gone completely berserk. I tried to run off down a corridor somewhere, I didn't get very far because A) I hit a wall and B) The drip thing fell over. I was restrained by some nurses and given bottled water to drink. They then found me a bed, an emergency bed, and I was put into it. Now I was given water to drink, 2 litre bottles, and I was drinking the whole thing in one go and demanding more, and I was like this throughout the whole night and of course some of the water then managed to go through my system so I was desperate to go for a number one, but I would still need more water. So I was like that apparently up until about 3 or 4 in the morning. Drinking and weeing constantly before I finally managed to go to sleep. About 6 or 7 o'clock I was woken up by the doctors saying how pleased he was to actually find me, because I had been put in the Urology ward instead of the audiology ward.

Oh my goodness.

So he said, "we're going to take you to the eye hospital part of the hospital, we want to make sure there's been no permanent damage to your eyes". I'd gone in there because there was something wrong with my ears. So needless to say, they checked my eyes, no damage at all except that I'd been dehydrated, they couldn't find anything wrong with my ears, not that they actually checked because they'd been too worried about my eyes and then I was discharged. So I now have a living will that states I would rather die than go to the Royal Sussex again.

Right. Did you, I mean I sense there's more of the story coming, but did you or any of your family make a complaint or anything like that or did you just want to leave it well alone?

We did make a complaint.

You did?

We did make a complaint, and it was being dealt with, and they said they had changed their procedures and were very, very sorry and that was about it. It was then suggested to me that I could sue the hospital but by that time I don't want anything more to do with the hospital, leave it well alone, they need the money more than I do.

[44:03]

And you also had quite a lot going on at the time.

Exactly, yeah. So there I am, I've now been deaf for three weeks, with no hope of my hearing returning or even a clue of why I'd gone deaf at all. So the question is: Now what do I do? I tried going back to work, and again with the assistance of my boss I can't fault at all, it wasn't working, so I had to leave. It took me a long time to get any benefits, mainly because I wasn't able to ring people up and go "what do I do about this form, what can I claim for etc.?" This is where my dad helped me out a huge amount. It was just so frustrating, I couldn't see anybody, it was very difficult to make arrangements to see people. There was one friend who I'd arranged to see, and I was waiting at the door and well over an hour had gone by before I gave up. I then wrote him a letter saying "I waited for you for an hour, didn't turn up...what did you do?" he said he came 20 minutes early but there wasn't an answer at the door. Now you, or anybody else would have heard the doorbell, but because I had to sit there and wait, I missed my friend coming to see me for the day.

But he knew you wouldn't have been able to hear the door bell.

Exactly, so even though he was a good friend at the time, you just think to yourself *oh my god*. Now as you can probably imagine, I was getting extremely depressed, I'd lost my job, I was now on benefits but not having enough money to live on really, struggling very much

financially. I had no hope of getting a new job, in fact I was put on incapacity benefits because I had no hope of getting a new job and I hadn't seen any friends really for a long time, I'd seen one or two, but I had been out socially, they'd come round to see me. So I was getting very, very depressed. When I'd go out on my long walks there would be times when I was looking at the cliff thinking *it's a long way down*. I have to say there was one day when I sat down on the edge of the cliff with my legs dangling over and I was thinking one little push, you know, and that's it. Wouldn't have to worry anymore. But, I thought to myself, if I did this, what would be the consequences to my parents? They've put a lot of time and effort into me and if I did this, if I jumped off the edge of a cliff, my dad would kill me.

[Laughs]

[47:09]

And at that point, I realised no matter how bad things are, and they were bad, they could still seem up, I could still look on the bright side of things. And I still had the support of my parents, bless them, and my brother, he was very helpful. So I just had to try and persevere.

That must have really taken something, to reach very far into yourself and find the whatever it was you needed to carry on.

You—at times like that, you really do find out what you're made of.

So what personal qualities would you put that down to, what did you have in you that meant you could carry on?

I would say there were two things: One is that, bizarrely, I am an inherently positive person, I try to look at any situation in the best possible light, if there's a tense situation, I'm the first one to crack a joke, even if it's in poor taste, just to break the tension. And I'm well known for that I'm afraid. The other thing is, certainly in my family, we've got a trait which is stubbornness we just don't want to lay down and die, we will do whatever it takes to succeed, and I think it's a combination of those two bits that made me pull back from the brink I guess. It was those jokes, *I can't do this my dad will kill me*, that was the thing which said to me, no matter how bad things are getting I can't do this.

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So that was actually a real thought that went through your mind?

It was a real thought that went through my head: I can't kill myself, my dad will kill me. And also I started justifying it more to myself, I can't do this because I'll hurt my parents, think of all the things that they've been through, think of all they're going through at the moment. My mum found it really difficult to cope with the fact that I'd lost my hearing, even going so far as to not use the communication guidelines that we had developed since I was a baby and treating me as if I could hear so she wasn't looking at me when she spoke, she would talk to me from another room, you know all the things you know you shouldn't do she started doing. Almost as a psychological reaction to the fact that her first born had become a little baby again.

[50:07]

And by this point I'm assuming that your parents weren't married, they were divorced by then?

They were divorced by that time.

Was that fairly recent?

Yeah, they'd got divorced maybe two, three years earlier.

Oh Ok.

Yeah, '99 they got divorced, so it must have been three years previously.

But during this very difficult time, were they able to be a support to each other?

Yeah.

That's fortunate.

Yeah, even though they weren't married, they were still very amicable to each other. It was almost like they had to pull together to support their eldest son.

It's a good job, because that would have made it even more difficult.

Absolutely. My dad was living in Seaford at the time and my mum was living in Peacehaven. My dad came round every week without fail and in fact that's a habit we're still into today, we still see each other every week. And they both did shopping, cooking for me and kept my spirits up. About three months after I went deaf I had a hearing therapist, maybe speech, hearing therapist called Saskiya Harden at the Royal Sussex, who sent me an appointment to go and see her. And she was making sure that I got all the help that I needed, she arranged for sensory impairment people to come round, and they provided me with a doorbell which flashed, gave me a fire alarm which, if there was a fire, there was a pad under my pillow which vibrated and would get me out of bed. There was also an alarm clock with a pad underneath my pillow. Yeah, fire alarm...alarm clock...oh and the doorbell that was also attached to another pad. So I had these three pads under my pillow, any time one of them went off it was like I was in an earthquake it was absolutely horrendous...I ended up putting the pads underneath the mattress because it was just so.

If it was to vibrate during the night, would you know which one it was?

No, I'd be waking up thinking: What the hell's going on! But yeah, that was very good, very helpful and it also meant that if anybody rang the doorbell I would know they were there, so that was my first step towards independence and that was fantastic.

[52:48]

The next thing she did was refer me to this charity called The Link Centre for Deafened People and I was not in the least bit interested because they would not be able to give me my hearing back I got a letter from this person called Beryl Indge, introducing herself as an outreach volunteer for the Link Centre for Deafened People saying that she had a hearing loss and she would like to come round and talk to me about it and my first thought was "well whoop-dee-do good for her", screwed it up and threw it in the bin. I was still very depressed at the time, and I was getting letters and forms through from council, government, all various things saying you need to get this and you need to apply for that and it was just yet another letter; and the last thing I wanted was someone telling me how they'd also gone through it woop-dee-do.

Fortunately, that was the day my dad came round. And like when I was a kid, the first thing he did was sit down, have a cup of tea and ask me, "so what have you been up to?" so I showed him all the letters, and told him there were a couple in the bin. He said, "oh tell me about them, are they important?" "Oh this lady called Beryl writing to me" he said to me, "Are you doing anything that's so important you can't have her round for a cup of tea?" "I guess not." So I wrote back to her saying "yep, please come over whenever." And I'm so glad she did. Because even though the Link Intensive Program helped me out immensely, she was the one who convinced me to go on it. I mean she was a great-grandmother, profoundly deaf in both ears, cochlear implants, her husband Ken came along and they were both such lovely people. And she was the one that gave me inspiration, and if it wasn't for her I would not have been able to make the first steps to where I am today. I owe her such a huge debt of gratitude.

And what was it that she did do you think?

Well she explained that she also went deaf very quickly. She also when through this tremendous depression, she had these feelings of frustration, that she couldn't do anything and it made me think, yeah, she's just like me. So we're both deaf, our lives are over boo-hoo. Then, she said, she went on the Link Intensive Program. It gave her the skills and knowledge to get back into society again, to get back into a social life. I thought, "ooh", it's not just about being deaf, but it's actually about getting better. Because that's how I was thinking about it at the time, I had an affliction, a condition a disease: I needed a cure. And what she made me think about it was, it wasn't something that I needed a cure for, it was me needing a better mental attitude to deal with it, and that was the most crucial thing that she gave me. She then told me more about the intensive program about what you actually do on it, and that made me think, "well perhaps I ought to go". So in November I did, and that was just the first step in giving me the confidence, and the realisation that I can do—that I can get back into society.

[57:00]

So just before we talk about the intensive program, you went in the November following the June that this happened, I mean at what point did somebody actually say that "your hearing isn't gonna come back" and also at what point, I mean did you have a realisation moment when you said to yourself "this isn't gonna come back"?

No. Nobody ever said to me, "your hearing is never gonna come back". After that traumatic episode at the hospital I didn't have much to do with doctors at all, I had completely lost faith in them and they hadn't been interested in me. I've subsequently found out that they think I may have had an infection in my ears in my cochlear, but, the question they can't answer was: why was it only in one ear and not both, how did I get the infection, I wasn't ill...we don't know. Apparently, nine out of ten cases are like that, just listed as "unknown". The doctors actually know so little about how the ear works and what goes wrong with it. But again, there wasn't really a period where I said to myself, "I'm never going to get better, so what do we do next." It was just living day by day at the beginning. And as I say, after the intensive program I volunteered as a social group leader, which was just me really putting myself out there, because I thought the worst possible thing that I could ever do is going to involve a social group, so what do I do: I volunteer to run the damn thing. This is like when I was back at school, when I left high school, before I left high school I had a chat with a careers adviser. And the careers adviser said, "right well your deaf, so I wouldn't plan on having a career, but if you were to go into anything the worst possible thing would be retail because your deaf, you can't talk to people". So I thought, stuff you matey and the first job I went for was a salesman in a jewellery shop and I turned out to be rather good at it thank you very much. And again, that's my attitude to these things, people tell me I can't do things and I will go and do it, and I will prove them wrong.

There seems to be a very strong theme running through from when you were a child of pushing yourself and always doing the thing that is difficult but good for you.

Yeah.

And it sounds like that continued right up until this point.

Absolutely. So when I became a volunteer, I was joint group leader, social group leader with a lady called Christine. So we turned up at the group, and Beryl was part of that group as well, and it was a fantastic little group, it was a melding of minds. There were about six or seven of us, all determined to get the best out of this group as they could, so we arranged to go on day trips and all sorts of different things. And as I got more and more self-confident, I eventually left the group, and it was able to continue, didn't need my help, and it's still going strong now. So that was the first thing I did, then I became a Challenging Deafness Facilitator volunteer,

and that was also completely eye opening, because I was then facilitating a group of individuals, the one thing in common was they had all lost their hearing through various different means. My first thought was "my god, I thought I had it bad, what about her, what about him, and the stories they were sharing were just...well let's just say there wasn't a dry eye in the house for the whole six weeks, one day a week for six weeks. And that really was, a really inspiring time for me, it was almost like peer led support, other people sharing their experiences but then also what they'd done to –I don't want to say get better because that again implies a disease or a cure—but to cope better.

So you were a facilitator of that?

Yeah.

Were there any aspects of that you found quite difficult.

Just getting up and saying "Hello, my name's Andrew" was difficult. There was the expectation that I had all the answers. And I had a real problem trying to deal with that, but the whole point of being a facilitator was that I facilitated discussion within the group rather than saying "I've got all the answers." And because it was explained to me in that way and that's the way I was taught, that gave me enough self confidence to say I can do it. Again, I keep having to say this: I'm lucky. All the terrible things that have happened to me have been terrible, at the same time I've been lucky, every step of the way, to have the right conditions to deal with whatever those situations have been. I've had the right parents, the right friends, the right frame of mind. I mean, I'm lucky I've got the right brain that can actually lip-read. There are people out there who are far cleverer than I am, who can concentrate for far longer than I can, but for some reason can't lip read like I can. I mean, my girlfriend, for example, she is a very clever woman, she will deny this, but she is. She's a fantastically lovely woman, but she can't lip read, she's got the attention span of a gold-fish, a dead goldfish. So I'm lucky that I can lip read, to a very high extent. I'm gonna blow my own trumpet for a bit: As I say, I went deaf in June, in February the following year, 2003, I was sent for an assessment to have cochlear implants. As part of the assessment, they look at your ability to communicate, that's lip-reading, or just depending on your listening, or a combination of both. And I knew my lip reading scores would be high, so we had a discussion after we'd had all the various tests and I asked "what's the average score?" Most people can lip-read, they can get about 30% of what's

being said from the lips alone, the rest of it's from what you hear and body language and so on. So really good lip-readers can get maybe 35-40 per cent. I got 52 per cent.

Wow.

That's not saying I'm lip-reading 52%, I'm lip-reading the best of my ability, but then I can fill in all the gaps by working things out, and that's the crucial bit. It's like doing crosswords in your head in micro-seconds. I'm constantly trying to work out what people are saying and that's the hardest bit about lip reading. So anyway, that's my trumpet blown.

[01:05:00]

And just to carry on with that, what impact does that have on you – say lip-reading for a couple of hours, what effect does that have on you?

Well even though, as I say, I was born with a hearing loss and grew up with it, because I was having to rely far more on my lip-reading, the length of time I could lip read for went down tremendously. I could only have a conversation with someone for half an hour at the most before I would have to say "I'm sorry, I'm gonna have to stop now". In fact, when my dad used to come and visit me in the early days, we would have a chat for an hour, and then he would watch the TV for ten minutes while I just sort of closed my eyes, and then we would continue. So I didn't feel like I was just having a half hour conversation and then shoving him out the door. But then I worked on it and worked on it and my tolerance grew more and more.

So what is it that stops you, is it that your eyes are tired, or your brain is tired?

My brain is tired, I literally lose the ability to concentrate. I find myself looking elsewhere or thinking about other things rather than what somebody is actually saying. Now I have sort of micro-breaks, just for a second especially when I can pretty much guess what somebody is going to say next, I will look away for a second or two or think about something else for a second or two, and then sort of dip back in to the conversation. That helps, but if I do it too much then I lose the thread of the conversation. At times, I just need to be able to say "I can't concentrate anymore, can we take a break." Most times that's ok, but interestingly enough when I was having the assessment for the cochlear implants, the technician who was talking to

me about it, she said: "when you're talking to someone how much do you think you can hear?" and I said when I'm lip-reading and with what I can hear through my left ear, it's almost as if I just need to be able to hear them just a little bit more clearly and then I can hear them perfectly well. She said "that's your ability to lip-read". Up until then I hadn't realised how good I was at it, I thought it was perfectly normal because that's what I grew up with. I mean, my dad pointed out, that while we were waiting for the doctors at the assessment, one of the doctors came up to me and just started talking to me about various things and I said to my dad after she'd gone, "is she from South Africa or something, I'm picking up an accent?" And he goes, "how the hell do you do that, you can't hear her!" I said, "just by the shape of her lips". She's stretching out the vowels, and I know that's how they speak in South Africa.

So is it like...it's really fascinating, you're lipreading somebody and obviously you're seeing the shape like you're saying and you can see elongated vowels – are you translating that into a sound that you're making in your head.

Absolutely yes. It's almost as if I've got a library in my head of different voices as heard when I could hear and different accents – I'm not that good at accents but I can pick them up – and I can tell the difference between someone from Liverpool and Birmingham for example because the Liverpudlians tend to speak with much shorter vowels, and people from Birmingham tend to stretch out the vowels quite a bit. Interestingly enough, it's much easier for me to lip-read a man simply because I also notice their Adam's apple: If they're speaking in really low tones, their Adam's apple goes down low, so you can kind of use that to help work it all out. With a lady, of course, providing they really are a lady, there will be no Adam's apple.

[Laughs]

I've been living in Brighton too long, sorry.

[01:19:15]

I want to ask you more about the LINK Centre in a minute, but first, while you're talking about this, your hearing aids that you wear now

Yeah?

What sort of things do they allow you to sense?

Right. I spoke at the very beginning about my first hearing aid that was a box – that was 36, 37 years ago, and things have moved on tremendously since then. With these hearing aids in my right ear, I can tell the difference between a man and a woman's voice, I can tell that they're talking, it still sounds muffled, so I can't use it to hear on the telephone, but, with the information I get from them, that complements my lip reading so when I'm having a conversation one to one, I can following things well. I can't stress enough how amazing that is, the technology has developed so hugely since those early days. The ones that I'm wearing I only got a couple of months ago, the ones before that were good, but not as good as these ones, so you never know – in five, ten, fifteen years time there may be hearing aids which will allow me to hear as well as I could hear when I was younger.

Wow. And can you differentiate what sounds you're picking up, what you're getting from lip reading and what you're sensing from people's body language.

No. It's all one amalgamation. When I'm looking at someone I don't just look at their lips, I look at their eyes, with my peripheral vision I look at their body language, the fact they're making and so on and all of that along with what I'm picking up with my ears are all put together and because I've been doing that so long I can't say "Oh I'm picking that up with my ears" or "I'm picking that up just from the lips" I've tried this, when I've lip-read people with my hearing aids off. Often happens when I've just come out the shower and somebody else is waiting to go in. I will know what they've said because I've been looking at their lips but I will hear their voice in my head even though I can't hear, because I know what they sound like when I've got my hearing aids in and I attach that to what I'm working out from my lip reading. Hope that makes sense.

It does, it's really, really interesting. We'll just stop for a minute and have a break.

[End of Track 2]

[Track 3]

So can you tell me a bit more about your, I was going to say a week on the intensive program, I presume it was a week?

That's right, yeah. As I say, I was persuaded to go by Beryl, and even though at the time I was an ungrateful sod, because I didn't realise the amount of work that goes into getting the money that pays for me to go on it. Apparently in Brighton they rarely pay for anybody to go on the course so to get on it so quickly was lucky. Again, saying the word lucky again. So yeah, I went on there, and I was told I could bring anybody I wanted with me, and it's a reflection of the mindset I was in, but I took my mummy with me, mainly because I believed, at the time, she needed it more than I did.

Right.

Right from the beginning, she had had very little support in helping me, but this would be the first opportunity that she would have been able to talk to other people who were in a similar situation where their children or their partners and so on had hearing loss and what can they do about it. What help can she get to deal with her frustration, her loss etc.

So even though both your parents were involved and they visited you, you felt it was your mum who needed that extra support.

Absolutely. My father was upset that I had hearing loss, but he's a very practical person, he thought "this is terrible, what can we do to help?" and he gave me a tremendous amount of help we did a lot of discussing things. My mum I know is more emotionally less able to deal with it, if I can put it that way, I know it hit her the hardest. That's not saying it didn't hit my dad, but I know my mum needed more help. Because, as I say, she was unable to cope with the fact that I had lost more hearing and became less deaf aware, which is very, very bizarre. And besides, if I can be honest, I wanted my mummy with me. There's a comfort thing there as well, and I was at that kind of stage where I needed a lot of emotional support and in my family it was: if I needed emotional support I went to my mum, practical support my dad. They both did cross-overs, but that was basically how it was. So when we went on the program, it was one of the smallest ever programs, there were only four people including myself with partners

etc. and it was the first situation where I thought "wow, I thought I had it bad", there was a young man there, I think he was in his early twenties, who had had a car accident or something, and found he had brain damage. And at that point, there was an operation that could be done to possibly restore his hearing, so he didn't even know whether he was gonna be deaf or not, on top of that he had brain damage. There was a lady there who had lost her hearing 20 years ago and had lived her life as a virtual recluse, it was only because a work friend had heard about link and got her involved that way...but the frustration, the anger this woman had because she had received no help for 20 years. We all think we've got it bad, other people's situations aren't worse than ours...it just made me think "ok, time for going boo-hoo is over, I've gotta start getting on my feet again." So that was one of the biggest things.

Was that from day one?

No, that was I suppose towards the end. On the intensive program you've got lots of different sessions: you've got a session where you have all of the deafened people in one group and all of the partners etc. in another group in separate rooms, and you all talk about your own stories. A lot of release goes on, a lot of damp cheeks and all the rest of it, and that is the cathartic bit. You then start gelling with one another, that's the peer-led support bit, but then you've got the practical stuff, people talking about lip reading, sign language, finger spelling where you just sign out the first two letters of a word rather than sign the whole word, so finger spelling is actually a useful addition to lip reading, so I found that quite useful. There was equipment, there were all sorts of different things, but then you also have goal setting, which is a really sort of eye opening bit: I had to set myself a goal to complete by the end of the week, at the end of the week I had a goal to set myself within four weeks, and by the end of that first week I had the first beginnings of confidence, I was laughing and joking with other people and motivating other people which is obviously part of the self healing bit. And so for a joke I said "in four weeks I'm gonna get myself a girlfriend, that's my goal", took me a little bit longer than four weeks but I did manage it in the end. But yeah, the week itself is good, it's VERY intensive, so much goes on – at the end of the day you're absolutely wiped. But it's just the first part and the biggest thing about it is the recognition that someone else can only do so much for you and at the end of the week it's a case of "well they've done their bit and the rest is up to you." I do feel they might need to do a bit more of that: "we've done our bit the rest is up to you" but that's what I certainly recognised. When I came home on the Friday evening I was absolutely shattered and I thought to myself, "well great, they've done their bit, now it's up to me, what

am I going to do next." And by then I'd already agreed to be a volunteer, that was the social group leader bit – I'd been recruited already – and my mum and I certainly benefitted from it in various different ways. We've always been close, but it helped repair the damage that that three or four months had done.

Did she start doing some of those things that are more deaf-aware again?

Yeah, she did yeah. But I also – that was the first point I recognised she was going through an awful lot. Because I was going "oh she's all terrible about me", I had even begun to think what my parents must be going through, so that was an eye opener from that perspective as well.

Did you have an opportunity to talk about that together?

After the week, yes. On the week, no, mostly because both of us were too tired. Which is quite interesting, because even though she wasn't depending on lip reading or any communication support, throughout the week the sessions are all so draining for emotional reasons, but there's also concentration, there's so many different things you do, so regardless of whether you're deaf or not or deafened or not, it is intensive. Fantastic, but intensive. Then there's the reflection bit afterwards, and you've got to do all the work which you've been taught about in that week.

[08:45]

Some people that I've spoken to before have said that when they go home it's like a dip, like, you feel all "geed" up by the week but when you're at home your life is the same as it was before. Did you experience that?

I did, for the first day. But then I made that decision "right, they've done all they can, now it's up to me to do the rest". Well funnily enough, one of the things that we had talked about during the week was friends and family and I started thinking about the friends I'd made back in high school in the hearing impaired unit, because since I'd left Pinner in '88 I hadn't met a single other person who had an obvious hearing loss. So it made me think "well perhaps I should" because there's not necessarily a community there, but there are people who are the same as me, and because I'd been ejected from society I wanted to belong somewhere, if that makes

sense. So I was told about a website called "friends reunited", and like that series of books written by Lemony Snicket called A Series of Unfortunate Events well this is the series of extremely fortunate events. When I was in high school, I had this friend called Nyan, and in the year below there was a girl called Ravit. Nayan and Ravit were still friends, well when I signed up to "Friends Reunited", about half an hour later Nayan also signed up, saw me on there and contacted me. About half a month later met up with him and several other friends, all had a great time, exchanged contact details and whatnot. Couple of months later, he bumped into Ravit, exchanged contact details and so on, and also gave her my contact details. A couple of months later, Ravit was at a dinner party and across from her was a girl called Amanda who I first knew when I was at nursery school and primary school and we were girl and boyfriend then, in fact when we were six years old I told my mum we were going to get married and have six children. So, by so series of extraordinary events, we then got in contact just as her marriage was breaking down. We became friends, and then once the divorce came through we became partners, and that was about four and half years ago.

Wow.

Yeah. And that's been a very interesting relationship, because she also has a hearing loss as well. Oh boy.

And how does that work? How do you communicate, I mean is it true there's double the communication difficulties because there's two of you without hearing?

You could say that, yes. The other issue is I'm currently living in Eastbourne. She lives in Potters Barr which is north of London. Because both of us have a hearing loss we can't use the telephone. So what we do is, we've both got mobile phones so we text each other...a lot, we also use instant messaging on the computer, we've got webcams and things like that. So almost every night, almost, we tend to have a chat online, and because we can see each other we can lip each others' lips if the signal's good, but we're also typing out what's being said, so that's our main form of communication, that, emails and texting. So even though we can't use the telephone we are still very much connected. Face to face is a different matter, where...I am the living embodiment of this phrase: "deafened people are the worst people to be deaf aware"

Meaning you are not deaf aware or she isn't?

I get frustrated because I know how people should be communicating and I am very intolerant of Amanda's inability to lip read. I don't think I'm anything special, you see, and therefore everybody should be able to lip read as well as I do. And of course Amanda can't. She's very clever, she's amazingly creative, you should see the cards and the drawings she does – absolutely fantastic, but she can't lip-read as well as I can, but she can hear better than I can. So I get very frustrated when I'm trying to chat with her even though it's not her fault.

So is it a more comfortable relationship when you're communicating through technology than when you're communicating face to face?

Hmmm...I'm going to get into trouble now aren't I? Possibly so...because when we're talking online then there's concentration there. But when we're out and about, I mean Amanda's got three kids – three smashing kids - but if we're out and about there's lots of distractions. And something else I ought to mention is if you have a hearing loss then you miss out on all the ambient sounds. If we're in a room for example, you can hear people walking outside in the corridor, so I know they're there, you know somebody's just about to come through the door, well I wouldn't, and neither would Amanda. So we're constantly looking away from whoever's talking to us just to see what's going on. And of course, because I know she's not lip reading me I then stop and am waiting for her to look back at me before she's then attracted by somebody else walking past. So that can be frustrating for me. But when we're online, for example, then she's concentrating on the little screen in front of her and the words, so yeah.

So have you come up with any strategies to avoid being frustrated with it, or are you just at the stage of being frustrated with it?

We tend to cope, and then every so often I get angry, have blow out, then we apologise – kiss and make up.

Right.

In answer to that, this is the thing, we both have skills, we both have knowledge, but it isn't a simple answer because we're both human beings. The only answer, really, is that we both love

each other madly, that's the only thing that keeps it together. I can't say that, it's not quite right, but regardless of those difficulties, we somehow manage to cope, let's put it that way.

Despite the difficulties, it's still worth continuing with.

Oh god, yes.

Because of what the relationship means.

Yeah, absolutely.

[16:19]

Now this reminds me, if we can just go back really quickly. When you had that experience, where the hearing disappeared in your right ear, you said that shortly before that you'd had a girlfriend...what happened with that?

Well, I never heard from her again. I did hear from another friend, one of those who wrote letters to me, that they had been contacted by Julie saying "he's not responding, he's dumping me, what have I done wrong?" And of course, by that time it was too late to explain. I'd only been going out with her for a few weeks, about four weeks so

It wasn't a very deep relationship yet.

No. Nothing like what I've got with Amanda at the moment. It was just the beginning of the relationship, I lost a lot of other friends through the same way, just when you're in that kind of situation, you don't think too logically. Now, it's easy to say, "oh, loss of hearing - must write to my friends as I can't phone them." I didn't have a mobile phone in those days, I couldn't text them. So because I was tardy getting round to writing to them, I lost a few friends that way.

[17:39]

And talking about the texting, the webcam and the internet and all that sort of thing, is that something that you use for all different sorts of things?

Oh yes.

Can you tell me what some of them are?

Well because when I was living by myself I had to obviously contact my utility company or whatever and they tend to have "text phone" numbers which nobody ever uses, I couldn't afford a text phone, they are very expensive and expensive to run, but they do have email. So I wrote to them saying, "I can't phone you up, I don't have a text phone, can I have an email address I can write to?" and more often than not they grumble about it but then eventually they say yes. And I'll be able to email any inquiries I have, so that's where email, in particular, is very useful. The great thing about email and texting is that it's socially acceptable, it's not something specifically for deaf people, there's no social so there's no social cache [sick] about using it. If I meet someone for business or whatever, I give my business card and my phone number and it says quite clearly "text only". And most people won't even think twice about texting or emailing: it's cool. So it's removing the barriers, but also the social stigma attached to being deafened.

[19:12]

That's great. I think that leads quite nicely into the work that you're actively involved in here in Eastbourne. Do you want to talk a bit about that?

Right, well I mentioned earlier on that I started working, sorry I started volunteering for LINK. That gave me self confidence so that when a one day a week job came up at LINK, I then went for it. Lucky enough to get it, that led on to another one day a week so on and so forth until I became full time for LINK. It was great opportunity because I was in a deaf-aware environment if you like, and then when the last project I was working on finished I was made redundant. We are living in a recession in the moment so there was no funding for a new project so I had to leave. I thought "not a problem" I've got a nice CV, lots of skill, there'll be lots of people out there begging me to work for them. I've now had I think it's almost 70 interviews at 70 different companies.

In what period of time is this?

From August up till present day. That's July 2009. Almost a year, I think it's, yeah, 68, 69 interviews. I've had several second interviews, so I've got up to the last few, but somehow, I've yet to have anybody say to me "yes we want to employ you". I know times are hard, I know that every job I've gone for there've been 30, 40 or more people going for the same job, why am I not getting them? I don't want to say, "it's because of my deafness." Because that's not something you can actually prove, but come on.

So your feeling is that it's because of your hearing loss?

Yeah.

But it's not easy to say that.

No, because there's no way you can say to someone "can you tell me the reason why I didn't get the job?" I used to in the beginning, I'd say "thank you very much for writing to me, is there anything I could have done so that I know for the next time?" And the answer's always been, "oh the other person had more experience, had better qualifications, this that and the other." Now the sort of jobs I've been going after have been to do with either admin or training, and I've been doing those sorts of jobs for fourteen, fifteen years on and off. So somebody must have had an awful lot of experience, an awful lot of qualifications every single time. I don't know. I don't want it to sound like sort of sour grapes, but it's certainly a possibility if you've got large numbers of people applying for the same job, you're less likely to go for somebody with a disability. Simple fact.

I mean, who can you say that to?

Exactly, you can't prove it. If you do say that, then you sound like you've got sour grapes, there's no way you can definitely prove it. All I can say is this: ever since I was first employed, the longest I was ever out of a job was four weeks, and that was during the last recession in the early '90s. I managed to get myself a part-time job, then very quickly onto a full time job. We're in the middle of a recession now, and I'm more deafened, so whereas before I could use

a telephone, now I can't. It sounds bizarre, but that distinction between being severely, and now profoundly deaf, the ability to use the telephone and not use the phone, between just about coping and not being able to cope without support is a big distinction. And I'm sure that that has had an effect on my employment prospects. It's got to a stage where I've now registered as self-employed, and I now give talks to charities and businesses and so on deaf awareness. I've had a few, not many, but I'm just starting out on that. So that keeps me busy along with something else I do: I'm a borough councillor.

[24:13]

Do you want to tell me something about that?

Sure. While I was still working for LINK, the local council started up a new role as "disability champion", and I had a few things that I felt we should do better in Eastbourne. I kept writing to the "champion", so called, and they didn't do anything, no responses. And I thought, "this is not good."

What were the things you wanted to change?

Well the council itself had no real commitment to disability equality. Or they had an equality plan, but there was no evidence of things actually changing. The town hall, for example, if you wanted to go along to any of the meetings like planning or licensing or even for a council, it was held in a room where the acoustics were terrible, there was no communication support, and if you were in a wheelchair, you wouldn't be able to use your own one because the lift is so small. You have to use their own. Which is terrible, absolutely terrible. And there was nothing that the existing champion was willing to do. I was in an interesting tradition in that LINK at the time, one of the trustees was a guy called Stephen Lloyd who was a parliamentary candidate for the Lib Dems, in Eastbourne, and one the patrons is Nigel Waterstone, who is the MP for the Conservatives in Eastbourne. So I thought, "ooh, if I want to do something with politics, speak to one of those two guys". I contacted Stephen, and he came round that afternoon, had a lovely chat with me in the office and told me about how I could be an activist – obviously for the Lib Dems, and how if the Lib Dems gained control of the council then they'd be able to do various things. I'm still waiting for a response from Nigel. [Laughs] Anyway. To cut a very long story short, I did become an activist delivering letters and things

like that, and got chatting to the existing councillors. And then the local elections came up and I was asked whether or not I wanted to be a candidate. I said, "yes, on one condition: if I do get elected I'm the disability champion." They went, "yeah, ok." And I got in, I worked my socks off, it was absolutely terrifying because I started canvassing in... September 2006 and I then had to start knocking on strangers doors, people I didn't know. So from a lip-readers perspective, this is terrifying. I'm knocking on someone's door who I don't know, it's night time so it's dark, they've got a hall light on so their face is in silhouette, asking them to move and stand a certain way so I can lip read them and then ask them one of the most personal questions you could ever ask anybody: "what are your political voting intentions at the next election". But somehow I did it. I was absolutely...well I won't say exactly how I was feeling because it's going to be on a public record, but I was very, very nervous. But I did it, I managed to speak to lots of people, I worked my socks off and I got elected.

Well done.

2,007 votes. And it's easy to remember, because it's 2,007 votes in the year 2007. I got elected with the second highest number of votes and interestingly enough I was up against the leader of the council at the time. So I got rid of the leader of the council.

Wow.

And I was made disability champion. And I've managed to achieve all the things I was writing to the previous champion about. I have full communication support at all the meetings I attend at the council, whether it's planning, licensing, full council whatever, and that's connected to another screen so that anybody else who comes and watches will be able to read the screen as well. The rooms where all the meetings are held are now on the ground floor, in a fully accessible room so if you're in a wheel chair you can get in, if you have vision impairment you can get in and find your way around easily. It's a nice, brightly well lit room, I've got rid of the robes that we used to wear, so all these barriers which stop people finding out who their councillors are or whatever, I've managed to break down. And there's lots of other little things as well. We've got something called a "disability involvement group" where you've got disabled people engaging with the council, and because I've been working with them the group have managed to do huge amounts of things. We've got a budget, agreed by the county council, specifically for dropped kerbs now in Eastbourne, where we never had anything

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before. We've got a new art gallery that's opened up and because I've got the disability

involvement group involved, that gallery is now incredibly accessible. We even got the colours

of the signs changed so its contrast is good enough for vision impaired people to read it. Even

the buttons on the lift have been changed so that vision impaired people can use them, you

know, lots of little things like that. And that's been really satisfying to be involved with.

Yeah, and do you intend to continue to be involved in that?

Oh yeah, oh yes! Even if after the next election I get chucked out I will still be involved in

politics in some way. But certainly with lobbying, lobbying other people as well. I've been

hassling the Department of Transport, and I do mean "hassle" because they've had Review of

exactly how drop curbs are created and how much tactile paving [Sp?] should be on the curb.

I'm saying the Review is worthless because it was not done with any consultation of vision

impaired people, the people who tactile paving is supposed to help. So I'm saying you got to

have a Review. Yeah, loving all that.

Sure. So can I ask you the most personal question anybody can ever ask you: what are your

voting intentions in the next election?

Liberal Democrat.

And that's very emphatic?

Absolutely, yes. I used to be a Conservative, but I feel that the Liberal Democrats certainly are

more about equality and inclusion than any other party. Perhaps more so than the BNP.

[24:13]

Ha, yes I would imagine so. So finally then, can I ask you about how you see yourself, now.

Right. That's a big question.

Yeah I know. [They laugh]

The simplest answer is: I am not the same person I was seven years ago. Not by a long shot. I have, now, a sense of self-worth, I have self-confidence, I'm doing things that seven years ago I could never even dream of doing: if you said to me, that person sitting on the edge of the cliff, "would you ever get involved in politics? Would you ever see yourself working? Would you ever see yourself lobbying for change in government? Would you ever see yourself having a girlfriend again?" The answer would be: Bye, bye aaaaaaaaaaah. It would just be completely incomprehensible. Even now, there are times when I think to myself, "what the hell am I doing". I mean I've just got a project started which is going to create a website where every building, service, hotel etc. is going to be assessed for its accessibility.

In Eastbourne.

In Eastbourne. And I've now got the support of the Hospitality Association the Federation of Small Businesses and so on, I've got the "big boys", all coming on board with my ideas. When I think about what I've done there I'm like "wow that's me, I've done that." But then seven years ago I couldn't even go to the shops by myself because I was scared that people would start talking to me. I've come along way and I've got a long way to go, but it's going back to the fact that if somebody said to me I can't do something, I'm gonna do something about it. Pure a simple. And it all started with my parents determination to give me the best possible start and then when I lost my hearing it started again with Beryl because if she hadn't written to me and hadn't come to visit me I wouldn't have come to LINK, so there's a few people I owe huge amounts to, that's for sure.

Wow, that's fabulous, very interesting, and thank you very much for being interviewed today. Is there anything else that you want to say?

I think I've said quite enough, thank you very much! Thank you very much for listening, I hope you found it useful.

Thank you Andrew.

[End of Track 3]

[End of recording]