



Unheard Voices: interviews with deafened people

Jayne Rugg
Interviewed by Jan Sanderson

British Library ref. C1345/06

IMPORTANT

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Interview Summary Sheet

Ref no: C1345/06

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Rugg

Title:

Interviewee's forename: Jayne

Sex: Female

Occupation:

Date and place of birth: 1953

Date(s) of recording: 26th October 2008

Location of interview: Hearing Link head office, Eastbourne

Name of interviewer: Pam Blackman

Speech to Text reporter: Emma White

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Interviewer's comments:

[Track 1]

Good morning.

Just for the record, my name is Jan Sanderson, and it is Sunday, the 26th of October, 2008. I am interviewing Jayne Rugg for the Unheard Voices Project, Eastbourne, East Sussex. Can I just ask you to state your name, your date of birth?

Jayne Rugg. 14.8.53. R-U-G-G, and Jayne with a Y.

Can I just ask you your maiden name?

Deacon.

Can you just spell that for me?

D-E-A-C-O-N.

Thank you. Can you tell me the place that you were born?

I was born in Wanstead, London.

And do you remember your mother's occupation?

Yes. My mother was a nurse. SEN nurse. Yes.

And your father's occupation?

He worked for the Civil Service.

I am really interested in knowing a little bit more before we go further about your family background, so if I ask if you can actually remember your grandparents?

Grandparents? My mother's father, my father's father, died when they were both very

young, so I did not have grandfathers, but I knew my mother's mother, my grandmother, very well, and my father's mother, not so well, but my maternal -- my mum's mum I knew very well.

What was your mum's mum's name, your grandmother on your maternal side? What was her name?

My grandmother? Annie Hardesty.

On your father's side what was your grandmother's name?

Hardesty. Oh. Ethel Deacon. Yes.

That is fine. Thank you. What about brothers and sisters? Have you got brothers and sisters?

Yes. I have got one brother. He's two years younger than me. Andrew.

Andrew?

Yes.

Whereabouts did you actually grow up? Did you live in the same area all the time?

We grew up in Essex. Romford, Essex.

Did you live there all of your childhood?

Yes. Yes, until I was 26. Yes.

You actually went to school in Romford?

Yes. Suburbs, yes.

You spent all your school life going to schools in the area that you grew up in. When you left school, did you actually go to a college, or on to further education?

I did -- until I left home at 26, everything I did was around the area, yes. College in Romford. Schools. Yes. So I grew up in that area and did everything there until I was 26.

Did you enjoy school?

No. Not really. No. Not until my hearing improved a bit. No. I struggled with it, really. Yes.

Was it because of the hearing loss that you didn't enjoy school very much? Can I ask you what your difficulties were?

Frustration. Yes. I wasn't aware at the time, but looking back, yes. It was my hearing loss, but I didn't know that was the reason at the time that I had a hearing loss because I was a child, and so yes, I was frustrated a lot of the time. Yes, and.

When you were at school and the early years, is that when the hearing loss first became -- you say you didn't know that at that point you had got a hearing loss. What about friends at school? Have you got any special memories from school around that time?

I think -- no, not special memories, not very nice memories, really, more -- when I was very young I found it very much a struggle, but again I didn't know why. I mean, it must have been because of the fact that I had this bead in my ear which didn't come out until I was in senior school, so that must have been the reason -- but nobody knew I was deaf and I didn't know I was deaf, and nobody knew the bead was in there, and so I was a deaf child in a normal school, I suppose, or partially deaf, and special memories? Do you mean happy memories? Yes. Yes. I did make friends, but I have always found it has been a one-to-one friendship. I have always made very close friends, not the sort of person who had lots of friends, presumably, again, because that

is how I get on better with people, one-to-one, and that is what was happening when I was very young as well, I suppose don't know.

At that point you wasn't actually aware that you had got the hearing loss, so you wasn't actually aware that that was why you preferred the one-to-one as opposed to the group situations? Is that what you are saying?

That's right. Yes. I wasn't aware of that, but I can -- I realise now that was the reason, yes.

What about when you had actually in your lessons? Did you actually struggle during the lessons? Were you able to hear what the teacher was saying or did it cause any problems during the lessons?

The lessons, they were a complete nightmare, because I wasn't a very confident child. That was probably due to my hearing loss as well, or maybe, you know, a bit of me anyway, and so I didn't push myself to the front of the class, and so I didn't hear what the teacher was saying a lot of the time, I was in a bit of a daydream most of the time, I suppose, sort of wondering what everybody was doing and trying to catch up and, you know – it was terrible. It really was awful. I remember one teacher saying to me, "Do you want to come and sit at the front, Jayne", I must have been at the seniors then, and I think in their senior school I started to push myself up the front a bit more so that I could hear better.

Did you assume that the fact that you --everything wasn't clear obviously you weren't aware that other people couldn't hear the same – that other people could hear more than what you could hear, so did, at any point, you ever feel that you were different from any of the other children?

Yes. Yes. I remember in the junior school, when the nurses came round to give us hearing tests, and we had a ruler that we banged on the desk when we heard a sound in the earphones and I remember being very young and knowing that I should be able to hear more than I could, and because I was so nervous I remember banging this

ruler on the table not hearing anything but I knew I had to bang the ruler so I kept banging it. I knew I should hear something, and, you know – so I think they realised I had a bit of a -- you know, I was -- everything was very difficult. I didn't actually go and see anybody about my hearing loss after having these tests with the school. I don't remember anybody referring me. No. They didn't. To hospital. No. They didn't.

[09:55]

Did the school -- you mentioned the nurse doing the hearing tests, and obviously you mentioned keep banging the ruler because you knew that that is what they were expecting from you, even though you couldn't actually hear the sound.

That's right.

Did any of the nurses, or the teachers, actually pick anything up from that? Did they recognize anything from it?

Well, if they did, I wasn't aware of it. I remember -- what happened was that I -- eventually, this was over a long period, eventually in senior school my mother did take me to the GP. One ear was discharging, and the other one had impacted wax, and she took me to the GP and I remember syringing this ear with the impacted wax and I was on the ceiling with pain because nobody knew but when he was syringing my ear this bead that had been in my ear for years and years and years was getting pushed further and further in, and it was the most awful thing. I can remember walking back from the GP surgery screaming my head off, and the GP didn't know because this bead was covered in wax and he couldn't see what he was doing, and in those days, you know, now, they would take the child to the hospital and give them a sedative or something and examine them properly, but there was none of that then, and I was just distraught. The pain was unbelievable. Years -- well, I am not sure how long it went on for, months and months, the same sort of thing, every week I would go to the Doctor's and he would try some different drops to try and loosen what was in there and eventually it did become a bit loser, I suppose, and my mum, being a nurse, she could see this sort of stuff coming out, so she got some tweezers and pulled it. She

didn't delve inside and she brought out all this horrible stuff and put it on the table in front -- she took this out, I could hear the clock ticking, the first time in my life. I must have been about, I don't know, 12 or something. Something like that, and we put all of this, she just kept pulling this out, put it on the table and got her tweezers, and in the middle of this was this pearl and I had been -- I must have been a baby. We don't know how it got there, whether my brother pushed it in, whether I pushed it in, how it got there, but it had been in there and it caused me all this, and that came out, things were a lot better. I could hear, but, of course, it set up all these infections, because the ear was so damaged with all the syringing and everything. I did actually get to the hospital once before that happened. I remember now. They did send me to the local hospital once, and the surgeon, or the ---put me on the bed and he did the same thing the GP did, got the syringe out and did the same thing, and I did the same thing with him as I did with the GP, ended up on the ---and I remember him saying, shouting, at the top of his voice, you know, he was one of these surgeons with the bow tie, "Get this child out of here", and I did the same thing when I had been to the hospital, cried all the way home, but that was before my mum got the bead out. But I also had a lot of nasal problems as well.

If I can just go back just a touch just to what you have said about when the -- when your mum got all the debris out of your ear, and you heard the clock tick for the first time, did you actually recognize it as a clock ticking? Did you know that that is what it was?

Well, I must have done, yes, I must have -- yes. I say -- well, yes. Yes. I mean, I remember everything. I mean obviously I could hear, I wasn't completely deaf, you know, before the bead came out, but suddenly everything was just loud, you know, really loud, but then, of course, I started -- I had -- the infections started after that.

When you -- after this debris had been taken, your hearing became more clear and you were more amplified, did it make an improvement at school for you? Did you find a difference when you had actually at school?

Oh God yes! Oh God! When I started senior school, we had exams every summer to get our position in class, and I remember the first year, so I must have been -- the first year of seniors, 11, 12, I came 23 out of 32. I remember this like yesterday because it made so much difference. The second year after that I came 8th in the class and the year after that I came 2nd, and so the hearing made so much difference to the exam results, you know, but then, of course, they were -- you know, I had all the infections. I had very bad nasal problems as well. Whether this is all connected, how do we know? But I had polyps in my nose that got bigger and bigger and bigger, and they didn't come out until I was about 21, and I have been told that polyps are an allergy, they are created by an allergy, so maybe I had some sort of allergy -- I still have infections now in my ears but my nose is a lot better, but I don't think this helped, you know, my head was full of horrible things.

[15:59]

You said when you were at school, that you actually had, like, the one-to-one contact, and you had got friends, but it was always on a one-to-one basis. Can you recall what kind of things you did after school, or when you weren't at school, what kind of play or activities that you actually followed?

I actually did what normal -- I don't like to say this really but I had imagination. I mean I don't think -- I mean obviously my childhood did suffer because I couldn't hear properly, but I was able to -- I did have friends, you know. I don't think I was aware that I was very different from other people, but -- because obviously the hearing I did have was enough to -- but it wasn't anywhere near as good as it had been, as it could have been, rather.

When you were at school, were you members of any, you know, school clubs or youth clubs? Did you go to anywhere like that?

I don't think we did clubs in those days. I used to go home and do what every mother wants their child to do now, go outside and play in the street, you know? And I did all those things. You had -- we lived on an estate, and the children, we went into each other's gardens, and, you know, this is how we lived. It is a little cul-de-sac and we

all went into each other's gardens and I used to walk the dog off for miles and really, when you think about it, it was an -- it was just how you would want your children -- I don't remember being in much at all. Out all the time. But it is schoolwork, I think, it is school that I noticed, because when you are -- you know, in school you have to -- you are sitting in a classroom. When you are out you can move to where you want to hear, can't you, subconsciously you are moving to where it is best for you, but you cannot do that sort of thing in school, can you, so much. Am I making sense?

Do you find that you actually found coping strategies without even realising?

I think my hearing loss, when I really noticed that I was having to create strategies was when I was a bit older. I wasn't aware of doing that when I was younger. No. I don't think I knew that I was deaf. Well, I didn't, did I? This bead had been in my ear for years and years, and I suppose in some ways, you know, I think why wasn't something done, you know? I cannot understand having had children myself, how things were different. You know, I mean these days, you see, in some ways I think that doctors were somebody you didn't sort of talk to then, you took them -- if they said, like he said to me, the surgeon, "Take this child away", that is what you did, whereas now you wouldn't have that, would you, and the surgeon would say, "Well, we will do something and find out what, you know, is wrong with her ears", and it just didn't happen then. I cannot believe how it just went on for so long, the way I was, how it wasn't sorted out. I think my mum, when she was doing her nursing, the nurses ran around the doctors then. When she was doing her training, you know, whatever they said went, and so when I had all these problems, she wasn't going to -- she just went with whatever they said, which wasn't very much because I was screaming all the time in agony.

[20:22]

What about your brother, Andrew? You know you were growing up and you had this hearing -- a problem with the bead in your ear, and the constant running backwards and forwards to your GP, did -- how did your brother react to this? Did he actually - was it supportive? Did you find that he used to maybe try and protect you, or help you in any way?

No. No. Not when I was young. No, because he had problems. He had very bad asthma, when he was a child. I mean -- so he was a bit of a problem for my mum too, you know, so she had a child with very bad asthma and me, so it was quite difficult but no, I don't remember him -- I don't think -- I think I managed okay. Obviously, I couldn't hear out of one ear at all but obviously what hearing I had in my other ear was enough to make my life okay. It wasn't anywhere as good as it could be, but I don't think people were -- any of us were quite aware of how it could be much better.

In your family, I mean you have mentioned that your grandparents -- well, your grandmothers -- were you aware, or is there any history of anything, anyone with hearing loss or ear problems that you know of?

No. No. There is not any history of that. I really believe that what has happened to me could have been prevented. Everything that has happened to me could have been prevented. Well, oh dear. Having said that, I don't know. It is difficult, isn't it? I think it is such a -- my hearing did get better at one point. I mean the infections stopped for about two years, when I was in my thirties, and they did stop -- you know, they dried up. I had to go in hospital so many times and have the -- I have had a tympanoplasty, and a mastoidectomy, but I had to go to hospital numerous times and have them evacuated, all the debris, lots and lots of times. I had huge polyps in my nose that the surgeon said were the second biggest he had ever had removed, this is all part of the same story, so I just think that when I lost my hearing completely my whole body packed up, it had had enough because I think I had a virus and that is when my body decided enough is enough, and my hearing just stopped. Well, it went down over six months, but everything that went before, I just -- and I felt so ill at the time as well, but nobody really knows why I lost my hearing completely, but obviously the infections and everything.

It wasn't -- there wasn't any family history of that?

No. None at all. No.

You were the first one?

No history, no.

How did your parents deal with the --

Polyps are in the family. I know my cousins had polyps in his ears. That's right.
Yes.

How did your parents deal with the problems that you were having? I mean I know you have mentioned that your mum -- what is your mum's name?

Audrey.

You mentioned that your mum, Audrey, actually had been a nurse, and she was able to get this bead out of your ear, and you were aware that you had an hearing loss. Were your parents fully aware that you actually had a hearing loss or was that something that only you recognized?

Oh yes, I think they were aware that I did have a hearing loss, but -- yes. But, you know, she took me to the Doctor's, and this is what happened, you know, and I wasn't -- and eventually I went to the hospital just that once, and then that is what happened and she took me home again, and just by chance this happened, she was able to pull it out.

[24:59]

Can you remember how old you were when your mum actually took you to the hospital?

Yes. I was probably about eleven or twelve, probably about that time, when it came out. Yes. About that -- after all these months and years of him syringing and trying all the different drops it loosened, and it must -- and then eventually she pulled it out, you know. There must have been about 11 or 12 something like that. I was in senior school. That is when my schoolwork started to pick up, so all my childhood, really,

until I was about 12, I had had this bead in my ear, and the infections started when I was in junior school in the other ear.

[25:40]

Have you any more childhood memories, you know, other things that perhaps you remember from your childhood, maybe good times or where you went on holiday, or any family occasions? Is there anything like that that sort of stands in your memory?

I have to think for this. Well, yes. I mean yes, we used to put plays on in the garden and that sort of thing and I had a dog that I absolutely adored, yes. So yes, I remember having -- the best thing that happened in my childhood was getting a puppy. That was the best thing absolutely. I still absolutely love dogs and so that was the best thing for me, and I think any child that grows up with a dog is going to be happy, you know. She was lovely, and --

What was her name?

She was a cross between a lab and a collie, but -- and she was quite nervous -- we actually bought her, I mean this sounds terrible saying this now but we went to Romford market one Saturday, the four of us, and you know in those days they had all these puppies in like a huge cages on wheels, and every Saturday the dogs would be in the market and we would go and say, " Oh Mum, please let me", no-no no, but eventually they said okay, you can have one, so we wanted -- we looked in this cage and there was this little one at the back, you know, shivering at the back and you know they say you are not supposed to have the -- you should pick the one that is very, you know, what's the word? I don't know. Not the nervous one sitting at the back, anyway, and she is the one we picked. She's lovely, she was. We had good family holidays too, yes.

What did you call your puppy?

Cindy. Everybody called their dog Cindy in those days.

There were quite a lot of popular names, weren't there, that were regular names. Rex for a boy, Cindy for a girl.

Yeah there were yeah. My mother-in-law, she had a retriever that she called Heidi, and then sort of when she retired they bought a schnauzer and she called that one Heidi too. I said to my husband, "That is a funny thing to do ."

What kind of holidays did you have as a child? Did you go caravans, hotel, or camping?

Oh, guest houses, yes. Caravan a couple of times. I used to go swimming a lot. Maybe that didn't help either, yes. I loved swimming. I mean if you have damaged ears, I am sure that swimming doesn't help at all, and I loved the water.

[28:50]

Were you ever advised by the Doctor, you know, as a child, that ---to keep your ears dry or did they give you any advice in that respect?

Not -- no. I don't remember my mum ever saying, no. I remember another thing that you are told not to do at all these days, but my mum was very one for, like, I suppose my ears must have been quite dirty, you know, she was always sort of poking around with them with the, you know, and I remember she used to sort of -- because in those days they didn't have cotton buds so she would get the end of a hankie and twirl it round and put it in and I would be coughing, you know when you have had, you know when the doctors syringe your ears or do anything to your ears, any procedure, if they go in you start coughing, don't you. It is a sort of -- and I was forever doing that. She was always cleaning my ears out. I don't think that helped, you know, with the old hankie twirled at the end, so all these things, when you have a very damaged ears anyway, I don't think they helped, but --

Did your mum, being a nurse and actually cleaning your ear out for you, was she ever tempted to actually try and treat it with a home remedy or anything like that? Or was it always treatment from the GP? Did she use any home remedies?

Yes. She tried the usual warm olive oil, I was forever having olive oil poured into my ears, I mean too much olive oil. It was amazing. We were getting through bottles of the stuff. It was terrible. All the time. Oh yes. She did try. She did try, but I mean there were lots of things that happened that I don't understand why, and it is a shame, I mean my mum is in a nursing home now, but it is a shame that when you don't get to the age I am now I cannot talk to my mum rationally like two women and ask her questions, and when I actually went completely deaf I couldn't talk to her or my father for a long, long time because there were so many things that I questioned but I couldn't ask them because they were questions I wanted to ask them about what happened and why didn't this happen and, you know, but they were very upset at the time because I had lost all my hearing so I couldn't ask them the questions I wanted to ask them. I blamed them because I think you do blame your parents That is what everybody does. I am frightened about what my girls are going to blame me for but yes, I went -- I was very angry, very depressed. There were a lot of questions I wanted to ask them and -- but I could have caused a huge rift in the family because -- yes. There were lots and lots of things that I cannot understand, being a parent myself, if that happened to me, you know, as regards my hearing. I just cannot understand why things went on as they did. Why things weren't done. I know I was probably very, very highly strung, very difficult, but it was because of my hearing loss, I was frustrated, because of these polyps growing in my nose which were huge by the time they were out, huge, I thought I was dying of cancer when I saw them, and nobody -- just dreadful.

What age did you become aware of the polyps?

When I was about 12, about the same age. I remember thinking my nose is always blocked. Forever -- as a child, when you see photos of me I have always got a big hankie stuck up my -- here, sleeve, or here, you know, there was never any pockets, it was a huge one of my dad's hankies, they didn't have tissues in those days, huge hankies everywhere so everything was running. My ears were running, my nose

was running, and when I was about 12 or something, looking in the mirror, you know when you start to get to 12 or 13 you sort of scrutinise yourself and my nose felt very blocked and I remember standing in front of the mirror having a look, you know, like this, and something was sort of glistening up there, and I could feel it right up top here when I put my, you know, and they got bigger and bigger and bigger. Well, on this side, bigger, bigger, bigger.

Did it actually make you feel ill? I know it made you feel uncomfortable.

No. That is the really weird thing, because all these things that were going on with my nose and my ears, no. I didn't feel ill. No. I was very thin. I have always been very thin, probably thinner than I -- because of the constant infections I cannot put weight on. My dad is thin so I don't think I would be big but I am too thin and I was always very, very thin as a child, especially at the top because I couldn't -- I never breathed properly because of the polyps, and because of the ears always running, so it was all this infection all the time, you know, sort of things going on in my head but it didn't seem -- my chest was okay, I couldn't breathe but through my nose. I never knew what it was like to breathe through my nose. Never. I never tasted my food for years and years until these polyps came out. Years and years and years. Never.

[34:22]

You mentioned feeling very angry, and having lots of unanswered questions. Obviously, some of them directed towards your mum, as you have already said, but you obviously -- some of them directed towards the medical staff, the GP, that was actually attending to you at that time. You have also mentioned that the specialist said, you know, take her away, take this child out the room, get rid of her, did they actually follow that through at any point, once you had actually been and had the clearance?

That is exactly what I mean, you know, you saying that. Yes. I mean that wouldn't happen now, would it? Well, if I -- I mean if I was talking to my mother, you know, like this, but it is very difficult when you are -- it is your mother you are talking to, and obviously she would be very upset if I said to her, you know, why didn't you --

why did you just walk away? Why couldn't you say, "I want something done to this child. She is screaming for a reason. She is in agony for a reason", but it was only when they were actually syringing, when that finished, I mean I do remember having earache as a child, though, goodness, yes, oh God, yes, because I had abscesses as well. I had everything. It has been absolutely awful, but yes, I mean obviously I would say to my mum now if she was sitting – you know, I cannot understand why you didn't do something. I was just terrible. Absolutely awful, but it was just these isolated periods in between I suppose we just sort of plodded on. I don't know, but things are easier now, I mean you just give a child a sedative and you would examine them. You would talk to them. Nobody spent time talking to me. I cannot understand why people didn't sit me down and just talk to me, you know.

Was your father supportive or, you know, with the medical treatment, or with the diagnosis?

No. I don't remember my dad being much part of this, you know. Remember, this is all going over years. It is not like -- there were so many different things that happened, with my nose and my ears and -- it is sort of like been going on all my life, really, until I went deaf completely. It is almost like somebody up there saying, "Right, she's had enough now. That is it".

What age -- obviously all this happened, and it was quite an eventful and quite a traumatic childhood for you, and you had got all these emotions, the anger and the frustration, and the unanswered questions that you were looking for answers for. How old were you when the problem sort of flared up, reached its peak, whereby you were referred back to the hospital? How old would you be then?

When it sort of reached its peak? Well, yes. Yes. Well, what happened was, when I was about 18 or something I decided to go to London -- these polyps in my nose were getting bigger and 26 bigger. I had a huge bump in my nose. They were so big you could see them, that I had a massive bump in my nose. I cannot understand how my mother didn't sit me down and talk to me -- I was obviously very, very emotional and she obviously didn't want to upset me. She could see what was going on. I mean

she must have been -- well, she must have done, but I was very good at covering things up, because I was so scared, frightened, really frightened, but anyway, I remember going up to London for an interview in the Bank of England, and I knew I would have to have a medical and I had got these huge polyps in my nose. I mean this is unbelievable. I just cannot believe what these people must have thought of me, but anyway, I remember going with my mum to London for this medical, I had got the job but I had to pass the medical, and we were in this beautiful old building, you know, we had to go right up the top and have this medical and I had these huge things in my nose and she sort of said something, I don't know what she said, but I was right -- I was almost on the edge of sort of madness by this time because it was just awful, and of course as soon as she said this, a stranger, you know how it is, sometimes when a stranger says something you can respond so much -- somebody had noticed this, people must have noticed my nose, we are talking about my nose now, she said "well, we need to get it looked at", and I just ran out of there and ran out of the Bank of England in London screaming. I mean I was just desperate by this time. My mum came out after me and I remember we went and sat in a cafe in London and I was crying.

[Break in recording]

You were saying about you went for the interview at the Bank of England, and in actual fact the lady that was there giving you the medical actually mentioned something about your polyps, and you ran out of the building. Can I just ask, did you actually get that job or did you take that job?

No, because I didn't -- the medical wasn't completed, and I was just -- ran out of the building, so that was the end of that. You know, I wasn't going to -- I had these things growing in my nose that I knew about and I knew that everybody else knew as well, and anyway, I think everything came to a head then. My father, he belonged to the Civil Service, and they had a private medical scheme, and it was a chest hospital, it was for chest diseases, I think, but anyway, what happened was I think actually somebody suggested that I went to see a Doctor in Wimpole Street about my nasal problems eventually because I couldn't go on like this, I would have become a hermit, you know, they were very, very -- well, they were -- it is difficult to explain, but I

used to be able to sort of push them back, you know, push them back-up my nose and all sorts of things, but -- so what happened was I went to Benenden in Kent -- no. What happened was I went to see Mr. Richards in Wimpole Street. He was an ear, nose and throat surgeon, because I knew that something had to be done, and the polyps were very, very bad. My ears were running like mad, and I was frightened stiff, and what happened was I met this -- he was a young consultant, Mr. Richards, and I remember going into this huge great old waiting room, a consulting room, and he was sitting behind a huge desk, and he just talked to me, like nobody had talked to me before about my problems, a bit like sitting here, really, I just talked, and he knew, he could see by just looking at me that really -- I made it seem that my problems were with my ears because I was so embarrassed about my nose but he knew that -- he said to me, "Can I examine you", and I knew that I had actually got to London, so I had to do something now, I had had all this -- all these years, but now was the time, so he took me into his little treatment room and he had a look at these polyps, well, I thought they were cancerous. I was so frightened. He said they are polyps, which I had never heard of before, they are little bunches of grapes and people have them growing all over the place but you have them in your nose, and they were very, very big, mine, and he said there is nothing at all to worry about and I just cried, because I thought, well, I didn't know what to think. I thought I was very -- it was something awful. They were huge and they had got bigger and bigger and they had put my nose out of joint. I had the biggest bump in my nose you had ever seen, and he was lovely. He had the perfect bedside manner, and all my life I have seen so many doctors, and not one of them had been like this consultant. He was absolutely perfect. He wasn't much older than me but he was just perfect. He took me back into his consulting room, sat behind the big desk, and he looked at me and he was very handsome too. (Laughter) He looked at me and he said, "Jayne", he said, "Do you trust me?" And I was just in floods of tears the whole time, and I did. I did trust him. He said, "Right, before we sort out your ears we have got to get your nose sorted out, and this is what I want to do". He said, "First, we will take your polyps out and at the same time we will do an SMR". It is a nasal resurrection, not resurrection a resection, an SMR, a polypectomy, an SMR and then I will do a tympanoplasty on your right ear so that will hopefully enable you to wear a hearing aid and then I will do a rhinoplasty so you won't have the bump in your nose that the polyps have created, and it was like I had been given the biggest Christmas present in my life. This Doctor was perfect.

Absolutely perfect. And so it was just marvellous! So that was the start of things improving a bit, really. And then I went down to the waiting room and my mum was sitting there and I just cried and I said 'he's going to do something', so then we went home and then I went into this private hospital in Kent, and he took the polyps out of my nose. I was only in there a couple of days, and it was just so lovely because everybody was -- wanted to help me and they were so nice and I had a blind physiotherapist, I remember that. He was very nice and I remember when he took the packing out of my nose suddenly I could breathe for the first time in my life properly as well, you know, I could breathe by then. My ears were still running but I could breathe so that was the start of something good. That must have helped everything up there, the tubes being cleared, you know, so that was marvellous, so I could breathe. I still had this massive great bump in my nose but that didn't matter, I could breathe. I am not quite sure how long after that, maybe less than a year, I went into Charing Cross Hospital in London, where he worked as a surgeon as well as having private practice, and he did the tympanoplasty on my right ear, which -- these operations, are never, they never tell you they are going to be 100%, well, like any operation, you never quite know how they are going to turn out but it did enable me to -- the infections dried up just slightly, but I did wear a hearing aid in that ear, so that was good. I was able to wear a hearing aid.

How old were you when you actually got your hearing aid?

22.

[47:12]

If I can just come back, I mean this is absolutely wonderful that you have actually found someone that is actually listening and doing something for you, but if I can just come back, in the meantime, I am quite interested to actually know when you had actually been for the job at the Bank of England, while all this was going on, did you actually seek further employment? Were you employed anywhere?

Oh yes. Yes. I was in work most of the time, yes. I didn't really have -- I wasn't unemployed. When I left school I worked as a trainee pharmacy technician in the

local hospital, and I actually did go and work -- after the interview in the Bank of England I went to work in a typing pool in London. It was round about that time that I had the polypectomy. Yes. So yes, I worked in a typing pool in London, and when I had the hearing aid fitted, after I had had the tympanoplasty I decided to go back and - - because I was better able to hear, and I wanted to do something which was a bit more stimulating. It makes all the difference, doesn't it, when you can hear you just want more, don't you, you just want to grab everything and, you know, it is like being blotting paper, suddenly you can hear and you want to take in everything and I just wanted to carry on my studies so I actually left the dispensing -- student dispensing technician's job because I wasn't getting on with the studies because I couldn't hear but once I had had the tympanoplasty and had the hearing aid I went back to that and finished the studying, but I always wanted to be a nurse, always. When I got the hearing aid I wondered if I could perhaps do my training, become a nurse, so I went for an interview at Charing Cross Hospital in London, and went for an interview in Southampton General, and I decided I wanted to come down south to work, and I actually got the job as a trainee nurse at Southampton General wearing a hearing aid. I actually did meet somebody, I think, a sister, at some point during the interview somewhere who wore a hearing aid of the she was an older sister and she had been nursing for years and she managed, she said, but it was a complete and utter nightmare. A complete nightmare for me. Because I think if you wear a hearing aid and you haven't got infections, you obviously get on a lot better than if you wear a hearing aid and you have got infections because I was forever -- the tube was getting filled up with muck and you were forever having to run off somewhere so I could blow through the tube because I couldn't hear anything without the hearing aid. My left ear the hearing was not good. This was the one that the bead was in all those years ago, I couldn't wear a hearing aid in that ear, it was impossible. I couldn't wear two hearing aids, so the ear I did wear a hearing aid in was just about okay, but it was just a nightmare most of the time. Having to just -- filling up with all the gunge and it was a struggle, a complete struggle. The nursing I started -- I remember one particular day, when you change shifts, and, like, I would come in at 8 o'clock in the morning and sister, who had been on all night would be sitting there, we would all be sitting in a semicircle round her so she could tell us what had happened during the night so we knew what to do during the day and then the cleaners would come along with their vacuum cleaners, you know, and they would start -- and that was the end of me

hearing anything, you know, she may have been -- she could have been miming. I couldn't hear anything because the cleaners were cleaning round while sister was telling us about all the patients and so the cleaner would go off and sister would say, "Well, off you go then", and I would say, "Well, where do I go?" I didn't know what was going on. It was absolutely awful.

Did you ever actually make the sister aware that you couldn't hear what was being said because of the background noise from the cleaners, or did you just carry on regardless?

Oh yes. People knew I couldn't hear but, you see, people's reaction is, "Well, what is she doing this job for?" But I suppose, really, I pushed myself too much in every area, you know, sort of like the polyps and the hearing loss, I tried to cover up almost as if, you know, too proud, I suppose, because that is the way -- I think -- I don't know. I suppose I was just -- it wasn't -- I mean, these days if you have a disability, people -- it is a different thing altogether, but somehow I felt it wasn't right then. It didn't feel like -- I don't know, but anyway, and then the crunch came when one of the patients said to me -- he shouted something at me across the ward and I didn't know what he said and he said "what's the matter with this nurse? Is she deaf or something?" and I thought, "This it". I had six months of training. I thought I could manage it, but I couldn't, so I left then and it was awful. The worst thing I ever did. People say to me, you know, would you have liked to have carried on your training? No. It was -- no. If I had my life again, yes, I would like to be a nurse but everything would have to be right first. You have to have -- I feel, to do it properly you have got to be able to hear properly, and, you know --

[53:09]

After you had actually seen the private -- the Doctor privately at Charing Cross Hospital, and you got quite emotional because at last someone was listening to you and someone was actually interested in solving the problem for you, and you mentioned that you actually went out into the waiting room and your mum was waiting. What was your mum's reaction to the fact that the Doctor was actually going to do something for you?

Well, complete and utter relief. She was overjoyed to see that I was. I mean there are lots of unanswered questions that I would like my mum to have answered, but in her own way I think she felt she was doing her best, but I don't think she was very forceful -- I mean not that that is -- that is not a bad thing, I don't mean that is a bad thing, but I think it is a lot to do with the generation thing. You didn't push yourselves in those days. If there was, like, a Doctor, a consultant, their word was it. That was it. You didn't cross them, or question them, and -- but she did want my best interests at heart but she wasn't strong enough to -- I don't think -- to push it. She was relieved for me, of course. I think. I was just a different person. I remember walking down Wimpole Street -- there have been times in my life when I felt just pure joy and that was one of them. Walking down Wimpole Street, the sun was shining, and my life was going to turn around, you know, my nose was going to be -- I could breathe, I would have my nose straight, I was a young woman, you know, I looked awful. I had the biggest -- and the bullying and the -- when people talked to me they would look at my nose, you know, like when you lip read, like I am looking at your lips, and I used to -- because I am not a very confident person myself, I used to feel embarrassed because people were looking at my nose when they were talking to me and the same when I lipread now I feel embarrassed that the person I am lip reading will feel embarrassed that I am looking at their lips but it used to be people looking at my nose when I was speaking at them so everything was going to be resolved. I would have a straight nose, I would be able to breathe, I would be able to taste my food and I would be able to wear a hearing aid so that I could hear better. And I had this lovely man who was going to take care of me. Wonderful.

Once you had actually had the surgery and your polyps done and your nose done and all the other operations, the other surgery, what was the reaction, perhaps, within the whole family? Did you feel more included, or more excluded? Was it a good reaction that you got from your family? Were they happy for you, or your brother, your grandparents, your father --

Oh yes. They were happy for me. Yes. They were happy. Yes. I was overjoyed. I always felt -- I never felt they weren't involved with me. I never really felt they didn't love me. I don't want that to come across. No. I never felt that. I just think a lot of it was the generation thing and that -- you see, these days we all talk about our lives,

like I am doing now in anything and everything, and nothing is taboo. Everybody knows everything about everybody but in those days it was different, and I think people were a lot more proud in those days, and, I mean, I do think that things could have been different, mind you, but that may be talking from somebody of my generation. I mean I think why did my mum not do this, why did they not do that, I cannot understand it, but I am sure in their own way -- I never felt they didn't love me. We did have a lot of fun. You know, no, not that at all. I am sure they must have asked themselves some questions later, why did we let this -- I am sure, but I do feel sometimes that some things are better left unsaid. I don't know. I don't really know. I just want to say I don't feel they didn't love me at all. They did. But there are things, I think, that could have been different. Yes. And I am sure that deep down they probably think that too. Well, my mum, she is in a nursing home now and her mind is not right, so a lot of questions will never be answered.

[57:52]

Because of the -- this was all happening, obviously, as a young lady, a young woman. Did the fact that you couldn't hear right and the fact that you were so self-conscious and embarrassed by the polyps and by the shape of your nose, your features, you mentioned being bullied, but if I can just ask you about relationships, did you find it easy to get into, you know, personal relationships with the opposite sex? Did you have boy friends or dates?

Oh God yes I did. Do you know honestly, I mean that is another thing I just don't understand because yes, I did. Because these polyps, not so much my ears, I mean obviously I did have runny ears, but that you can -- unless they are running all the time you can sort of conceal it, you know, and I had long hair, I have always had long hair because of my ears, you know, because of the infections I didn't want -- even now, you know, but yes, I couldn't breathe through my nose.

If we can actually go back to the question about boy friends? Just tell me as much as you feel comfortable telling me.

Yes. I had boy friends, but obviously the main embarrassment were the polyps that were in my nose, you know, especially down one side were very big, but I was able to sort of just press the side of my nose and they would sort of pop up. It sounds absolutely horrendous, doesn't it? Well, the Doctor did say they were the second biggest that he had come across, and, you know, when they took them out they sort of used them for training purposes. It is not funny. It was actually awful, but I was very good at concealing things. I couldn't breathe, mind you. Obviously people used to say to me all the time, I remember the teachers saying to me at school, have you got adenoids Jayne, I didn't know what they were, I did not have adenoids I had polyps, but I didn't know that at the time, but they were always saying to me have you got a cold, you know, because I always had these huge hankies sticking out of my shirts and my ears were always running, but no, with boy friends, I managed to conceal it. I don't know. I don't understand it myself.

What kind -- you know when you were actually courting, before, you know, while all this was going on in your between age years and early twenties, what kind of past times did you follow then? You know, when you went out? Did you socialise? Did you go to pubs? Did you go to theatres? What kind of things did you do when you went out on a date?

Yes. I used to do -- when I got the hearing aid, obviously, things improved a lot. I think -- yes, I did what all other girls of that age did, you know. I used to play squash, go to discos, just the normal things, you know. I had a normal life, really. Well, apart from the fact I couldn't hear properly and my nose was bunged up and everything. I just concealed everything very well, I think. I think the biggest thing, when I had the polyps out, that improved my life vastly, and having the hearing aid, and really, I always feel that from the age of about -- well, I remember the best time in my life has been since I got married, but before that it was a struggle with the hearing.

[01:02:00]

You know you mentioned when you got your hearing aid, life improved for you. Before you got your hearing aid, how did you used to find – what method did you find

was the easiest for you to communicate with people when you weren't sure of what had been said? What was the easiest method for you?

I think because I always -- I mean I wasn't actually aware of using methods. It is funny, isn't it. I wasn't really aware of having any particular methods. It was just like, you know, I cannot say, you know, like people say they have been lipreading for years, that sort of thing. Well, I suppose for years I have been putting myself in the position where I could hear, but you are not conscious of doing it. I was never comfortable in a big group of people or socially, I suppose that was why, because I couldn't hear properly. I have always much preferred, all my life, one-to-one. I have made some very good close friendships, but I am not very good in a big group. Probably that may be why, I don't know, or maybe I just like the--

Did you find that when you got the hearing aid I know your whole life changed, but did you find, as time went on, it got a little bit easier for you? Did it take quite a long time for you to adapt to the changes once you had had your hearing aid, or did the changes happen almost immediately?

Oh no. I mean it was wonderful. For me, anyway. I just -- I must have been craving it or something because I had the hearing aid it was just the most wonderful thing. For me then. I did not have any tinnitus or anything. Everything sounded a lot clearer. I mean I still couldn't hear much out the other ear but having enough in this ear, it was just wonderful. Absolutely wonderful.

Over the years you mentioned that it has deteriorated over the years. When did you notice that it first started changing and actually getting worse where the hearing aids weren't as effective for you?

Well, I suppose when the infection started to -- when it runs more and you have to keep taking the hearing out to blow through the tubes to clear the tubes, that is terrible because I found that the job I had was quite stressful, so I was hoping with a hearing aid that was not working for me all the time because of the infection, and trying to be on top of the job, learning the job. We were setting up this manufacturing department within a hospital, and it was all new to everybody, and so I found that very, very, very

hard, trying to -- a new job and -- but, you see, if I had my life again I would say why did I struggle so much? Why did I have to prove to myself that I could do all these things? Why didn't I just say well, I want a simple job, an easier job where I don't have to struggle but I don't know I just—I just.

How old were you when you noticed that it was actually deteriorating, that your hearing loss was deteriorating?

Well, I suppose I was in my thirties. Yes. I suppose in my thirties. Mid thirties I really started, maybe. I think what happened was, is that I had the hearing aid up to high and I think in a way that probably damaged the hearing I had left as well, because when I had children, you know, I was conscious of turning it up and knowing that it was a little bit too loud, but that was better than having it maybe a bit softer but I couldn't -- and I remember walking them to school and the traffic being so noisy and thinking, "I know this is going to damage what hearing I have got left", but I just felt I couldn't do anything about it. I didn't want to turn it down. I don't know. I suppose about mid thirties, really.

[01:06:57]

How old were you when you met your husband?

27. He didn't know I had a hearing aid. I remember when we went to France together, and it is funny, isn't it, because I suppose when you are young you are still a bit self conscious, but I remember we were in France together, we were sitting there, and I said to him you know I have got a hearing aid, I thought it was the most awful thing, and of course he didn't blink. I mean, so what, you know, not so what, I don't mean that but it didn't worry him, of course not, but to me it was awful. Terrible isn't it, really, there is nothing wrong with having a hearing aid but I was young then, you know.

How many children have you got?

Two. Two girls.

What are their names?

Caroline and Claire. They have been here to the Link Centre. They came with us for the week, rehabilitation week nine years ago. 2000.

You mentioned that your hearing has got actually worse as you have got a bit older, and that you had already got the children. Can I ask you a little bit more about the impact, you know, that they actually had on your family life? You have mentioned turning your hearing aid up to be able to hear more the quieter sounds, but can I just ask you a little bit more about the impact, how you actually coped with the children when they were little and in the family environment?

I don't remember it being too much of a problem actually because when you are in a house with children, the acoustics are quite good, aren't they, and there is only like you, me -- I didn't work. I -- I was glad when I got pregnant because I find working with hearing loss a bit of a struggle, doing what I was doing but I suppose it is what job you do, isn't it, really. I mean, you know, but I just sort of carried on and then when I got pregnant with my first child I left and I was relieved, really, you know, that I had an excuse to not work, you know, because it was just too much. Everything had been a struggle all my life and this is what I wanted, you know, but when you are in an environment like a house, you know, and there is all the soft carpet and the curtains and just you and the children, it was okay. I didn't find it a struggle, really. I was actually quite enjoyed -- I mean obviously I wasn't hearing, but, you know, it is not an environment where you have to struggle so much, is it, when you are in your own home with your children, and you are in control, and, you know, if your hearing aid fills up it is fine, you just take -- but when you are in like a professional environment, working like I was, it is awful. Absolutely awful. It was in a wrong job completely. And I just couldn't get enough information. I couldn't do my job properly. I wasn't on the ball enough.

How old are your daughters now?

Caroline is 24, Clairee is 21.

As they got older and as your hearing loss deteriorated, did you find that your husband – what is your husband's name, again?

Tony.

Did you find that Tony and the girls, did you find that they were very supportive, or perhaps when they reached their teens did it create any problems, the fact that your hearing was deteriorating?

It did create problems terribly for me because I felt quite in control of my life, sort of, you know, with me and the children growing up, and -- but it did create problems because I was used to running their lives. I was able to use the telephone, if I held it in the right position, with the hearing aid ear, not the other ear, I couldn't hear, I was able to do that so I could organize all their activities. I mean obviously things like going to see them in school plays and things, you know, I didn't hear that, but on the whole, we managed okay. I could hear what they were saying most of the time, they - - you know, over the years they get to know how to speak to you more, it just becomes a natural thing but it did create problems when I lost my hearing completely because from being a mum, you know, when you are a mum you do a lot of things, you answer all their questions, they direct a lot of their questions to you, suddenly they were doing that with my husband and they were talking to him and -- because I couldn't hear anything and it was all new and mum was crying all the time and screaming and when I was actually in the process of going deaf for me, it was like I was dying. I was dying. I was crazy. I had so much tinnitus, and at night time, when the children had gone to bed, I remember being in bed and I had so much noise in my head. I was screaming. I was crazy. Tony was saying 'shush', the children will wake up, and I was screaming because the noise was just unbelievable in my head, and I couldn't hear anything but I had all this noise in my head and that was the end of a life, as I had known it, when I lost all my hearing in May 2000. So obviously, I mean it was difficult because I wasn't the mother they knew. Actually losing my hearing, it going down quite sharply, took about six months, after I had had the mastoidectomy. I don't think that was anything to do with it, I think it would have happened anyway, but I was pretty ill anyway before I had the mastoidectomy. When I went for the operation, and they were examining -- well, going through the pre-op forms I have to

fill in, the doctors, I knew that something big was going to happen in my life. I just knew. The way I felt in my head. I didn't feel very well at all and yet looking at me they said well, what is wrong with you? I was crying, and I said I don't know. I just don't feel well. I just don't feel well, and I was about to have this mastoidectomy. , but you are all right, we have done blood tests, we have had chest x-rays, I know. I cannot put it into words. I just feel really ill, but you look fine. I know. I can carry on, I can get my family their dinner, I can carry on but I don't know. There is something going on and I don't know what it is. I mean they obviously knew my hearing wasn't -- but it was a whole body thing, and I said I don't know what is the matter with me but I just don't feel well and of course the thing is, they have got to decide whether to operate not, and I thought well, they say it is all right, so -- and I thought well, so I went ahead with it, with the mastoidectomy, but really I have never, ever felt so ill in all my life as I did after I had had that. What I felt before I felt worse after that. I don't think it was the actual operation. Well, I think the anaesthetic, the whole trauma of it, so after that -- and then six months after that I was completely deaf.

[01:14:44]

What kind of impact did it have on your life as a family? Did it have any impact on your relationship with Tony? The fact that you were ill, and the fact that you had now lost your hearing?

Yes. He has always been very, very, very supportive. I couldn't have got through it without him. No way on this earth. No. No. He has been fantastic. But obviously, yes, it is a strain. Because you know we came to the link centre for a week in 2000, and it was great, and they told us all these coping strategies, and everything, but I know that when you get home things are just the same, you know? You know when you -- everybody, like the children were doing their -- everything carries on as normal but you are dying. I was -- it was like a living death. So when it affects -- well, yes. You cannot communicate properly. We had had a few months of getting used to this because my hearing had gone down, so when it went completely, well, actually, anybody who has a residue hearing, even if you have the slightest bit of hearing you are still in the hearing world, but once you have lost that completely there is nothing --

it is no comparison. You can have a little bit of residue of your hearing, you are still in that hearing world but when you have lost your hearing completely, it is a different ballgame altogether, isn't it. Completely different ballgame, I think. It is like when I go to lipreading classes I am the only one who has lost their hearing -- well, like -- there is a lady with a cochlear implant and she does very well. I have been told I cannot have a cochlear implant, but of course, the only way is by lipreading or with the screen here, so I get everything that the teacher is saying because she is lipreading very well, very slowly, but then everybody else with a little bit of residual hearing or the -- can get things when they -- repartee. That is what I miss, the repartee. I do not get any repartee now. Little interesting bits of conversation, you only get what people want to say to you, so, you know, so you don't hear the interesting bits so life has got no atmosphere. It has got no atmosphere, you know. That is what I feel anyway. Always have felt since I have lost my hearing. There's no fun.

[01:17:35]

You have mentioned that they have told you that you cannot have a Cochlear implant. Is that for medical reasons?

Well, when I lost all my hearing I went to see a Professor of something or other, hearing, at Southampton, in Southampton, and he did -- he spent about two hours doing all these tests and he told me that I did not have a working cochlear, and you have to have a working cochlear for an implant, and he had no idea why I had lost my hearing. I had no answers. I felt so ill over all this, physically very very ill, and I decided -- I haven't been to a Doctor about my ears since -- after about six months after I went deaf. That is it. All these years. I haven't seen an ENT man at all.

Was it at that point when he actually told you that you couldn't have a cochlear implant, that you wasn't a suitable patient for an implant and you have not seen another Doctor ever since? Is that correct?

I wasn't suitable -- no. Yes. I haven't seen -- not because I wasn't suitable for a cochlear implant, that is not why I haven't been, I haven't been to see a Doctor because I have had enough. I have come to the end. I had had enough. I thought if I

can physically make -- if I can recover physically, in other words, don't feel so ill I would be able to cope with the deafness and that is what has happened. I feel physically a lot better. It has taken a long time but I feel physically a lot better so I am able to cope now but my ears are terrible, so I am sitting on a time bomb, really.

[01:19:40]

Can I just backtrack just slightly? Because you actually described how you actually felt like it was a living death when you actually lost your hearing altogether, and the impact that it actually had on you personally, on how you actually felt. Can I just explore those feelings just a little bit more? When you realised that you had lost all your hearing altogether, that was in May 2000, and obviously you said it was just an existence for you. What was the state of you, emotionally? How did you feel emotionally?

Bereft. Completely and utterly bereft as if -- well, I did see some doctors, they start to talk to you about the emotional problems, you know, because it affects -- for a couple of times after I went deaf I did meet one or two doctors who were very patient and had written down -- wrote down everything for me and one of them described that actually when you lose all your hearing it is like losing somebody close to you. It is like a death in the family, and that is exactly what it was like, and the emotions that you go through, they say there are seven stages of grief, and you go through anger, frustration, despair, depression, frustration, all this, I went through everything. Everything. I didn't speak to my mother and father, they used to come over. I remember them coming over to see how I was. I didn't 'phone anybody, only my immediate family. I was able to go through the motions with my family, the children were fed, watered, and everything. I tried to keep exactly the same at home. I don't think they were emotionally scarred by it at all, because Tony and I, we managed, you know, everything they needed they still had, but I was dying inside and we were really struggling but when you are a parent you just keep going. Well, I did, so that kept me going, I think, the family, but really, yes, so I went through all those -- I didn't speak to my -- when my parents came round to see how I was, we would sit at the kitchen table and I just couldn't answer them. I was just distraught and they tried to talk to me like they had always done, and I just didn't want to talk to them and they used to talk

to each other to try and make things normal for me and they have always been with each other, they have always talked a lot and laughed a lot and joked a lot so they were sitting at the table and life was carrying on as normal for them. They were trying to make things normal for me, but I just wasn't interested so I didn't talk to people for a long time. I would only talk to -- I didn't go out of the house, and my little girl, she was in the last year of the junior school, so she was about nine -- well, she was coming up ---no. She was in year 5, and she had to walk to school on her own after that. We live in town so she was able to. it is about a ten-minute walk to her school but I had been taking her, but when I lost my hearing completely I couldn't go out of the house, and we decided that she was probably old enough and capable enough of walking to school on her own which was lucky, and that is what she did from year 5. She walked to school on her own. I couldn't go out of the house. I just cried and howled most of the time. Tony had time off when I really needed it. They were very good. His firm were very supportive. He was able to work at home a couple of days a week to help me out but on the days he didn't he would be leaving me crying, he would come home and I would be crying.

Did you actually --

I felt like the world was black. A black place.

Did you actually have support through that time when you had actually coming to terms with the total hearing loss and the emotions and while you were going through the grieving process, did you actually have any professional support for that, or did you take any medication or anything like that?

Yes. There was a lot of support if I needed it. I was very lucky, yes, because I have heard that people don't have -- yes, I was very lucky where we live. I was with the hearing place, you know, at the hospital, so there was the hearing therapist who tried me with all the different hearing aids before I went deaf. I had the consultant, and I had the Social Services, the hearing people there were very, very good. I got quite friendly with one lady, you know, who used to come a lot. This was fairly early on, when I had just gone deaf in the May and just before that, and I was still in the hearing world, to a certain extent so I didn't actually start going down into a decline, if

you like, until -- I went deaf in the May I still felt I was in the hearing world but as time went on, and things started to -- that is when things really got bad, and yes, I had a lot of support but in the end because I felt so ill, I didn't want to talk to anybody, I had had enough. I didn't want to go anywhere, do anything, I just wanted to just work it out, so I didn't really want to interact with anybody so I cut myself off from everybody, apart from my family, you know, and I wasn't very sociable and I didn't want to see anybody, so that finished.

[01:25:35]

What about the impact on Tony, you know, the fact that you actually didn't want to socialise? Did it have an impact on his social life, and on your relationship, your personal relationship, your physical relationship? Did it put a strain in that area, or did you just find a way to deal with that situation?

I don't actually feel -- I would say that actually having gone through all this I have seen a side of Tony that I wouldn't have seen if it had not happened and he spent so much time with me listening to me, he's just -- so I don't really think -- obviously things like talking, you know when the light is switched off and all those sorts of things, all the spontaneity has gone. That is the thing with going deaf. You don't get the spontaneity so that's gone, and that is hard, but I think he was very depressed, at one time he had to take antidepressants, well, I was taking them too. I didn't take them for very long because I didn't feel they were doing any good at all and he didn't either but I think it has affected our relationship to a certain extent I mean, because he gets cross with me sometimes and, you know, he has a stressful job, and I don't think it has affected us so much that we would -- it would break down the relationship, though, no. It makes things harder. Any disability in a family makes things harder for you, but you have to learn -- as you were saying earlier, when you are right at the bottom the only way is to go up and it is right. You just have to make the most of what you do have, and I know it is what people say, it is a cliché, but you do find joy from other things more when you are deaf, you know. I mean but -- as far as our physical relationship and everything, I don't think it has changed anything, really, but I think that is to do with a couple, isn't it, really. I think that -- I think maybe a conversation would be less -- you know, we sort of had more fun, maybe. Have more fun. The fun

has gone out of it a bit. Yes. I mean I cannot hear his voice any more. I really miss that. When – he has got quite a deep voice, hasn't he? I don't know, I seem to remember he has got a deep voice, and I remember -- unless it has gone up a bit shouting at me all the time, I don't know, but I remember when I was going deaf, saying to him just say something, because it was very distorted my hearing as I was going deaf, so I only got certain consonants, you know, and I remember I didn't want the sound of his voice to go, and when it went completely I was distraught, so I very, very much miss hearing his voice, and laughter, you know, I don't think we have as much laughter. I mean not that he's a huge big joking sort of man, but it is the fun side of things, isn't it?

Can you actually remember, is it stored in your memory what his voice sounds like?

His voice? Yes. Yes.

Can you remember can you?

The children's. Of course they have grown up now but -- because it is funny, my daughter is doing an English degree in Manchester, and we were talking the other day something about how clear voice is, and I said to my sister-in-law, well, I don't know what Clairee's voice is like because she was a child when I lost my hearing, and she said oh, it is very clear. Very clear.

Do you rely on your daughters to actually tell you what someone's voice -- do they try and describe someone's voice to you so that you can sort of visualise it? Is that what you are explaining to me?

Yes. I think when you have lost your hearing, you probably remember, you are desperate to know what something sounds like, like in the hotel this morning I said to Tony, is the music playing, when we were all having breakfast, and, you know, music, when I was going deaf, the transitional stage from going down, those six months, it was a spiritual thing because I had the most beautiful noises, music in my head. I have read about this somewhere. It was just absolutely unbelievable. I couldn't believe -- so I do believe there are so many things that happen that we just don't know

about, that are beyond our -- we will never know about, and this is one thing in my life that, in a way, I feel quite privileged to have experienced this music in my head. It was like -- I don't write music, but if I could have written music, when this was happening, it was absolutely the most beautiful, haunting music I had ever heard in my life. The music that John Taverner composed for Princess Diana's funeral, that music I could hear then. It was haunting, that music. Did you have music when you were losing your hearing?

Yes, I had it as well.

Just absolutely amazing. I just -- but it has gone now.

[01:31:28]

Was that a part of the tinnitus that you actually -- the music that you heard, did it come -- because obviously the tinnitus, we all describe it as hearing different sounds and some people describe it as hearing music, so was that the tinnitus, do you still have the tinnitus or was that separate from the tinnitus?

No. No. This was music. No doubt about it. I have tinnitus now and it is terrible. Absolutely awful. No. This was music. It was just -- and I know I have read that, you know, they say that musical people often have this when they are going deaf, but no. This was just -- I used to say I have got all this music in my head. It is just wonderful. I was desperate to write it down but I cannot write any. It was just -- I miss music because when you are deaf, with the tinnitus, all the time you don't get any peace. It is like mental torture. It is like you don't -- I mean you do have -- there are highs and lows, sometimes it is worse than other times and sometimes I think oh, this is wonderful, there is not much noise in my head at the moment but other times I just want to die it is so bad and I feel ill then when it is so bad.

[Break in recording]

[01:32:57]

So you mentioned about listening to music? and how you wished you could actually write the music. It actually brings me to my next question of is there anything in particular, hobbies, and interests, that you actually do now?

I do now? Well, I have always loved reading, so I read, is the word, "Voraciously"? I don't hear my voice at all, so I am very conscious of not pronouncing things properly, but that is the word, I think, voraciously, so I have always done that and I have just read the book, *Deaf Sentence*, by David Lodge. Have you read that? I recommend that to any deaf person. It is absolutely -- well, it is a novel, it is a fiction, but it is funny and good. So that is always -- I have always read, so that has helped me. At the moment, I go to lipreading classes. I am very much quite happy at being at home, so in a way I always felt that for me, going deaf, I wasn't one of these sort of people that has to go to every club and everything that is going. You know, I quite like to be in the home and those sorts of things so it wasn't -- so it was very isolating when I went deaf but I didn't feel that I was missing out on -- I missed out on having my friends over talking. Talking is -- you know, having a laugh and spontaneous conversation. That is the thing I have missed most. It is not going to clubs and -- but, having said that, we have set up a little club, Tony and I -- well, I say a little club, but we advertise through the Link magazine for anybody who lived near us who had hearing problems and would like to meet socially and now there are five of us, three hard of hearing, two spouses, who meet together, you know, once in a while and we -- well, we really enjoy that, just have a meal, you know, and a chat. I go to lipreading classes now but it has taken me all this time to pluck up the courage to go to lipreading on my own because I did go to a few classes before, when I first went deaf, but I was just too emotionally wound up in the way I felt to go because everybody who was there, again, most people could hear and I couldn't hear anything and I just felt different, completely different, so what keeps me going now is -- the children have left home now so I decorate. Do lots of decorating, but I am also busy with my mother and father because my mother is in a nursing home, my father is 86, so he's good, there is a lot going on in the family, and my brother lives nearby with his wife, so I am quite busy, you know. I do see friends regularly that I saw before I went deaf, and I will say this to anybody who is listening, so I never for one minute thought that I would be able to sit down and have a conversation with my best friends when I went deaf like we used to, but although it is not the same for them, obviously, I can lipread

them like they are speaking and I never thought I would get to this point, so what they say, there is life after deafness and I didn't think there would be but there is for me.

Do you feel that you have actually come a long way since you actually first went profoundly deaf in May 2000? Do you feel like you have actually made progress?

Yes. Absolutely. Yes. I do feel I have come a long way but a lot of that is because physically I feel better. I always knew, right from the very beginning, that I would be able to cope with this deafness if I hadn't felt so ill, so I realise, I think, that the reason I went completely deaf was because I was ill. The virus that attacked my ears, because they were the weakest point of me and I just had so much struggling with listening and everything, I had had enough, and I think that somebody had given me -- well, it wasn't a release then, of course not, but I think you have to get something out of a situation to move on, and I wouldn't say I wouldn't want to hear again or say anything like that because of course I would, but it is the peace you get with being able to hear properly. The peace that comes with it. I would just love to sit in a room with silence and hear a pin drop. That would be a dream come true. Just to have hearing, perfect hearing for five minutes, have all this noise gone, and just sit and listen to the silence and maybe some birds singing and maybe Tony saying, "Jayne", and hearing the girls laugh. Yes.

[End of recording]