



Unheard Voices: interviews with deafened people

Tony Rugg
Interviewed by Stephanie Pennell

British Library ref. C1345/32

IMPORTANT

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Interview Summary Sheet

Ref no: C1345/32

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname:	Rugg	Title:	
Interviewee's forename:	Anthony	Sex:	Male
Occupation:	IT Consultant	Date and place of birth:	1955, Bridgend

Date(s) of recording: 14th March 2009

Location of interview: The City Inn Hotel, Bristol

Name of interviewer: Stephanie Pennell

Speech to Text reporter: Mirella Fox

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Interviewer's comments:

[Track 1]

This is Stephanie Pennell, interviewing Tony Rugg, on Saturday 14th March 2009 for the Unheard Voices project in the Bristol City Inn hotel Bristol. The Speech-to-Text reporter is Mirella Fox. Anthony Rugg is the hearing partner and his wife has already been interviewed for this project. Tony, could you please give me your full name.

Anthony Clifford Rugg.

Could you please give me your occupation and if you had one a former occupation?

I am currently an IT security consultant working for Lloyd's banking group; before I worked for ICL which is a computer group. So basically I am into computers.

Could please give me your name and date of birth, sorry, your date of birth and place of birth?

14th October, 1955, and I was born in Bridgend in Glamorgan, South Wales.

Could you tell me your father's occupation?

My father was in the construction industry, so he built houses and small factories.

And your mother's occupation?

My mother had various jobs. She worked in a jewelers; she worked for a forestry firm, garden centre, so she was a Jane of all trades.

Thank you. Now, could I ask you about your family background? Thinking in terms of your grandparents, can you tell me anything about your grandparents?

My grandparents on my mother's side they died when I was very young, I think I was about 3 so that would be 1958. They lived in Monmouth, which wasn't England and wasn't Wales at the time, it was in the middle. But I believe Christmas Eve one year, they were gassed at

home, because they left the gas fire on, some tragedy like that, I vaguely remember which was very sad. So I didn't really know my maternal grandparents. My paternal grandparents, my grandfather was called Percy. Unfortunately I can't remember my grandmother's first name. But yes, they came from Greenwich in London, and I think my grandfather worked on the Thames barges, which is obviously an occupation that doesn't exist any more. And my Grandma, she ran a small cafe, for all the barge men working on the river.

Thank you. Can you talk a little bit about your parents?

Yes. My mum and dad, unfortunately my father died nearly 4 years ago now, when he was eighty; my mother again unfortunately is in a nursing home in Northampton, near my sister. And she is 85; but yes, I had a very nice childhood with them. We moved quite a few times around the country, because my father was into construction, and we ended up going where the work was, so we started off in Wales, and then we went to the Midlands to Stratford on Avon which was very nice, and yes, I had quite a nice time in the school holidays. I used to go round with my dad to the construction sites, so while he was sorting things out there, I would sit in the shed and play with my Lego. And I even learned how to drive a dumper truck when I was about 12, so it was very exciting for a young boy.

Did you have brothers and sisters?

Yes I have an older sister, Sue, Susan; she got married when she was 17, so I only really knew Sue up until I was 12 years old. So she lives in Northampton now, and I see her more often now because I go and see my mother up there. So I see her more now than I have ever done I suppose.

Were you close to her as a child?

Well not really, because we didn't really live together at home at the same time, because we both went to boarding school, when I was young in South Wales. So, although our schools were only two hundred yards apart, I never actually saw her there because she was at a girls' school and I was at a boys' school and in those days we weren't allowed to talk to each other.

[05:56]

That was my next question in fact about education. Can you tell me about the schools you went to as a child? And the whole route of education upward?

Right okay. I started off at St. Johns Preparatory School, which is a private school in south Wales. I think because my grand, my mother's parents died early, there was some money in the family that provided for our private education. So, right from the age of five I went to this private school from the age of five until 13, and when I was ten my parents moved to the Midlands so rather than being going to school every day I became a boarder. So I actually stayed at the school full-time. Then when I was 13 I took a common entrance exam and went to another private school called Warwick Public School in Warwick; so there I did my O levels as they were then, and my A levels and finished in Warwick I think it was 1969. I went to Central London Polytechnic, which is now called the University of Westminster. And I studied Business Studies and Spanish. I then graduated four years later with a degree, and that was the end of my education, or my formal education at that time.

Fine. Did you go straight into employment after that?

I did go straight into employment. I know a lot of people have a gap year, but I had my gap year before I went to university. I worked for nine months to get some money together so I worked in a baked bean factory, I worked putting up fences in the fields, I was a Corona salesman selling pop and I did all sorts of things to earn money. And then I went to Canada to Vancouver Island where I had a relative that nobody had seen since the war, but he gave me a job and he put me up for a few months. He even found me a car. I bought an old 59 Chevrolet and then drove across Canada and then when I ran out of money, I flew back to from Toronto to London and then I went to university. So that was a good break. After my A levels I decided I had enough of exams and education, so I had the year off at that point.

Going back to your education, as a child then in private school, and then becoming a boarder, and staying away from home if you like, did you have any particular effects of becoming a boarder and being away from home?

Well I became terribly home sick. I always remember the first day back at school or at term was very traumatic every time. It never got any easier. But as I say, after the first week

everything was fine. It is just I suppose the thought of that first week it was very difficult. But I wasn't alone; we were all in the same boat. So, to me it was just part of growing up.

Did you have many friends at school?

Yes always had lots of friends.

Do you think you were popular?

Well I had lots of friends yes, I suppose I was popular. I, in the junior school I became the head boy, it was very small. There were only a hundred boys in the school. So, you know, I was the tallest, so that probably made me the most important!

[10:48]

Moving on a bit. Did you have particular hobbies over that time?

I remember collecting stamps. A lot of young boys did at school at that time. Very old-fashioned now but I remember I had my grandfather's stamp collection as well, which went down very well. So I was always very popular with the stamp clubs swapping stamps because I always had the oldest ones. I have always liked sport so I used to like playing cricket and football. And athletics and then I played rugby later on as well which I thoroughly enjoyed.

Was that part of the school ethos if you like?

Yes, of course. Especially the senior school, and again in those days school was six days a week including Saturdays. But we always had sport on a Wednesday afternoon and a Saturday afternoon, where you go round the local schools playing rugby or cricket, life was much more competitive at school in sports terms. So I think it is missing these days, but I am becoming a grumpy old man like that!

[12:18]

Tell me about your time in Canada?

In Canada. Well, where I actually went was a place called Salt Spring Island and I looked it up on the map before I went, and it was a small island between Vancouver and Vancouver Island, so I thought, well, it has to be very small I thought. And there must be a bridge going from Vancouver to this small island. But it was a two-hour ferry trip because as you know in Canada everything is much, much bigger. When I arrived there, I didn't know who I was going to see, what he looked like, but he met me off the boat and he was larger than life, he was he had silver hair, he was an estate agent and he had a fantastic house. And the work he helped me out with was on his own house; he was having a special house built by the sea. These islands - how can I explain - they are like the Greek island only with trees on, and it was absolutely amazing. So we built this amazing wooden, everything is wooden, they don't have bricks of course. One particular story I don't know whether I am digressing, but one particular story we had to go to one of his clients' houses and pick up a piano to move to their new house. But this house was on a rock in the middle of the harbour, basically a big rock. So he got some of his friends with a big fishing boat, a trawler, and we all went out to the island to pick up the piano, and when we got it back on the boat, we stopped in the middle of the harbour, and we got some crabs from the crab nets, brought them on board and of course being a big fishing boat they had a galley and a stove and so they boiled up the crabs, and then out came the bottles of whisky and beer and there were about eight of us and we all just had a party on the boat. And then we finally got back to land, we put the piano in the back of a truck, an open truck, and four of us sat on the back on the sides with two of them playing the piano as we were driving through the countryside. Worse for wear! But I was 19 and it is something I will always remember.

That sounds wonderful.

It was.

Thinking of that house, how did it compare to your own house?

Well it was a ferry house but we always lived in very nice houses, because my father was in the construction industry. He knew what a good house should be like. So and because there was obviously an inheritance from my mother's parents when they died, my father never had a

mortgage. I only found out about that about ten years ago. But to have life without a mortgage must have been amazing. But we always had a nice house to live in, always four bed roomed detached, nothing over the top but they were always very nicely done.

Did you have land with that house?

No, no. We were usually in towns. We didn't live in the country.

[16:20]

Moving on a little bit, apart from the time in Canada, did you have other holidays away?

I quite often used to travel. My father was always very good at encouraging me to travel. So, when I was still at school, I think I was only 16, 3 of us went hitchhiking around Europe, can you imagine that happening now? But so, yes, 3 of us, we hitchhiked to Germany, because we met some friends on a German exchange trip. We thought it would be nice to go see them. So, we hitchhiked to Germany, very cheap. We did actually lose one of us on the way back, because when you hitchhike it is very difficult to have 3 people, so we used to split up, two and one. One day on the way to Luxembourg youth hostel, our friend didn't turn up. So we thought, Oh dear, so we rang up his mum and dad who weren't very happy. And we came straight home, and Interpol was contacted and it was about four days before he turned up home and said to us, "where on earth have you been? I had a great time in Paris"! So, it was all right in the end. So I was very used to travelling on my own. We had an Inter-rail ticket, which is where you travel round Europe for a month on the train. I did that twice, once on my own which was even better because you meet more people when you are on your own. So there is all sorts of stories to tell. But I won't bore you with it here.

You mentioned the two fellows you went with. Are they particular friends still or are they just for that time?

They were for that time. I haven't really seen them since I left school.

Do you have friends from school that you are still in touch with?

Just the one. He is called Wilf, he lives in France now. He married a French girl called Gislene, and going to his wedding in France was quite an occasion.

Moving on. Do you have any religious beliefs?

No, not really. I suppose I class myself as a Christian because I have been brought up that way. But we don't go to church very often. It is not that I am against religion, I am just a.... just I.... just don't.

And what about politics, do you have an interest in politics?

Not really. We talk about politics at work a lot; obviously. But I must admit I am generally apolitical, so in other words, basically anybody who gets into government they are all as bad as each other! So a normal sort of view I think.

[20:07]

Moving on now to talk about health care professionals. I would like to talk about your wife's situation.

Of course.

And your situation and how you are affected by what has happened to your wife. When did you meet your wife?

I met my wife in 1979, 1980. It was when I left university. And I applied for a job with a company called ICL which is a computer company. And they asked me where I would like to work, of course I didn't mind where. I said London. And I ended up in Southampton. But I lived in a small village. I found a room in a cottage in a little village outside Southampton. And it was there are about four or five houses full of professional people, young professionals, who had just left university. And one of them happened to be Andrew who is Jayne's brother, so that's where I met Jayne, through Andrew, in Southampton.

So, did you start to go out with Andrew or did you just decide that Jayne was a good thing?

Can you talk through that process?

Through the process? Well, it was a bit like a fairy tale really. We lived in this small village; it was about five or six houses all thatched cottages. And each one had about four or five single people in. So if ever you wanted to go out for a drink there was always somebody who was willing to go with you. We all had our own different sorts of sports cars. So I had a Triumph, other members of the village had MGBs and on Sunday morning we all get up, not too early, about ten o'clock, we would all get up and polish the cars until they are all sparkling and then we would all drive to the pub in the country. As a group. We all had parties together, so it is very much a small community. So Jayne obviously took part in those activities with us all as a group. Then it was through that group that I met her. I seem to remember the first time I saw Jayne was when I knocked on her brother's cottage door and went in, and there was about four or five girls, 3 chaps, and I noticed the blonde girl in the corner. And that was Jayne.

And you started to go out together?

Yes.

After that. And you got married in 1979 did you say?

1981.

81.

Or 1982. I had better get this right!

Where did you live when you got married? Did you go you stay there or moved on?

We bought a house in Romsey which is just north of Southampton. We bought a small two bedroom house on the outskirts of Romsey and it was about 19 and a half thousand pounds I think, an enormous amount at the time. And Andrew, Jayne's brother, also lived in Romsey, about a mile away.

[24:20]

And could she hear at the time?

Yes, yes she could hear, she had a hearing aid. But, no her hearing wasn't too bad at all at that point.

And did you have children, do you have children?

Yes. We have two daughters, Claire and Caroline.

How old are they?

Caroline is 25 this year and Claire is just 21.

And can you tell me you don't have grand children presumably?

No, no grand children.

Can you tell me then when Jayne's hearing loss really started to go badly?

It was deteriorating all the time, not too badly, but then in 2000 Jayne had an operation a mastoidectomy on the one ear, to try and improve the infections that she, she has continuous infections in her ears. So she had a mastoidectomy in 2000, or 1999. About three months after that her hearing had completely disappeared from both ears. We never really got an answer why, they said it couldn't have been the operation because that was only on one ear, and her hearing went in both ears. She had lots of hearing tests and I remember going in with her, and they couldn't find any hearing anywhere, so the cochlear, the nerves, nothing, so we have never had a reason why although Jayne was feeling very ill at the time, she had the operation. So we suspected it could have been a virus of some sort. But nobody has put their hands up and said this is what it is

What hospital was it?

It was Southampton Chaley Beat Hospital. Which is a private hospital.

That was in 2000?

1999 the actual operation I believe.

And you say that Jayne was very ill?

She felt very ill. When the anaesthetist came round to talk to her just before the operation, Jayne was very upset and saying I feel awful. But they went ahead with the operation.

How did you feel about her having the operation?

Well, I felt it was part of the treatment that was suggested by the consultant. So there was nothing wrong at the time. I think she had been with this particular consultant for many years. So he was very well trusted and very senior consultant. So we saw no reason why the operation would be not a success.

Who was the consultant do you remember?

I am afraid I can't remember, now. He has retired since but I can't remember.

After the operation, can you describe how she was? After presumably it was a full general anaesthetic?

Yes, that is right.

How did she seem to you after the operation?

Well, she had had an, she has had operations before, she felt, no, she seemed no different at the time. She could still hear as well at the time, there was nothing strange about that. And I think she came out within a few days. So there was nothing odd that immediately came, was apparent.

And then afterwards?

Then after that, more and more as she still had her hearing aid, it would be whistling more and more. She would have to try and keep turning it up, so obviously she was actually losing her hearing. I think at some stage we went back to the hospital, which was Southampton General Hospital, to the Audiology department, to see if we could get a better hearing aid. I remember we went in there, they said have you had a hearing test, we said no. So they said, okay. Well let us have a hearing test. So I remember going in to the padded room, where you have the hearing test; it didn't feel quite right, Jayne was obviously not responding that she should have been or was expected to. And when we came out the audiologist then went to talk to a doctor, and there was obviously apparent that Jayne was almost totally deaf at that point. There was nothing there, so it was only at that point it was discovered that the hearing had almost completely gone.

So that was the first time that she had a hearing test?

After the operation, yes. Yes.

[30:06]

Yes. What were your feelings and emotions about over all that time?

Very, very difficult time. Jayne was obviously getting more and more frustrated of hearing less and less. The hearing aid was whistling all the time. And the children picked up on that as well; obviously. Jayne was telling me that she could hear music in her head, not so much tinnitus at that time. But more it was actually music and she said it was such beautiful music. Which obviously I found it difficult to understand, I knew what she was telling me but obviously I can't imagine what it was like. But it was, but then -- we had further hearing tests after that first one just to see exactly what the situation was. And I remember going into this padded room again with Jayne, and she had some headphones on and I could hear the noise coming out of the headphones. It was so loud it was, I could almost had to cover my ears up it was so loud. But Jayne couldn't hear any of it. I think it was at that point that it struck me my God, Jayne is totally deaf. But I think again, perhaps we were walking home soon after that, and another point we were walking through town and we live not far from the fire

station. This fire engine came up behind us, and of course the siren was blaring. And it actually hurt my ears. But Jayne was totally oblivious there was a fire engine right next to us. So again at that point it is these sorts of moments of realisation that come across at that time.

Did you feel there was anything you could say to her?

Not at that particular time. Obviously Jayne was getting more and more depressed with it all. But I think we both were. It was a very dark time in our lives. Obviously we had two teenage daughters, or just about teenage. So it was difficult for them. Claire at the time, I think she was nine, so she had to start walking to school on her own, which wasn't too bad because it is quite close. But even so, up until then, Jayne was taking her to school, that stopped because Jayne didn't want to go out. She didn't want to face people. So basically Jayne closed down as a person, she used to sit in the window watching me go to work in tears and then I would come home and she still be in tears sitting in the chair. And that it was a very difficult time, obviously for Jayne and myself.

How did you feel about that?

Awful. Sometimes I had time off to help her through, but you know, at some point life has to go on, I have to go to work to earn the money to keep things going for the girls, everything else. So you just carry on. Some people say Oh, it is brave and, you know, but that's what you do. You just carry on I am afraid.

[34:08]

How did the girls react to it?

Well, very well. I mean, I think most of the time they just carried on with their lives. They are teenage girls they are at school. Life just carries on. Obviously communication became more and more difficult, but they started to learn to cope same as Jayne and I learned to cope. But obviously it was different for them, but we still had, they still brought their friends round occasionally. So yes I think coped quite well.

Do you feel that the fact that they were there helped Jayne to divert her attention perhaps

from herself in to her daughters, and indeed to you, to make her feel that actually there are other things to cope with when they were there, perhaps the time that she was on her own was different, but when there were people there it was slightly easier, because she had to do things for you?

Well I think it helped Jayne because she went all of us do I suppose at difficult times, almost into autopilot. I mean, Jayne was a mum. She is the mother of the house. So she had to feed us all, water us, keep the house clean and tidy. And just keep it ticking over. So that is that kind of basic activity that Jayne could do without communicating with anybody else. So I think that gave her something just to hang on to. Yes.

You mentioned that Jayne talked about music in her ears, which presumably was tinnitus. Have you had any experience of tinnitus at all in maybe having a sign us problem or even having had a tape of tinnitus played to you, do you know what that is?

I think I haven't had it personally. I do get what I call noise in my ears, but it is not bad tinnitus. But I know for example if I take drugs, I mean anti-biotics, that I get a ringing in my ears. I know I have something in side. But when we went to the LINK centre for a week, as part of that programme, I think we did have headphones on with noise to give us some idea of what it is like.

Did Jayne have balance problems?

No, fortunately that's one thing she has never had.

Were there any other side effect that's she had as a result of the operation? And the condition?

Well, she is, Jayne has quite a few health problems. She has bronchiectasis, which is a lung condition. It is not bad but enough to give her a cough most of the time; it can get infected. She has other things like polyps she has had, all through her life she has had lots of health problems. All part of her first interview I read the notes this morning, and it is pages and pages of health issues basically. And people not really understanding the sorts of things like obviously when you are deaf or hard of hearing, people don't notice so much as I am sure you

know, it is not a visible thing like being blind. Again with the bronchiectasis, she had polyps up her nose, huge polyps when she was a teenager. So at certain times in her life it has been very difficult for her. I think a big problem when she went deaf was the depression, I think that it caused. She described it as going into a black hole and almost you can physically see it. I remember her sitting in this chair when I went to work and it really was like she was in a black hole and it is so difficult to help her get out of that. But it has taken a long, long, long time, but yes, things are a lot better than they were then.

[39:03]

Can you recall the attitude of medical staff that Jayne had dealings with?

Well, generally my impression was they are all very helpful, obviously we have seen so many staff. But most of them are positive experiences I think. I mean, obviously sometimes you come across some people who aren't deaf aware, not just in the health service but anywhere. So occasionally I would have I would go in with Jayne to see the doctor, and the doctor would talk to me, he wouldn't look at Jayne. He would talk to me and I would communicate with Jayne. And to me that makes me cross. But I don't know, but a lot of people are very good but some people just don't want to know or they are too embarrassed. I don't know. But it is quite common though I think isn't it?

Do you always go with Jayne to her hearing clinics? Or was it just over that very difficult period?

I go to most of them. Probably less now than I did before, as she becomes more confident. But for example, with, we had problems with our GPs, so our original family doctor in 2000 she wasn't very sympathetic towards Jayne's condition. She was a very good doctor if you had a broken arm or you had a headache or she would say, right do this. And that was fine. But I don't think she could cope with Jayne's depression. It was very difficult, but then also we had a couple of other doctors in the same practice, and I remember one particular incident with I think it was a locum doctor, she came from Portugal or Belgium I think, very young girl almost the same age as we were, she was younger, and she helped Jayne a lot. She used to listen to what Jayne had to say. But from my point of view, I remember this doctor saying what about you Tony? How do you feel about this? And that was the first time anybody had

asked me about my feelings and what was going on and that was about 18 months after it all happened. I found almost became emotional; at that point because nobody had asked me before.

During the treatments, during the initial and during the actual time of the operation and immediately afterwards, were you consulted, were you asked questions about how Jayne felt or reacted or anything?

I don't think so, no. I was purely there as an interpreter.

Do you feel that would have been useful?

At the time, no, I don't think so. They did talk with Jayne quite a lot and Jayne doesn't hide any of what she is feeling about things. If she feels worried she will say so. So, I don't think I could have added any more to what Jayne was saying.

Do you feel that could you have said to a doctor well actually, before this happened my wife was this sort of person and now she isn't and can you tell me why?

Did they ask me that question? They might have asked us both that question together. Because I was with Jayne most of the time, I was never on my own with them. So I don't, they may have asked me specifically. Do you see what I mean? It is difficult to split it out. To me it was all one big horrible experience.

[43:48]

Yes. Do you remember the line of referrals or was it too long ago or indeed too unpleasant to remember like the person you first saw and then who referred you to whom?

Goodness me. Because we had been seeing doctors all through our married lives really, for Jayne for hearing, because she has had a hearing problem ever since I have known her. So when we first got married I think we went up to London a few times to see the consultant. I think St. Thomas' hospital. Yes, so I have seen them all. So I can't remember -- no, Mr. Morgan, I remember the consultant who did the operation, Mr. Morgan he was the

surgeon. He was very good as a surgeon but not very good at listening to Jayne. So, he could look in her ears and say this is the problem and be reassuring. But he wasn't very good at actually talking to Jayne; he was more like the carpenter who would go in and do a good skilled job, but not very good in the kind of a social skills.

Did you feel the nursing staff was supportive of Jayne?

Yes, yes very much so in the hospital, they were very helpful, yes.

Moving on now to what we call the interventions, the hearing aids. You said Jayne had, did she have one or two?

Before the operation she had one hearing aid, yes, and after shall she only ever had the one hearing aid.

And hearing therapists, sorry, no, did she ever consider having hearing dog?

We have thought about that. Because we have some good friends or I have seen here today Chris and Steve, who have a hearing dog called Yogi, and they are part of our small social group at that Jayne started or Jayne and I started a couple of years ago. So we have considered a hearing dog, but Jayne feels that she doesn't want to draw attention to herself going out of the house, with a hearing dog. She likes to be in the shadows, yes? We have talked about the advantages of a hearing dog so that people do know that she is deaf. So perhaps we will treat her a bit better, but we live in Romsey and we have been there for 20 odd years now. So people know Jayne. Also having a hearing dog is a very big commitment, because you the hearing dog is with you all the time and you have to keep training him and looking all the rest of it. So we love dogs, we have had a dog and we will have another dog soon, but not a hearing dog, Jayne doesn't feel she would like a hearing dog.

Is that her decision rather than yours?

Yes, definitely Jayne's decision, yes, yes.

And does she have a cochlear implant?

No, no. Straight, about six months after she went deaf she went back for assessment in Southampton Hospital. They said cochlear implant was not right for Jayne; at that time. Basically she hasn't been back to see any ENT man since then. You might think that strange, but I think she has had enough, she doesn't want to go back, and she still has terrible infections in her ears. But she can cope with it. So obviously the experience of the operation going wrong, in effect, she just doesn't want to go back and see them any more, she can cope. So if it ain't really broke, don't try and fix it!

You feel the same do you?

I think I do now, yes, yes.

[48:34]

As far as communication methods are concerned, how do you manage?

Just about. Lip reading. Jayne is fortunately very good at lip reading. Even with my beard and moustache! We did toy with the idea of signing but, as Jayne said, she doesn't really want to do that because she is still part of the hearing world, she is not part of the Deaf world. So if she learned to sign, who would she sign with? She goes to lip reading classes even now, she is only just got enough confidence to go on her own. But I think that's more of a social activity rather than learning how to lip read. It is a relaxed atmosphere in which she can communicate with other people. Indeed, even though none of the other members of the class are profoundly deaf, like Jayne, she feels that it is one thing that she excels in more than anybody else. Because she always understands what the teacher is saying. So that's good, that's good.

What about finger spelling? Is that something you can do?

Yes, yes we did that very, very early on. And it is something the children learnt to do early as well. Yes. We use that quite a lot.

Do you enjoy doing that?

Well, I only use it as an aid to lip reading so it is only usually the first letter of the word. I know some people do it on their fingers fly; we are not like that at all. It is just the odd letter, just a help.

And do you have technology and equipment in the house?

Yes, yes we do. This is one thing that I found helped me as the hearing partner when everything went wrong. I thought, you know, I have to do something. So the one thing I could do was try and find out about all the technology. As I said earlier, part of my, it is my job to know all about computers. So therefore these things don't worry me, so I threw myself into the Internet and doing all sorts of research to find out what was around at the time. I went to the, there is a I work for -- at work they have a charity foundation that help staff basically, various areas, so I went to them and explained the situation. So I managed to get a grant from them for a couple of Minicomms, a video recorder that recorded subtitles at the time. We had a very good hearing therapist that came from the local council, there are very good facilities there in Romsey. We are very lucky. So through that we had the paging system that linked into the door, the telephone, and the fire alarm, the smoke alarm. We had a small portable light that we put on the back of the door. I think we learned about that when we went to the LINK centre. So all sorts of things I have tried to keep up with.

[52:22]

I didn't ask you whether Jayne was employed, before, earlier and then later?

She had a job when we first got married, she worked in the hospital as a pharmacy technician. But once we had children she was a full-time mother at home. She had a part-time job occasionally.

The part-time job was that when she was a mother?

Yes.

Right yes. And when did she stop that?

About 1995, I suppose. Perhaps later.

Was that as a result of her hearing beginning to go?

Well, it was getting worse. Yes. She worked in a teashop in Romsey, in the kitchen. And I remember her saying, it is when she took the job, once she applied for the job she explained that she couldn't hear very much. So therefore waitressing wasn't, wouldn't be very good for her or answering the phone. But the lady said, Oh that's all right. We just need you for washing up and working in the kitchen. But of course, if the phone goes, somebody has to answer it. Or if there is nobody taking an order, so Jayne did get wrapped up in some of these things which was very difficult for her. But Jayne is a, she sticks to things, she tries very hard at everything. So, it was a two years or so I think before she eventually gave it up.

Do you think that she will ever want to go back to work? Is it hard to say?

It is very hard to say. But Jayne has always very much liked talking to people, she is a people person. Very sociable. I think that's one thing she misses above all else, is just sitting down with her mates and chatting. You know. Gossiping about the world. The spontaneity of a chat just doesn't happen any more, that's the one thing she really misses I think

[54:55]

How do you feel about that?

Well, it is true that the spontaneity of discussion communication has disappeared. I mean. The silly things like telling jokes, it is very difficult to tell a joke or share a joke with somebody who is deaf. Because you can't get the, if you miss the punch line, by the time you have explained it you have lost it. And Jayne knows that as well and it is that spontaneity of the fun time that goes.

Okay. Thank you. Let us just take a pause there.

[55:51]

Tony, moving on now to the impact of hearing loss. We have already covered a little of it. But I would like to talk about self-esteem in terms of Jayne's loss of self-esteem. And how this has affected you. It if you could describe examples of how she has lost her self-esteem and how you react to this?

Obviously, it is very difficult for Jayne as you say; she has lost her self-esteem, her self-confidence. She doesn't like going out, she is better now than she used to be, but obviously every now and then it sort of comes back not as bad as it was. So although we never used to socialise an awful lot, we didn't go out four or five times a week to meet lots of people, obviously it has curtailed an awful lot of that because going out in groups is one of the most difficult times for Jayne. She is very good on a one to one but with a group of people, obviously, communication is that much more difficult. Family occasions can be difficult as well, because quite a few of the family live locally, so quite often there maybe 7 or 8 people at a gathering of the family, and of course they are all keen to talk to each other. But that can leave Jayne out in the cold quite often. So I find that sort of occasion is quite difficult for me as well as Jayne. Because if I just turn round and talk to every body else, I feel as if I am cutting off Jayne as well. So there is always that feeling of guilt behind everything. Perhaps I shouldn't be, but it is just the way that you feel inwardly. Because obviously I have known Jayne now for 27 years, so and I know what she is going through or, well, I think I know what she is going through. So I try my best to most of the time to bring her into the conversations and but sometimes it is not always possible. And obviously I am no saint either; I am not perfect all the time. I am just a normal person. But it can be very difficult. But most the time we, it works out fine. But obviously we don't go out as much as we did. But I can't say I miss that an awful lot. It is something I have got used to. So I am getting on together is just as good, it is more difficult. But we do, we have always liked for example word games, Jayne and I love words. So initially we started off playing a lot of scrabble; which is okay for two people, but if you have more than two it makes it a bit more difficult. But we have soon discovered this word game called Bananas. It is called Bananas because it is a small bag shaped like a banana but it is full of letters. Just like scrabble. Basically you throw them all on the table and you have 21 tiles each, and then you make up your own little cross word. And then when all the tiles have gone, and the first one to finish is the winner. And so that is really, really good for deaf people. I have to recommend it to everybody, because it is really exciting. But you are in your own little world and you don't have to worry what all the other

players are doing at the time. It is not like Monopoly, where you still have to communicate. This is purely on your own with your own little set of tiles and we play that 2, 3, 4 times a week. So we find that very good. And we do the cross words and things like that. So, so, yes we are fine. Yes.

Do you find you become more ingenious about certain things?

In what way?

In that way, not taking for granted the things that you used to do but looking for other ways round, like your game?

Yes, yes. You are always looking for a different, what the is the phrase, strategy the way to make things better. But it doesn't work the old way, try something new. I can't think any more examples though, but it is, time as well helps. About three years ago, and it wasn't me that suggested this, I think it was Jayne. She said it is about time we started meeting more people again. So why don't we advertise in the LINK magazine for people who just like to have a social get together? We didn't want to start up a big group with a hall and all the organisation with it. We just wanted to start slowly and perhaps meet somebody for a drink in the pub. So, we put an advert in the LINK magazine and we got two replies. So we said, okay, well let us for the first time, we said let us meet up in a pub called The Clump, which is local to Southampton. We thought this was a good idea, you see. So Jayne and I go to the pub. And the first person to walk in was Chris, who was as you know is six foot 8, no Steve, sorry, Steve is six foot 8, Chris his wife. And then Tim comes along, another friend, well of course in this pub it was very noisy. It had a wooden floor and so it was the worse place possible to have our first meeting! So we haven't met in a pub with a wooden floor again. But we are all still good friends after two and a half years and usually we meet in each other houses and so, that's good. So we all get together in a relaxed atmosphere and have a good chat. So, things are getting better. I am hoping that perhaps Jayne will one day maybe do a kind of volunteers job and helping other people, particularly deaf people, because she is a very caring person. She always wanted to be a nurse; she trained for six months but had to stop because she couldn't hear. So she has always liked people so perhaps one day she will feel confident enough to help other people. Because I am sure she can.

[01:03:58]

Can I move over to a slightly different subject? So far as Jayne's identity is concerned, on a more official level, shall we say, does she find herself being labelled, having a disability status?

I don't think it has affected us in an official status. I mean she does have a disabled card from the social security or Social Services, but that is and she gets disability living allowance. We've got a disabled rail card. She has a bus pass now, free bus pass. But I think that's something that we wanted to do so we can make use of all the facilities. I don't feel that I am one half of a disabled partnership. Does that sound right? So, I don't think Jayne really thinks of herself as disabled.

Can I talk now about your personal relationships. You have touched on it a little. But can you tell me a little about it in any detail? How you get on as a couple? And as friends?

Yes, yes. Communication is as you know at the very heart of these things. So it has put an awful strain on us. I remember an incident, I was at work and I was at the coffee machine. And it was only about six months after it happened and obviously it was very depressing time. But I remember a colleague saying to me, well of course, this is the sort of thing that will bring you close together. And my initial reaction was, well no, because it is trying hard to pull us apart. Because you can't communicate. I think it is the act of trying bringing yourselves back together again that, how can I put it, bring you closer together -- the deafness itself is a terrible thing and lack of communication. It is trying so hard to pull you apart. But then you know, over time we have overcome that. But you are always working against it. But I think we are closer together now than we were at the beginning. But you have to put an awful lot of work into it. I mean, with any marriage or should I say partnership these days, it is hard work to keep it together. But even more so if you have something like if you have communication issues. But yes, you know, we just celebrated our 27th anniversary, so we are fine; we have come through it all. But there is nothing to be complacent about I think, it is -- you have to work hard to keep on top of it.

Are there any times when you have had a lot of pleasure when something has gone wrong and which should have made you feel really bad but actually you laughed together at it because it

was so funny or so awful?

I can't remember anything that was really bad that it was so funny. Obviously funny things happen because of Jayne's disability or because Jayne is deaf. So for example, I mean, I think early on we were in Waitrose doing the shopping, and Jayne was looking over the delicatessen counter and saying, Oh, that beef looks all dried up and nasty! In a very loud voice. And of course everybody turned round and it was just so funny. So there are some funny things like that. But in terms of what happens to us together, I can't think of anything that was really so bad. You know, it is just again, the spontaneity is difficult, and again the night times as soon as the bedside lamp is turned off, then obviously that is final, that's the end of the day. But it is still very strange because I think I do it as well, but Jayne seems to forget sometimes that she is deaf. So, a couple of years ago for example, we would be waiting for one our daughters to come back from a night out. As you do, you know, you worry about them. About half past one in the morning, Jayne gives me a prod and says, is Claire back yet? And so, you know, what do I do, do I sit up and turn the light on and then explain or so you try strategies. So I give her a squeeze of the hand and she says, is that a yes or a no? And so you get into this, does that mean a yes or is that a no? So it is silly things like that. Sometimes are funny, sometimes are very frustrating. But, you know, that's the way it is. So we worked, we have learned to work our way round these things.

[01:10:29]

Right. Moving on now. Because Jayne doesn't work, how has it affected your financial status in any way? Or do you feel that your income provides enough money for you to live comfortably as you would wish?

Yes. Well, Jayne really stopped working full-time when the children arrived. 20 odd years ago. And I am fortunate enough to have a reasonably well paid job, so in financial terms no, we are fine. I don't have no problem with that at all. And I don't feel that Jayne should feel guilty for not working. Or I think she does sometimes, but for me, no. It is fine. Jayne looks after us. And the house and everything else. Not just physically but emotionally as well. So I don't have any problem with that. I think it would be nice if Jayne did have a job or some other activity, but from her point of view, so that she gets some other input into her life rather than just me talking about my work maybe. When I come home, which is not totally

understandable to Jayne anyway; whether she can hear or not. I mean, not many people know an awful lot about computers security and boring things like that!

I think you said Jayne gets disability –

Disability Living Allowance, yes.

Does she have any other benefits?

No, no.

On the subject of education and life long learning, are either of you involved in that now?

In education?

Yes and life long learning? In that aspect?

As part of my job I have to learn all the, learn new things all the time anyway, who is part of my job because I am in computer technology and particularly security. There are always new things coming out. So I am forever going on training courses and learning new things and just getting wary now, I thought I had left all of that behind, perhaps the young chaps can do that and girls. But I still have to go on training courses all the time. And Jayne I think before she went totally deaf, she did an interior design course, she liked doing that. So Jayne is always willing to learn things as well. She always has her nose in a book, about something or other. Our daughter is getting married in August, so we have had 12 months so far of planning and getting ready for that. So it is quite a lot going on.

[01:13:54]

So far as interests are concerned, you have talked about quite a few of the interests that you shared and that Jayne has and that you have. Can you talk a little bit about how your life styles have changed in a sort of general way, not specifically because you have talked about that in a sense. But whether you think there is room for manoeuvre to try and get it into a more positive light, if you like?

A difficult one. I think again I mentioned earlier that if Jayne had some interest outside of the house and the family, I think that would help both Jayne and me because she would be able to talk about something else and it would bring more into her life. Because at the moment it is all kind of, how can I explain it, almost two dimensional. She gets all of her information from newspaper, from the television, and an awful lot of information. But I think it is the people side of things and the emotional side and just talking to people and I think if somehow I can could see that as an improvement, if that could happen; at some point. I think one day it might. It just takes a long time to get there, to build up the confidence to do that sort of thing.

Yes. You said that you think Jayne is becoming more positive?

Yes.

I think. Does that mean you are becoming more positive?

Yes definitely. I think so, because, yes, whatever affects Jayne affects me and vice versa. We have been married for so long now that we are a partnership. So, perhaps it is a trite thing to say but when Jayne is happy, I am happy. That's the way it works. Yes.

Can you tell me about, moving on now, to the wider society friends and acquaintances.

Family and friends and relationships. How have they developed since Jayne's hearing loss?

Not you, but for the other people involved?

Well, Jayne's brother and his wife they live in Romsey, not far from us. And so does Jayne's mum and dad. So obviously we see each other quite a lot. Jayne's mum unfortunately is now in a nursing home, where so she is not really aware of how Jayne is. But her father, Vic, he is 86 now. Obviously he has always found it difficult to perhaps fully understand Jayne's deafness. He is the one of the family more likely to forget that she is deaf. But obviously he is older and it takes a long time. Andrew her brother is very good and Thelma, his wife. Thelma is a community nurse, and so she is very practical. She knows all the right things to do. She has helped out quite a bit sometimes, and they get on very well. They, Jayne and Thelma went to, Thelma is helping out with the wedding preparations and getting ready for sorting out where we are going for the evening do, I think.

So they have always been very, very helpful, yes.

[01:18:30]

Thank you. And on the subject of support net works, are you involved in charities and in the community? I know you mentioned your activities with LINK, can you tell me a little more about how you got involved with LINK? And what happened?

Right, okay. We first got involved with LINK, I think it was through the GP, I am not sure. This is initially after Jayne, it was not the GP, no, it was the hearing therapist from Social Services. Almost immediately after Jayne went completely deaf, because as I think I mentioned earlier, when we went to the hospital and she had that first main hearing test that proved she was almost totally deaf, that seemed to kick everything into action; as far as Social Services were concerned. So we had a very good hearing therapist who came to see us and she said, there is this place in Eastbourne called the LINK Centre, who I think will be very helpful for you. So it was that year I think, so almost within six months of Jayne going totally deaf, we went to the LINK centre for the week, the whole family. That's me, Jayne, Caroline and Claire. It was very interesting, it was inspiring. The people there gave us ways to help ourselves; I think they showed us there is life after deafness as they say. But then when you come home, obviously real life kicks in again and you are on your own and you got to try and cope. Obviously the hearing therapist did come round and Jayne and the hearing therapist were quite, very friendly for a couple of years. But it is not the same when you are on your own. For example, you go to the LINK Centre and they say, Oh when you are in a group discussion, particularly with a family, take an object with you. Like a teddy bear or whatever. And whoever has the object can talk and then you pass it round. Which is fine in theory, but when you go back home and you try it out with the family, it is sort of doesn't work, does it? People go back to having small discussions amongst themselves, like you do. So it is very difficult when you are back at home and have you to carry on try and carry on just living basically. So I think the only strategy you can, that really works is the day-to-day one, you just go from day-to-day and it just builds up. But you have to be patient and just keep going.

As a result of that LINK week, did you meet any one there that you kept in touch with?

No, no. Well, I think we might have sent a couple of emails but no, not really. Because it is quite a long way from Southampton and they didn't have any representation in Southampton,

we didn't have much to do with the LINK Centre. But, as I said, a couple of years ago when we started up our own little group, it so happened that Chris and Steve are active volunteers with the LINK Centre. So we get to know about what is going on through them now.

Thank you. Do you have any support at all from within the community within your community?

No, no, not really. I mean, no.

Could I ask you about access and awareness? In terms of legislation. Is Jayne aware of the things, of her rights I suppose and are you aware of the rights on her behalf?

I don't think it doesn't -- it doesn't affect us very much, because Jayne is at home most of the time. She is not, she is not working. So things are very much centred around the home. So yes, so apart from the benefits and things like that, which we are aware of and obviously try and make the most of, it doesn't really affect us. In terms of actually the workplace, I am aware of my own particular work area. I am aware of some of the deaf issues, well, because the people I work for the bank, Lloyd's Bank, they are very good with people with disabilities and helping out and also some of the computer programmes that we write for the staff to use; they always have to be what we call DDA compliant. So they always have to be usable by people with disabilities, whether they are deaf or blind or can't use their limbs. So from a professional point of view I am aware of certain things like that. Yes.

[01:24:50]

If Jayne was to need to go shopping without you, and had problems and you weren't there, that I suppose is the sort of thing I mean about awareness. Do you feel she would be able to cope and say look, I have this problem. And I need you to help me. A shop assistant for instance?

She does go shopping on her own to Southampton. Well, and also she does go shopping, the food shopping to Waitrose, she does go on her own. But she is very wary of it. Again it is not a black and white thing. Some days it is okay, some days it isn't. You have good days and bad days. But, for example, now I think she was in Bristol shopping centre for an hour on

her own before she met a friend. So I think she is okay a lot of the time. But she has her own strategies obviously for coping with these things. She tries to avoid the situations where people will be asking her questions, so she has learnt to live with that to a certain extent.

As far as discrimination is concerned, have you come across any discrimination, any examples of discrimination where you feel you have had to act on Jayne's behalf?

I don't think we come across any discrimination. Obviously, there are people who aren't deaf aware. As I say, who will talk to me rather than Jayne; or, you know, when they explain, when Jayne doesn't respond to their questions, I will say sorry, but Jayne is deaf. And you know, quite often the stand is I will just talk louder or shout and I say, no, sorry but Jayne is deaf. But no, no, no real discrimination as such, no.

Fine. So, we are reaching the end of the interview now. Are there any further points you think you would like to mention?

I don't think so. I think we have very well covered it over the last few minutes.

Fine. How do you feel about this project, this interview project as a hearing partner and indeed in the knowledge that Jayne has already done her interview? Do you have any specific opinions about it?

Well, I think it is fantastic that these interviews are taking place to be recorded for years to come. So perhaps researchers one day will be going through this information. I think hopefully it will help the understanding of other people in the hearing world exactly what it is like to be deaf. Because the vast majority of people have no idea what it is really like. And from my own, I suppose, selfish point of view, it is good that you are interviewing some of the hearing partners as well. Because sometimes you feel that you are the forgotten minority. Because it is a disaster that affects the whole relationship and I think it is good that some people have that experience recorded as well.

Tony, thank you very much indeed for this interview. It has been really interesting and very worthwhile. Thank you so much. And thank you, Mirella, too.

[End of recording]